

Patient, Carer and Family Experiences of Seeking Redress and Reconciliation Following a Life-Changing Event: Systematic Review of Qualitative Evidence

Final Report

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Liz Shaw, Hassanat M. Lawal, Simon Briscoe, Ruth Garside, Jo Thompson Coon, Kristin Liabo, Malcolm Turner, Michael Nunns, G.J. Melendez-Torres

Exeter PRP Evidence Review Facility, College of Health and Life Sciences, South Cloisters, St Luke's Campus, Heavitree Road, University of Exeter, Devon, EX1 2LU.

Corresponding author:

G.J. Melendez-Torres ([email: G.J.Melendez-Torres@exeter.ac.uk](mailto:G.J.Melendez-Torres@exeter.ac.uk); 01392 725651; South Cloisters, St Luke's Campus, Heavitree Road, Exeter, Exeter, Devon, UK, EX1 2LU).

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Requests for access to data should be addressed to the corresponding author.

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Contributions

The opinions expressed in this publication are not necessarily those of the Exeter PRP Evidence Review Facility or the funders. Responsibility for the views expressed remains solely with the authors.

Guarantor of the review

Professor G.J. Melendez-Torres

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Abbreviations

DHSC	Department of Health and Social Care
NHS	National Health Service
NHSLA	National Health Service Litigation Authority
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PRP	Policy Research Programme
UK	United Kingdom
USA	United States of America

Guidance on the type of review and how to read this report

This is a technical report structured to foreground the findings of the qualitative evidence synthesis.

Thus, the report is divided into three sections:

1. **Executive summary:** An executive summary providing an overview of the methods, key findings and implications for future research and clinical practise;
2. **Part 1:** This provides a background to the systematic review, a brief methods section and a summary of the main findings before discussing the main findings of the review in the context of existing research and identifying potential implications for future policy, research and practice;
3. **Part 2:** In part two we provide the full methodological detail including the search strategy, inclusion criteria, data extraction and quality appraisal processes and the full results of the framework synthesis.

Executive summary

What do we want to know?

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, going back as far as 20 years or more.(1, 2) Consequently, the Department of Health and Social Care (DHSC) is keen to understand options for a proportionate, time-limited, mechanism to address those cases where legitimate questions or grievances remain, and it is in the public interest to do so.

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 families feel that justice has not yet been achieved and remain traumatised and angry. Ministers have considered these calls to “establish a process that addresses unresolved cases, aimed at providing truth, justice and reconciliation, to address the concerns of patients, families and staff affected”. They have concluded that, rather than establish a process or separate inquiry, the need to investigate such cases should be considered on a case-by-case basis and that the DHSC should commission a review to understand and how to address this issue from the perspective of achieving resolution and/or reconciliation for individuals and/or their families who have experienced a medical adverse event. This gives rise to the following policy questions:

- What are the issues for the health system to consider on how to respond on a case-by-case basis to historical patient safety cases?
- How can the way the health system currently supports and responds to bereaved families, particularly those whose cases are historic (non-recent), be improved?

However, in order to address these questions, we first need to understand how the current investigation process is experienced and the features that seem to lead to perceptions of “truth, justice and/or reconciliation” among those affected.

We conducted a systematic review of qualitative evidence to improve understanding of the processes and outcomes of redress and reconciliation following a life-changing event from the perspectives of individuals experiencing the event and their families. This is with a view to developing a framework or typology to help the Department of Health and Social Care identify historical patient cases for which management has been perceived to be procedurally unjust and for which some further intervention might be indicated.

Research Questions:

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

What we did

Our review protocol was prospectively registered on PROSPERO.(3) The methods used to conduct and report the findings of this review were consistent with the best practice approach for the conduct of systematic reviews and reporting of qualitative evidence synthesis.

We sought primary studies about individuals who have experienced a life-changing event and/or family or carers seeking justice on behalf of the person who experienced the event regarding their experiences and/or views of redress and reconciliation processes following this event. Studies were conducted in high-income countries and the redress process occurred within health/social care systems, child protection or sudden death investigations, homicide reviews or any other service or professional context identified by our searches where findings could provide useful insights for the health care context. No limits to the age of participants or date of publication were set.

Potentially relevant studies were found through searching bibliographic databases with search terms derived from relevant journal articles identified in our scoping searches. This search strategy was supplemented with forward citation searches, backwards citation chasing and targeted bibliographic database searches. To identify grey literature, we searched Google Scholar and topically relevant websites.

We appraised the quality of all studies prioritised for inclusion in the framework synthesis using the Wallace Checklist (2004).(4) Studies were prioritised on the basis of their relevance to the health field. A sample of studies from outside of the health field were included in the synthesis if they provided data to support weaker subthemes.

We used NVivo software to synthesise the prioritised studies using a 'Best-Fit' framework synthesis approach based on the work of Daniels and Sabin (1997;1998; 2000),(5-7) which highlight key aspects of a procedurally fair redress-reconciliation process. This framework was revised in a series of stages, using a process of iterative coding to ensure the final themes and subthemes best represented the extracted data.

We worked alongside a variety of stakeholders and advisors to ensure our findings reflect the needs of individuals who will use them, including representatives from the DHSC and two individuals with lived experience of medically life-changing events.

What did we find?

Overview

Fifty-three studies (61 papers) met the criteria for inclusion in this review. The types of life-changing event included in these papers included medical(n=31), homicide(n=5), work-related death(n=4), suicide(n=3), missing person (n=1), death in police custody/following contact with police(n=3) and child sexual abuse (CSA)(n=6).

Forty-one studies (47 papers) were included in the synthesis. None of these studies reported experiences of individuals who were still actively seeking justice following a non-recent, or “historical”, medical event. All of the studies representing the views of individuals seeking redress and reconciliation following a medically life-changing event were included in the synthesis. Other life-changing events represented within the synthesis included homicide (n=3), CSA (n=2), employment/work-related death (n=2), death in custody (n=1) and suicide (n=2). The majority of these studies scored positively on at least 8 of the 14 items on the Wallace checklist (range 2 to 13).

Main findings

Four themes were identified by the framework synthesis; 1) Transparency, 2) Person-centred, 3) Trustworthy and 4) Restorative justice.

The three themes ‘Transparency’, ‘Person-centred’ and ‘Trustworthy’ represent the procedural elements of redress-reconciliation which should be established to support a fair and objective process. The elements within these three themes are interdependent with each another, with each element influencing others within the redress-reconciliation process. For example, it is likely that if the process is conducted using a person-centred approach that this will increase the transparency and trustworthiness of the process.

If the redress-reconciliation process is conducted in a way which is consistent with the procedural elements identified by this synthesis, it may support the development of a supportive, empathic relationship between justice-seekers and individuals seen as responsible for the harm. This relationship may support those seeking redress and reconciliation to develop a coherent narrative about the trauma they have lived. This presents the opportunity for justice-seekers to express their emotions whilst telling their own story and receive acknowledgement for the hurt they have experienced. During this process, those seeking redress and reconciliation can be supported to take

part in action which gives meaning to their loss. The combination of experience arising from a humanising process and the opportunity to develop a cathartic narrative and participate in meaningful action provides the foundation for the final theme, 'Restorative justice' which encapsulates how a fair process feels to those who have experienced a life-changing event.

It is within the context of the humanising and cathartic relationship between these stakeholders that the procedural elements of the redress and reconciliation process can be worked through, the harm and the impact on the individual can be explored, meaningful outcomes agreed upon and the emotional impact diffused, as people accept what has happened and learn how to incorporate the consequences of the event into their lives going forward. Thus, we propose that a fair process is dependent on both its procedural elements and the quality of the relationship developed between the different stakeholders. The latter has important implications for how those seeking redress reconciliations are made to feel, the extent to which they feel heard, and the degree to which their experiences can inform the process. This in turn can influence how fair they perceive the redress and reconciliation process and its outcomes to be.

We then considered how the key elements identified by the framework synthesis could be applied retrospectively to appraise if those seeking redress and reconciliation following a historical medical life-changing event have experienced a fair process. Thirteen elements of a fair redress and reconciliation process which could be applied to historical life-changing events 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 have influenced the redress-reconciliation 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*

What are the implications?

The features of a fair redress and reconciliation process support professionals involved with the investigation/inquest system to establish if those seeking redress-reconciliation following both a recent or historical medically life-changing event have experienced a fair process, or not.

Our findings may help patients and/or their families who are seeking redress-reconciliation know what to expect in terms of a fair process and could be used to help them articulate their needs at different stages throughout their journey.

It would be useful to establish to what extent the findings of this review reflect the experiences and needs of patients and families seeking redress and reconciliation following a historical medical event. This could be achieved through sharing the findings of this review with a greater number of individuals who have experienced medical harm, or other individuals, groups and organisations who represent them. Alternatively, a separate work of qualitative primary research could be commissioned to explore the experiences and needs of this group, with particular emphasis on their reflections on the need for a clear rationale for decisions made and their views on the resources available to support them to challenge findings/processes or resolve disputes.

Once work has been completed to validate the findings of this review, primary research to evaluate the extent to which existing structures and processes utilised within the NHS to promote redress-reconciliation reflect the components of the fair process as outlined within this report could be beneficial. This would provide insight into whether the processes currently being used are perceived as fair, with a view to reducing the number of people whose needs remain unmet for prolonged periods of time.

This review and any subsequent primary research have the potential for identifying areas in current practice which are not meeting the needs of people seeking redress and reconciliation and where changes need to be made. Some of these changes may initially be challenging to incorporate into the procedure-based systems used within healthcare settings and by other organisations supporting the redress-reconciliation process. Thus, further research regarding the most effective way to implement any proposed changes may be beneficial.

Part 1: Background, brief methods, findings and implications

This section of the report provides a background to the systematic review, an overview of the methods used and a summary of the main findings. For full methodological detail including the search strategy, inclusion criteria, data extraction and quality appraisal processes and the complete results of the framework synthesis, please see

Part 2: Full description of methods and framework synthesis results.

Background

Policy background

Systemic NHS care failings, such as those documented about Mid Staffordshire,(8) Morecambe Bay,(9) breast surgeon Ian Paterson,(10) and Gosport War Memorial Hospital,(11) indicate that the NHS can at times fail to respond appropriately to the concerns of patients and families.

Investigations or inquiries are either intended to establish the facts (usually through an independent process) or to identify opportunities for learning that NHS organisations can apply to improve care and achieve resolution for families. In 2017 the system for managing complaints against the National Health Service (NHS), the ‘NHS Litigation Authority’(NHTA), was rebranded ‘NHS Resolution’. This combined the three arms of NHTA, the National Clinical Assessment Service and Family Health Services Appeal Unit and moved from a defensive position to a focus on the early settlement of cases, with an emphasis on learning from past mistakes and prevention of future errors.(12) In addition, the new NHS Patient Safety Strategy was published in July 2019, providing a long-term plan for the NHS to continuously improve the safety and culture of systems.(13) In 2020 the creation of the ‘Medical Examiners’ role was announced, a position with responsibilities which aim to provide vital insight into deaths following problems in care and inform future improvements in safety and also acting as a resource for bereaved families.(14) The Department of Health and Social Care (DHSC) is working with system leaders and academic experts to consider what more can be done to drive improvements in the way the NHS handles complaints and feedback from patients. These moves represent the enactment of a desire to change the culture around dealing with patient safety issues and complaints.

Historical cases

Key stakeholders, including bereaved families and public figures, are calling for a process that investigates historically unresolved cases of suspected NHS care failures, going back as far as 20 years or more.(1, 2) Consequently, the DHSC is keen to understand options for a proportionate, time limited mechanism to address those cases where legitimate questions or grievances remain, and it is in the public interest to do so.

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 and angry. Ministers have received calls to “establish a process that addresses unresolved cases, aimed at providing truth, justice and

reconciliation, to address the concerns of patients, families and staff affected". They have concluded that, rather than establish a process or separate inquiry, the need to investigate such cases should be considered on a case-by-case basis and that the DHSC should commission a review to understand and how to address this issue from the perspective of achieving resolution and/or reconciliation for individuals and/or their families who have experienced a medical adverse event. This gives rise to the following policy questions:

- What are the issues for the health system to consider on how to respond on a case-by-case basis to historical patient safety cases?
- How can the way the health system currently supports and responds to bereaved families, particularly those whose cases are historic (non-recent), be improved?

However, in order to address these questions, we first need to 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.

Existing evidence

Scoping searches using MEDLINE did not identify any existing systematic reviews or primary qualitative studies examining patient or family/carer experiences of seeking justice for an historical serious adverse event within a healthcare setting. However, scoping searches did indicate that a small body of primary qualitative evidence existed which explored the experiences of patients and/or their family of redress and reconciliation processes for recent patient safety events within the healthcare field. Whilst this evidence appeared amenable to evidence synthesis, it was uncertain whether the quantity of this available evidence would be sufficient to fully address the policy questions outlined above. Thus, we also searched for literature outside of the healthcare field, specifically from criminal justice settings.

Aim

We sought to improve the understanding of the processes and outcomes of redress and reconciliation following a life-changing event from the perspectives of individuals experiencing the event and their families. This is with a view to developing a framework or typology to help the DHSC identify historical patient cases for which management has been perceived to be procedurally unjust and for which some further intervention might be indicated.

Research Questions:

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

Brief methods

Our review protocol was prospectively registered on PROSPERO.(3) The methods used to conduct and report the findings of this review were consistent with the best practice approach for the conduct of systematic reviews and reporting of qualitative evidence synthesis.(15-19) Below, we summarise how we identified relevant primary qualitative studies, quality appraised these and synthesised their findings. Full methodological detail is provided in

Part 2: Full description of methods and framework synthesis results of this report.

Identification and selection of papers

Potentially relevant studies were found through searching six bibliographic databases with search terms that were empirically derived from the titles, abstracts and indexing terms (e.g. MeSH in MEDLINE) of relevant journal articles identified in our scoping searches, in conjunction with a validated qualitative study type filter.⁽²⁰⁾ This search strategy was supplemented with forward citation searches, backwards citation chasing and targeted bibliographic database searches. To identify grey literature, we searched Google Scholar and a selection of topically relevant websites. Full details of our search strategy can be found in *Appendix A: Search strategies*.

Inclusion criteria

We sought primary studies about individuals who had experienced a life-changing event and/or family or carers seeking justice on behalf of the person who experienced the event regarding their experiences and/or views of redress and reconciliation processes following this event. Studies needed to be conducted in high-income countries with the redress and/or reconciliation processes occurring within health/social care systems, child protection or sudden death investigations, homicide reviews or any other service or professional context identified by our searches where findings are amenable to importing into the health care context. No limits to the age of participants or date of publication were set.

Inclusion criteria were applied to the title and abstract of each study independently by two reviewers (GJMT, LS, SB, HL), with disagreements resolved through discussion or referral to a third reviewer as required. The full texts of each study were then screened in the same way.

Data extraction and quality appraisal

Table 1 illustrates data which were extracted from included study. Data extraction was completed by one reviewer (LS, HL) and checked by a second (SB, JTC, RG, LS, GJMT, HL), with consultation with a third reviewer to resolve any disagreements.

Table 1: Data extracted from included studies

Data	Description
First author and year of publication	For example, Burns 2006
Type of publication	Is the study a journal article, dissertation, government or website publication
Country of data collection	For example, the Netherlands, the UK
Focus/Aim of review	The primary/secondary aims of each study relevant to the aims and objectives of the review
Field, type and consequence of life-changing event	The field the life-changing event occurred within (Medical, Sexual, police/prison, employment, CSA, suicide), type of life-changing event (e.g. medication error, delayed treatment) and consequence (e.g. disability, death)
Participants and age	Eligible participants as stated within our review's inclusion criteria, their mean age & age range
Other stakeholders and age	Other participants in the study who have not experienced a life-changing event and their mean age & age range
Redress-reconciliation process	Describes the stage of the redress and reconciliation pathway participants are providing their views on
Year of data collection	Year in which each study collected data from participants
Recruitment strategy	How participants were recruited for the study
Inclusion criteria	Criteria implemented by each study to determine eligible participants
Setting and method of data collection	Where the research was conducted (e.g. home, hospital) and how data was collected (e.g., focus group, interviews)
Data analysis	The type of data analysis method used (eg thematic analysis, grounded theory)
Quality rating	Quality rating as indicated by modified Wallace checklist

CSA=Child Sexual Abuse, UK=United Kingdom

We appraised the quality of all studies prioritised for inclusion in the framework synthesis using the Wallace Checklist (2004).(4) As with data extraction, critical appraisal was undertaken by one reviewer (LS, HL) and checked by a second (SB, JTC, RG, LS, GJMT, HL) with disagreements resolved through consultation with a third reviewer.

Synthesis of the evidence

We tabulated the summary descriptive data from all included studies and described it narratively. These data encompassed key features of the sample, methods and quality appraisal from studies prioritised for inclusion in the framework synthesis.

To ensure the review remained deliverable within the time frame available, we prioritised a sample of the included studies for framework synthesis. All the studies exploring experiences of redress and reconciliation following a medically life-changing event were prioritised for synthesis. In addition, we also prioritised a sample of studies where the life-changing event experienced was non-medical. These studies were identified through purposive sampling and contained data which supplemented subthemes identified in the health field, where there were few details or little evidence from the medical examples alone.

We imported the prioritised studies into NVivo v software and synthesised them using a 'Best-Fit' framework synthesis approach based on the work of Daniels and Sabin (1997;1998;2000).(5-7) Key concepts from this framework can be seen in *Appendix B: Stages of framework synthesis: Table 22*, and relate to key aspects of a procedurally fair redress-reconciliation process. This framework was revised in a series of stages using a process of iterative coding to ensure the final themes and subtheme best represented the extracted data (see *Appendix B: Stages of framework synthesis: Table 23-24*).

Stakeholder involvement

We worked alongside a variety of advisors from the DHSC to ensure the findings meet the needs of individuals who will use them. Further details on stakeholder involvement can be found in

Part 2: Full description of methods and framework synthesis results of the report.

Despite making contact with several organisations representing individuals seeking redress-reconciliation following a life-changing event, we were unable to identify many individuals with experience of seeking redress-reconciliation following a medically adverse event who were able to contribute to this review. Two people with experience of medically life-changing events were identified through existing patient and public involvement networks from the Faculty of Health and Life Sciences at the University of Exeter. They provided insight based on their lived experience of adverse medical events, which corroborated the findings of this review and identified important limitations of the evidence included within the review, thus influencing our recommendations for further research and clinical practise.

Results

Our results section is structured as follows:

- 1) **Summary of main findings:** presentation of the key findings from the framework synthesis and how these may relate to the research questions of this review;
- 2) **Descriptive results:** this section will summarise the key features of the studies included in our review, including key characteristics of the participants, methods and study quality;
- 3) **Overview of findings from the framework synthesis:** a summary of the key themes identified from the studies included in the synthesis. Full detail of the results of the framework synthesis can be found in

4) *Part 2*: Full description of methods and framework synthesis results of the report.

Following the write-up of the themes identified by the framework synthesis, we will provide further detail regarding how the content of these themes relates to our research questions, and particularly how our findings could be applied to 'historical cases' to determine who has already experienced a fair redress-reconciliation process.

Summary of main findings

- Fifty-three studies (61 papers) met the criteria for inclusion in this review. The types of life-changing event included in these papers included medical(n=31), homicide(n=5), work-related death(n=4), suicide(n=3), missing person (n=1), death in police custody/following contact with police(n=3) and child sexual abuse (CSA) (n=6).
- We prioritised 41 studies (47 papers) for inclusion in the framework synthesis. These included all the studies representing the process of redress and reconciliation following a medically life-changing event. None of these studies reported experiences of individuals who were still actively seeking justice following a non-recent, or “historical”, medical event. Other life-changing events represented within the synthesis included homicide (n=3), CSA (n=2), employment/work-related death (n=2), death in custody (n=1) and suicide (n=2).
- The majority of studies prioritised for framework synthesis scored positively on at least 8 of the 14 items on the Wallace checklist. Studies scored well on items requiring a clear research question, appropriate study design, adequate sample, data collection and appropriate generalisation of results. In general, reporting of the theoretical or ideological perspective of the authors, and the influence of this on study design, methods and findings, was poorly reported.
- Four themes were identified by the framework synthesis. The first three themes, 1) Transparency, 2) Person-centred and 3) Trustworthy highlight the procedural elements of the redress and reconciliation which need to be in place for the process and its outcomes to be considered fair. The final theme, Restorative Justice, considers how the relationships developed between the stakeholders within the redress-reconciliation process can influence the procedural aspects of the process. This theme considers how the redress and reconciliation process is emotionally experienced by justice seekers and how this may influence perceptions of its fairness.
- Thirteen elements of a fair redress and reconciliation process which could be applied to historical life-changing events were identified. These were as follows:
 - *Opportunity to develop a comprehensive account of the life-changing event and redress-reconciliation process*
 - *Key information made available*
 - *Joint reflection on systematic factors which may have influenced the redress-reconciliation process*
 - *Assessment of needs and provision of ongoing support*
 - *An apology*

- *Identifying and implementation of points of learning*
- *Achievement of other meaningful outcomes*
- *Access to a reasonable and consistent process*
- *Mechanisms in place to support the challenge of institutional_accounts and/or decisions made*
- *Opportunities for objective oversight or input*
- *Opportunity to meet those perceived to be responsible for harm*
- *Validation of experiences*
- *Meaningful action for those who have experienced harm*

These elements of a fair process could be used as a basis to identify historical patient cases where some further intervention might be indicated.

Descriptive results

Search results

The bibliographic database searches identified 4350 records. Following the de-duplication process, there were 2778 unique records from bibliographic database searches. At title and abstract screening, 2726 records were excluded leaving 52 studies to screen at full text. A further 1755 records were identified via alternative search methods, including forward citation searches (n=301), Google Scholar (n=720), backwards citation searches (n=20), targeted database searches (n=708), and website searches (n=3). We also included three studies which were identified in our scoping searches prior to the commencement of the review. Following the screening process, an additional 90 records were identified for full-text screening via the alternative search methods. In total 140 records were screened at full text. Of these, 79 records were excluded for the reasons listed in *Figure 1*: PRISMA diagram. For a full list of exclusions at full-text screening, please see *Appendix C*: List of excluded studies. In total, 61 records met the eligibility criteria for inclusion in this review.

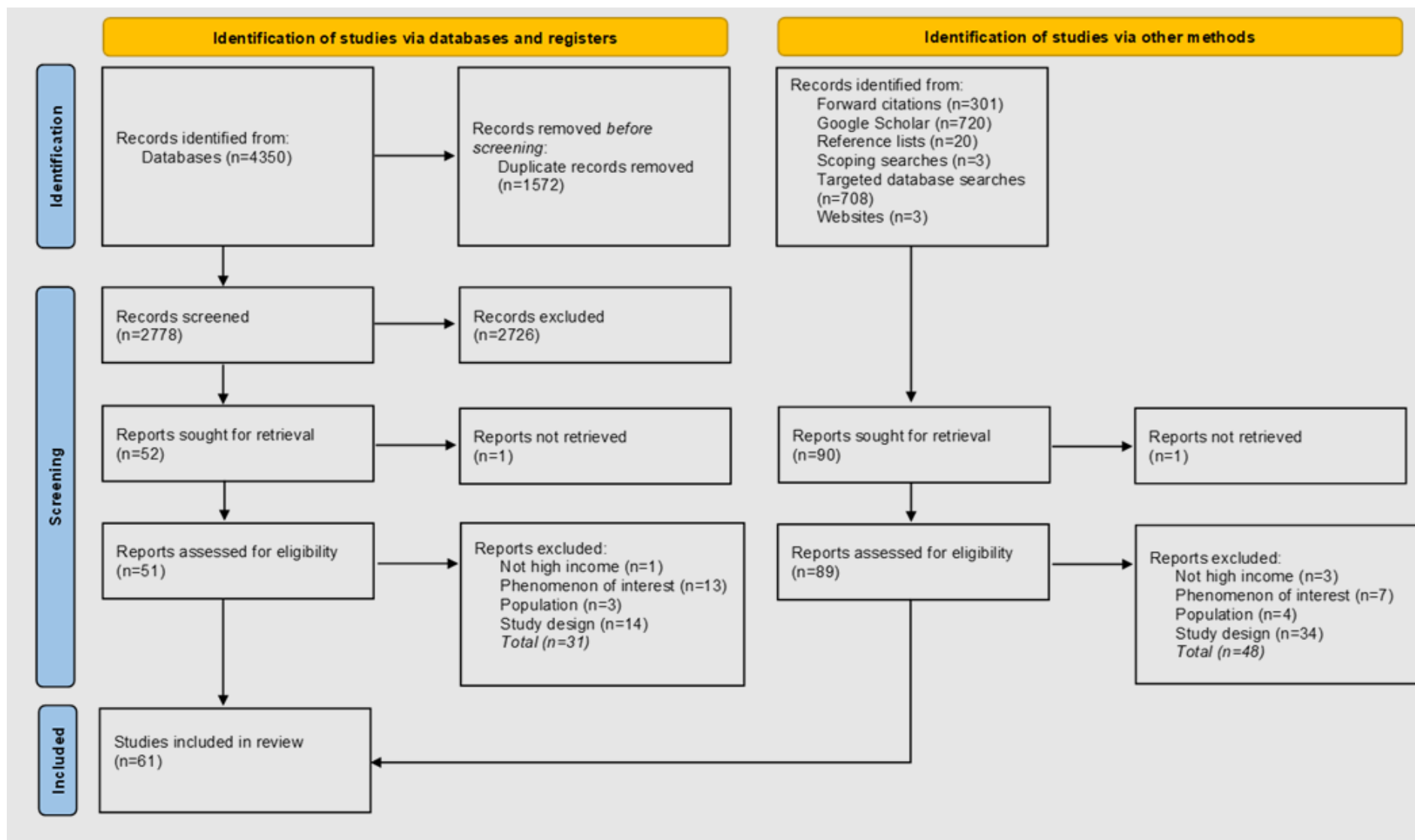


Figure 1: PRISMA diagram

Overview of studies

Details of study and participant characteristics for the 53 studies (61 papers) which met our eligibility criteria are summarised within the review overview table (see *Appendix D: List of included studies*). (21-27) The types of life-changing event included in these studies included medical (n=31),(21, 22, 24-56) homicide (n=5),(23, 57-61) work-related death (n=5), (62-67) suicide (n=3),(68-70) missing person (n=1),(71), death in police custody/following contact with police (n=3),(72-74) and child sexual abuse (CSA) (n=6).(75-81)

41 studies (47 papers) were prioritised for inclusion in the framework synthesis using the approach described in the *Methodology* section of this report.(21, 22, 24-60, 64, 65, 68, 74, 76, 77, 80) (69) *Table 2* illustrates the stage at which papers contributed to the framework synthesis. The key characteristics of the studies which were prioritised for the framework synthesis are provided below.

Table 2: Evolution of framework synthesis - papers contributing to each stage

Stage of framework	Papers added (N)	Supporting papers
Stage 1: Themes and subthemes derived from Daniels and Sabin(1997;1998;2000)(5-7)	Papers from the health field with the highest quantity of information relevant to our research questions: N=17	Bakbakhi,(28) Chiu(29), IPSOS,(41) Duclos,(30) Hagensen,(34) ledema 2007, 2011, 2012a,(38-40) Kim,(43) Martin,(45) McQueen,(48) Melville,(49) Moore 2017a, Moore 2017b,(50, 51) Myren,(52) Pyo,(54) Sorensen(55)
Stage 2: Addition of descriptive codes. Content moved within and across themes/subthemes	Remaining papers from the health field with a Medium or low quantity of information relevant to our research questions: N=18	Fisher 2016,(32) Gallagher 2009,(33) Loren 2021,(44) Kent,(42) Mazor 2010, 2012, 2013,(26, 46, 47) Piper 2014,(53) Wiig 2021,(56) Boumann, (21) Butler, (22) Kamin-Friedman,(25) Hernan 2014,(24) Hannawa,(35) Hovey,(36) ledema 2012b,(37) Etchegary,(31) Ocloo,(27)
Stage 3: Further iterative coding of information to descriptive codes. Changes in position and names of subthemes to reflect content. Structure of final themes influenced by external literature and content of second stage medical studies. Creation of final theme "Restorative Justice"	Papers from non-health fields which contained data relevant to weaker subthemes "Mechanism for challenge" and "Rationale for decisions. Also added papers which spoke to concept that for some individual's justice is not possible: N=12	Biddle,(68) Burns,(57) Eastwood 1998a/b,(76, 77) Englebrecht,(58) Maderia 08/10,(59, 60) Matthews 2012,(64) Chapple,(69), Ngo,(65) Saco,(80) Shaw(74)

N=Number

Publication characteristics

Table 3 contains details of the 41 studies (47 papers) identified that were relevant to our aims and objectives and included in the synthesis. The earliest of the studies was published in 1998 (76, 77) with 19 studies published since 2015.(21, 22, 25, 28, 32, 34, 35, 41, 43-45, 48, 50-52, 54, 56, 65, 80) Studies were conducted by teams from 11 different countries, with 12 studies coming from the USA,(26, 30-33, 44, 46, 47, 50, 57-60, 80) eight from Australia,(22, 24, 37-40, 53, 55, 64, 65, 76, 77) nine from the UK,(82-84) (27, 28, 41, 45, 48, 49, 68, 69, 74) two from each of Norway,(34, 56) the Netherlands, (21, 52) and South Korea,(43, 54) and one each from Canada,(36) New Zealand,(51) Sweden,(42) Taiwan,(29) Israel (25) and Switzerland.(35) Forty of the papers were peer-reviewed journal publications,(21, 22, 24-40, 42-47, 50-56, 58-60, 64, 65, 68, 69, 80) two government publications,(41, 77) one website publication,(74) 1 non-peer-reviewed journal,(48) and three dissertations.(49, 57, 76)

Participant characteristics

Across the 41 studies (47 papers) included in the synthesis, participants seeking redress or reconciliation included patients/victims only (n=9),(25, 27, 33-35, 42, 46, 47, 52, 54) relatives of patients/victims (n=17),(22, 26, 28, 29, 32, 37, 41, 44, 56-58, 64, 65, 68, 69, 74, 80) and patients/victims and their relatives (n=16).(21, 24, 30, 31, 36-40, 43, 45, 48-51, 53, 55, 59, 60, 76, 77) Other stakeholders were also interviewed in 19 of the studies (21 papers).(21, 25, 27, 31, 33, 36, 40-42, 44, 50-52, 55, 56, 59, 60, 74, 76, 77, 80) The mean age or age range of all participants was not reported in 21 of the included studies (24 papers).(21, 22, 25, 27, 30, 31, 36-42, 45, 49, 53, 55, 56, 58, 64, 65, 68, 74, 80) Either the mean age or range was reported for some of the participants in five studies (7 papers). (26, 44, 52, 59, 60, 76, 77) For the 16 studies (15 papers) which reported mean age or age range, participants' age varied from 12 years (76, 77) to 83 years.(24)

Individual study sample sizes for participants seeking redress or reconciliation ranged from one,(33, 37, 54) to 158,(74) with 23 studies (24 papers) having sample sizes 20 and below,(21, 22, 25, 27-31, 33, 34, 36, 37, 41-43, 45, 48, 52-54, 58, 64, 68, 80) 13 studies (15 papers) between 21 and 40 sample size,(24, 26, 40, 44, 49, 50, 55-57, 59, 60, 65, 69, 76, 77) and seven studies (8 papers) had sample size 60 and above.(32, 35, 37, 39, 46, 47, 51, 74) Adverse events experienced by participants in these studies were in the health field (n=31),(21, 22, 24-56) homicide (n=3),(57-60) sexual abuse (n=2),(76, 77, 80) employment/work-related death (n=2),(64, 65) death in custody (n=1),(74) and suicide (n=2).(68, 69) Of the studies that were in the health field, the majority were focused on the disclosure phase of the justice-seeking process(n=17).(22, 24, 26, 28, 30, 32, 34-40, 42-47, 53, 55)

Table 3: Study characteristics

First author, date Country Publication type	Aim/focus of publication	Field of AE: Type/name of AE	People seeking justice interviewed [N; Number Female], Mean Age [range]	Other stakeholders interviewed [N; Number Female], Mean Age [range]	Name & description of redress/reconciliation process process	Phenomenon of Interest
Bakbakhhi 2017 (28) UK [JA]	Parents' views on involvement in the PNMR process	Medical: Mid-trimester loss, Pregnancy termination for congenital abnormality, Stillbirth, Neonatal death	Bereaved parents [11; 8], MA - NR [early 20s-mid 40s]	NA	PNMR - review of all losses between 22 wks gestation - 28 days after birth	AE review
Biddle 2003 (68) UK [JA]	Bereaved people's experiences of suicide inquest	Suicide: Death	Individuals bereaved by suicide 16[15], MA - NR[NR]	NA	Coroner's inquests – NR	Coroner's Inquest
Bouwman 2018 (21) Netherlands [JA]	Role patients & families have in formal processes after sentinel events	Medical: Sentinel event, Suicide, Suicide attempts	Patient [4;NR], Family members [7;NR], MA - NR[NR]	Patient counselor [2;NR], Family counselor [5;NR], Director [3;NR], Members of family committee [4;NR], Psychiatrist [4;NR], Medical director [1;NR], Inspector [5;NR], MA - NR[NR]	Sentinel event analysis - Analysis of an unintended event, relating to quality of care & which lead to death of/ harmful consequence for patient	AE review
Burns 2006 (57) USA [Dissertation]	Experiences of murdered victims' families with the criminal justice system	Homicide: Death	Family members of homicide victims [23;18] MA - 53.8 [32-74]	NA	Death penalty - NR	Litigation process
Butler 2019 (22) Australia [JA]	Experiences of police presence in PICU after the death of child	Medical: Death [SIDS, Metabolic disease, Septic shock]	Bereaved parents [9;NR], MA - NR[NR]	NA	Coroner investigation - Identification of body & collection of statements from parents	Disclosure - Investigation

First author, date Country Publication type	Aim/focus of publication	Field of AE: Type/name of AE	People seeking justice interviewed [N; Number Female], Mean Age [range]	Other stakeholders interviewed [N; Number Female], Mean Age [range]	Name & description of redress/reconciliation process process	Phenomenon of Interest
Chapple 2012 (69) UK [JA]	People's accounts of their acceptance or resistance to the coroner's verdict	Suicide: Death	People bereaved by suicide [40; 28], MA- NR; [27-40 (7), 41- 50 (9), 51-60 (17), 61-70 (7)]	NA	Coroner process - Coroner decides which witnesses to call, what evidence to hear, interprets the evidence	Coroner's Inquest
Chiu 2010 (29) Taiwan [JA]	Patient's view of the meaning of filing malpractice lawsuits	Medical: Physician/ hospital malpractice, outcomes (vegetative state, irreversible complication, death)	Family members [13;8]. MA - NR [36- 45 yrs(6), 46-55 yrs (6), 56-60 yrs (1)]	NA	Malpractice claim - 1] Litigation, 2] Negotiation with hospital assisted by Department of Health	Litigation process
Duclos 2005 (30) USA [JA]	Perceptions of patient-provider communication after medical AE	Medical: Perforations, Surgical errors, Suture infections	Patients[16,NR], Spouses[3,NR], MA - NR[NR]	NA	3Rs - Encourages physicians to explain apologize, & what can be done	Disclosure - Communication
Eastwood 1998a (77) Australia [JA]	Same as Eastwood 1998b					
Eastwood 1998b (76) Australia [Dissertation]	Processes in the criminal justice system which impact upon sexually abused female children	Sexual abuse: Child sexual abuse	Female children 12, MA - 14.5 [12-18yr], Non offending Parents [11], MA - NR[NR]	Complainants witnesses [4;NR], Pact workers [6;NR], Legal personnel [3;NR], MA - NR[NR]	Litigation – NR	Litigation process
Englebrecht 2014 (58) USA [JA]	Experiences of homicide survivors within the criminal justice system	Homicide: Death	Homicide victims families [18;13], MA - NR[NR]	NA	Litigation -NR	Litigation process

First author, date Country Publication type	Aim/focus of publication	Field of AE: Type/name of AE	People seeking justice interviewed [N; Number Female], Mean Age [range]	Other stakeholders interviewed [N; Number Female], Mean Age [range]	Name & description of redress/reconciliation process process	Phenomenon of Interest
Etchegaray 2014 (31) USA [JA]	Involving patients & family members going through disclosure in event analysis process	Medical: NR	Patients [5;NR], Family members [4;NR], MA - NR[NR]	Clinicians [6;NR], Hospital administrators [13; NR], MA - NR [NR]	Medical Error Event Disclosure & Analysis - Identifies reasons for error & steps to prevent future error	AE review
Fisher 2016 (32) USA [JA]	Surrogate decision makers' [SDMs] perspectives on preventable care breakdowns of critically ill patients	Medical: Delayed, incorrect, missed diagnosis, medication, treatment & care, Premature/ inadequate discharge, death	SDM [70, 52] MA 53.7 [21-78]	NA	Raising concern on breakdown in medical care & communication - NR	Disclosure - Raising concern
Gallagher 2009 USA; [JA] (33)	Review of medical error	Medical: Wrong-site surgery	Female Patient [1]; Age 62 yrs	Medical personnel [1]	Disclosure strategy - NR	Post Investigation
Hagensen 2018 (34) Norway [JA]	Patients' perspectives of the occurrence of, disclosure of, & healthcare orgs' responses to AEs	Medical: Inadequate surgery; Surgery resulting in nerve damage; Incorrect anaesthesia, medication; Radiation injury; Deficient treatment	Patients[15,9], Median 61 yrs[43- 70]	NA	Health & Social Services ombudsmen - NR	Disclosure
Hannawa 2017 (35) Switzerland [JA]	What features of a disclosure- motivations, knowledge & skills do Swiss patients perceive as competent?	Medical: Medical error	Patient 63[40] MA 50.67 [22-80]	NA	MEDC - Predicts provider's disclosure competence vary as a function to which a provider discloses an error appropriately & effectively	Disclosure

First author, date Country Publication type	Aim/focus of publication	Field of AE: Type/name of AE	People seeking justice interviewed [N; Number Female], Mean Age [range]	Other stakeholders interviewed [N; Number Female], Mean Age [range]	Name & description of redress/reconciliation process process	Phenomenon of Interest
Hernan 2014 (24) Australia [JA]	Experiences of rural general practice & perceptions of safety in health care setting	Medical: Misdiagnosis, Delays in treatment, Deficient care procedures, Medication errors, Psychological harm	Patients & Carers 26[14], MA - 59 [27- 83]	NA	Disclosure - NR	Disclosure - Raising concern
Hovey 2014 (36) Canada [JA]	Re-interprets data from patients/ families who experienced medical AE	Medical: Medically induced trauma due to healthcare systems failures	Patient/family members [15;NR], MA - NR[NR]	Health professionals [6;NR], MA - NR[NR]	Disclosure & communication – NR	Disclosure
Iedema 2007 (40) Australia [Government publication]	What it is about open disclosure that works, for whom does it work?	Medical: Infection, drug overdose, Missed diagnosis, Wrong site surgery	Patients [15;NR] Family members [8;NR], MA - NR[NR]	Health professionals [131; NR], MA - NR[NR]	Open disclosure - expressing regret, keeping patient informed, providing feedback on investigations & steps to prevent recurrence	Disclosure
Iedema 2011 (39) Australia [JA]	Patients'/relatives' experiences of AE & incident disclosures	Medical: Death, Failures, errors or complications in medication, medical, diagnostic or surgical procedures, delayed treatment, & hospital- acquired infections	Patients [39;NR], Family members [80;NR], MA - NR[NR]	NA	Open disclosure – NR	Disclosure
Iedema 2012a (38) Australia; [JA]	Understand what patients & family members know of failures in care	Same as Iedema 2011				

First author, date Country Publication type	Aim/focus of publication	Field of AE: Type/name of AE	People seeking justice interviewed [N; Number Female], Mean Age [range]	Other stakeholders interviewed [N; Number Female], Mean Age [range]	Name & description of redress/reconciliation process process	Phenomenon of Interest
Iedema 2012b (37) Australia [JA]	Experience of woman whose husband died from AE	Medical: Vasopressin overdose	Wife [1], Age - NR	NA	Disclosure - explanation of AE, apology, patient's care plan, investigation & response to AE	Disclosure
IPSOS MORI 2016 (41) UK [Government publication]	Journey of parents with a child that experienced birth injury	Medical: Brain injury during birth	Parents/families with a child who experienced brain injury during birth [7;NR], MA - NR[NR]	Stakeholder [11;NR], Clinicians [4;NR], General public discussion groups [32;NR], MA - NR[NR]	Litigation - NR	Litigation
Kamin-Friedman 2021 (25) Israel [JA]	Objectives of Israel's Vaccine Injury Compensation Law	Medical: Vaccine-related injuries	Victims [3;NR], MA - NR[NR]	Legal practitioners [4;NR], Physician [2;NR], Jurists [2;NR], Researchers [2;NR], MA - NR[NR]	Vaccine Injury Compensation law – Experts determine connection between vaccine & injury	Post AE- Other
Kent 2008 (42) Sweden [JA]	Reappraisal of current handling of patient complaints in Sweden & elsewhere	Medical: Dental treatment error, Others- NR	Patients [6; NR], MA - NR[NR]	Representatives of patient support orgs & medico-legal specialists [NR], MA - NR[NR]	HSAN - Evaluates dissatisfaction reports sent by patients, their relatives or Socialstyrelsen	Disclosure
Kim 202 (43) South Korea [JA]	Experiences of patients & their families regarding disclosure after patient safety incidents	Medical: Surgical/procedure related, Diagnosis, Treatment, Death, Permanent disability	Patients [7, NR], Family members [8, NR], MA - 28.93[NR]	NA	Disclosure -NR	Disclosure

First author, date Country Publication type	Aim/focus of publication	Field of AE: Type/name of AE	People seeking justice interviewed [N; Number Female], Mean Age [range]	Other stakeholders interviewed [N; Number Female], Mean Age [range]	Name & description of redress/reconciliation process process	Phenomenon of Interest
Loren 2021 (44) USA [JA]	Experiences of parents & healthcare providers with communication about birth-related AE	Medical: Adverse birth- related new-born outcomes - Brachial plexus injuries, Respiratory problems, Fever/infection, Cardiac problems	Parents [27,20], MA - NR[NR]	Healthcare providers [47, NR], MA - 44.5 [NR]	Communication - NR	Disclosure - Communication
Maderia 2008 (59) USA [JA]	How do victims' family members & survivors form perceptions of offending criminal & conclusions about the "meaning" of the AE	Homicide: Death, Survivors of bombing	Individuals who were victims' family members or survivors of the Oklahoma City bombing [27;17], MA - NR [mid-30s to low-70s]]	Rescue worker [2;NR], MA - NR[NR]	Litigation -NR	Litigation process
Maderia 2010 (59) USA; [JA]	Understanding of closure	Same as Maderia 2008				
Martin 2021 (45) UK [JA]	Orgs responses to concerns & complaints that give rise to problems	Medical: NR	Patients & family members[18;NR], MA - NR[NR]	Staff[70;NR], MA - NR[NR]	Openness initiatives - raising concerns, harm disclosure, investigations into quality & safety	Disclosure - Raising concern
Matthews 2012 (64) Australia [JA]	Experiences of surviving families' institutional responses to workplace death	Employment: Workplace death	Relatives of victims of workplace death 7[6], MA - NR[NR]	NA	Ranges from disclosure to litigation - NR	Disclosure and Litigation process

First author, date Country Publication type	Aim/focus of publication	Field of AE: Type/name of AE	People seeking justice interviewed [N; Number Female], Mean Age [range]	Other stakeholders interviewed [N; Number Female], Mean Age [range]	Name & description of redress/reconciliation process process	Phenomenon of Interest
Mazor 2010 (26) USA [JA]	Events parents perceived as error and response by providers	Medical: Incorrect medication, Post- operation infection, Missed/Incorrect diagnosis	Parents 35[33]; MA - NR[21-59 yrs]	NA	Disclosure - NR	Disclosure
Mazor 2012 (47) USA; [JA]	Patients perception of preventable, harmful event & interactions with clinicians after event	Same as Mazor 2013			Disclosure & communication - NR	Disclosure
Mazor 2013 (46) USA [JA]	Patients' perspectives on problematic events & on clinicians' responses to these events	Medical: Perceived delays in diagnosis and/or treatment, Infections delaying recovery, Delayed response to surgical complications or chemotherapy side effects	Cancer patients 78[75], MA - 58 [36- 79]	NA	Apology & Disclosure - NR	Disclosure - Apology
McQueen 2021 (48) UK [JA not peer- reviewed]	Explore what 'good' patient & family involvement in healthcare AE reviews may involve	Medical: Adult death/ palliative care, Delayed diagnosis, Fall, Medication error, Mental health, Addiction, Suicide, Neonatal death, Surgical complications	Patients & family members 19[10], MA - NR [35-44 yrs (8)], 45-54 yrs (4), > 55 yrs (7)]	NA	AE review – explanation of what went wrong, why & receive an apology for any harm that has occurred	AE review
Melville 2012 (49) UK [Dissertation]	Investigate how claimants experience their lawyer's efforts	Medical: Minor injuries, Moderate injuries, Serious injuries, Death	Patients[19;NR], Family members [11;NR]; 30 total [18 female], MA - NR[NR]	NA	Litigation - Using law- firm to sue NHS	Litigation process

First author, date Country Publication type	Aim/focus of publication	Field of AE: Type/name of AE	People seeking justice interviewed [N; Number Female], Mean Age [range]	Other stakeholders interviewed [N; Number Female], Mean Age [range]	Name & description of redress/reconciliation process process	Phenomenon of Interest
Moore 2017a (50) USA [JA]	Experiences of patients and family members with medical injuries and CRPs	Medical: Death, Permanent physical harm, Temporary physical harm	Patients [27, NR], Family members [3, NR], MA - NR [18-20 (1), 21-39 (1), 40-64 (26); ≥65 (2)]	Staff [10, 4] MA - NR [18-20 (0), 21-39 (0), 40-64 (9) ≥65 (1)]	CRP - disclose AE, investigate, apologize, explain what happened, & proactively offer compensation	Litigation process
Moore 2017b (51) New Zealand [JA]	Factors that facilitate/impede reconciliation following patient safety incidents	Medical: Sentinel Injury; Serious injury; Major injury; Minor injury	Patients [6, NR], Family members [56, NR], MA - NR [20–39 (6); 40–64 (54); 65+ (2)]	Admin of public hospitals [12;NR], Lawyers specialising in ACC claims [5;NR], ACC staff [3;NR], Total - 20[10]; MA - NR [20–39 (2), 40–64 (18)]	Reconciliation - engaging with patients & families about an AE & offering remediation	Litigation process
Myren 2021 (52) Netherlands [JA]	Explore how patient participation at M&MM can be practiced and learning points to achieve change	Medical: Injury, Blood loss, Infection leading to prolonged hospital stay or readmission	Patients [8;NR], MA - NR[44-80]	Healthcare professionals [17;NR], MA - NR [NR]	M&MM - learning from choices & actions that lead to AEs which ultimately leads to improved healthcare & patient outcomes	AE review
Ngo 2021 (65) Australia [JA]	What are the reasons why family members may want/ not want an inquest after work AE?	Employment: Workplace death	Family members bereaved by a fatal work incident [40; NR] MA - NR [NR]	NA	Coronial inquests - Determine how a person died and circumstances leading to death	Coroner's Inquests
Ocloo 2010 (27) UK [JA]	Looks at the occurrence of medical harm	Medical: Medical harm [Misdiagnosis, wrong prescription, others - NR]	Adults with experience of medical harm[10; NR], MA - NR[NR]	Other participants [14 groups; NR], Individuals questionnaires[18;NR], MA - NR [NR]	Complaint procedures, professional regulation & litigation - NR	Litigation process

First author, date Country Publication type	Aim/focus of publication	Field of AE: Type/name of AE	People seeking justice interviewed [N; Number Female], Mean Age [range]	Other stakeholders interviewed [N; Number Female], Mean Age [range]	Name & description of redress/reconciliation process process	Phenomenon of Interest
Piper 2014 (53) Australia [JA]	Analyse rural patients'/ families' experiences of open disclosure	Medical: Delayed treatment, Ongoing suffering, Death	Patients & relatives, [13;NR], MA - NR [NR]	NA	Australian Open Disclosure - Expression of regret; explanation of AE; steps to manage & prevent recurrence	Disclosure
Pyo 2019 (54) South Korea [JA]	Life experience of victims of medical accidents	Medical: Physical disability [Paraplegia]	Female Patient [1], Mid -30s	NA	Medical litigation - Victim has the burden of proving medical malpractice	Litigation process
Saco 2018 (80) USA [JA]	What injustices do homicide survivors experience? How does the system perpetuate these injustices?	Homicide: Death	Homicide survivors among experts [12; NR], MA - NR[NR]	Other experts [24;NR], MA - NR[NR]	Judicial process - NR	Post litigation/ Post Justice seeking
Shaw 2007 (74) UK [Website publication]	Procedures that surround investigation of deaths in prison & police custody	Death in custody	Families of persons who died in custody [158;NR], MA - NR[NR]	Caseworkers [NR], Legal practitioners [23;NR], NGOs [NR], MA - NR[NR]	Disclosure & Inquests hearing - NR	Coroner's Inquest
Sorensen 2010 (55) Australia [JA]	Patients & health professionals experience of Open Disclosure	Medical: NR	Patients [15; NR], Family members [8; NR], MA - NR[NR]	Nursing [20;NR], medical [49;NR], Clinical admin managerial [59;NR], Policy coordinators [3;NR], MA - NR[NR]	Open Disclosure - Health managers & clinicians are accountable to patients for the outcomes of care	Disclosure

First author, date Country Publication type	Aim/focus of publication	Field of AE: Type/name of AE	People seeking justice interviewed [N; Number Female], Mean Age [range]	Other stakeholders interviewed [N; Number Female], Mean Age [range]	Name & description of redress/reconciliation process process	Phenomenon of Interest
Wiig 2021 (56) Norway [JA]	Next of kin's perspective of a involvement in new regulatory investigation process of AE	Medical: Death	Next of kin [29,NR], MA - NR[NR]	Regulatory inspectors [NR], MA - NR[NR]	Regulatory Methods Innovation - to improve user involvement in regulatory practice	AE review

ACC = Accident Compensation Corporation; AE = Adverse Event; CRP = Communication-and-Resolution Programs; HSAN=Hälsa – och Sjukvårdens Ansvarsnämnd (The Swedish National Medical Responsibility Board; M&MM = Morbidity & Mortality Meeting; JA – Journal Article; MA = Mean Age; MEDC = Medical error disclosure competence; NA – Not Applicable; NR – Not Reported; PNMR = Perinatal mortality review process; 3Rs = Recognize, Respond, Resolve

Characteristics of methods

A summary of methods employed in participants' recruitment, data collection and data analysis in the included studies can be found in *Table 4*. Purposive sampling through contacts such as targeted organisations, informants and support groups was a major recruitment strategy.(24, 28, 30, 31, 35, 36, 40, 45, 49-52, 55, 57, 58, 64, 68, 76, 77) Other examples of ways in which participants were recruited include mailing letters,(22, 34, 59, 60, 74) advertisements in print media, websites, news and/or social media,(26, 37-40, 43, 48, 54, 59, 60, 65, 69) and snowball sampling.(29, 41, 51, 80) Although data collection occurred between the years 2003 to 2019 for 26 studies,(24, 26-29, 31, 32, 34, 35, 37-45, 48, 50, 51, 53, 54, 56-60, 65, 69) the years for others were not reported.

Qualitative data collection technique involved focus group/group discussions (n=7),(24, 28, 30, 35, 56, 58, 80) interviews (n=34),(21, 22, 25-27, 29, 31-34, 36-54, 57, 59, 60, 64, 65, 68, 69, 76, 77, 80) focus groups and interviews (n=2),(56, 80) and questionnaires containing qualitative questions (n=1).(74) Additional methods such as observation, field notes, document analysis and interview guides were employed in 23 studies (29 papers).(21, 22, 25-27, 29, 31-34, 36-54, 57, 59, 60, 64, 65, 68, 69, 76, 77, 80) Focus groups and interviews were carried out face to face (n=21),(22, 30, 31, 34, 37-40, 43, 44, 50-52, 54, 55, 57-60, 65, 68, 69, 76, 77, 80) and/or via telephone (n=15).(31, 32, 38, 39, 43, 44, 48, 50-52, 55, 57, 59, 60, 65, 68, 80) One study had a participant who returned their response to interview questions via email (39) and the remaining studies (n=11) did not report the mode of the focus groups or interviews.(21, 25-27, 29, 30, 33, 36, 41, 45, 49)

Of the 41 studies (47 papers) included in the synthesis, nine reported using grounded theory to guide the analysis of collated data,(21, 25, 30, 45, 50, 58-60, 68, 80) one was guided by sociological theory,(42) and one guided by philosophical hermeneutics of Gadamer,(36) while the others were not specifically reported. Techniques employed include but are not limited to thematic analysis and/or constant comparative technique,(22, 28, 68, 69) constructivist inquiry,(76, 77) discourse analysis,(39, 40, 53) and directed content analysis.(32, 44, 46, 47) Expanded detail is provided in *Table 4*.

Table 4: Study methods

Author, Date Year of data collection	Recruitment method	Inclusion criteria [patients, participants]	Data collection setting Data collection technique	Type of analysis performed (name/brief description)
Bakbakhi (28)2017 [2015]	Purposive sampling used to recruit. Participants identified via key informant (bereaved parent and co-investigator), local Bristol Sands support grp, and International Stillbirth Alliance	Experienced a mid-trimester loss, stillbirth, neonatal death, pregnancy termination for congenital abnormality	Small private conference room in neutral venue outside hospital premises Focus group using interview schedule, field notes & observational behaviour log	Thematic analysis: six-stage process: familiarisation, generation of initial codes, searching for themes: reviewing themes, defining themes, naming themes
Biddle 2003 (68) [NR]	Recruited from a local suicide support group of a national bereavement orgs, contact made by attending annual conference, advertising in newsletter & snowballing	Individuals bereaved by suicide	Face to face and telephone Semi-structured In-depth interviews using a topic guide	Data collection and analysis using a constant comparative technique. Transcripts coded to identify & organise emergent themes& compared across transcripts. Interview topic guide revised accordingly. Matrices used to compare themes' occurrence
Bouwman 2018 (21) [NR]	Contacted a convenience sample of 28 mental healthcare institutions in Netherlands	NR	NR Document analysis and Semi-structured interviews	Transcripts analysed following iterative grounded-theory techniques. Results from policy analysis formed structure. Codes developed and evolved through discussions. Inductive approach combined with deductive methods
Burns 2006 (57) [2005]	Contact with Victim's Services Center in the Attorney General's Office provided access to names & addresses of family members of homicide victims	Relatives of homicide victims that offender is on/ previously on death row, awaiting re-sentencing, or done sentence already	Face-to-face in the respondents' homes or place of employment or telephone Semi-structured open-ended in-depth interviews	Cutting and pasting of pertinent quotes from interview transcripts into index cards. Researcher examined themes emerging from the data and placed them in appropriate categories
Butler 2019 (22) [NR]	Included mailing letters, phone calls from social workers associated with bereavement follow-up, and advertisement at bereavement support grps	NR	Conducted at location of the parents' choice Semi-structured interviews	Thematic analysis as outlined by Braun and Clarke. Line by line coding of transcripts. Codes relating to parental experiences of police presence explored for broader concepts and collated into themes. Themes developed into a concept map

Author, Date Year of data collection	Recruitment method	Inclusion criteria [patients, participants]	Data collection setting Data collection technique	Type of analysis performed (name/brief description)
Chapple 2012 (69) [2007-2008]	Through GPs, support grps, websites, Coroner's office, advisory panel, newspaper, local radio program, conference, safer custody grp, snowball sampling	People bereaved by suicide	All but one was interviewed at home In-depth Interviews	Participants read transcript for checking & modification. Data reread, coded and examined material under codes. Experiences and responses examined across the whole data. Qualitative interpretive approach used combining thematic analysis with constant comparison
Chiu 2010 (29)[2006-2007]	Snowballing method. Further details NR	NR	NR Semi-structured interviews	Thematic analysis: inductive approach grounded in data
Duclos 2005 (30) [NR]	Recruited through malpractice insurance company involved with 3Rs. 3Rs staff telephoned all potential participants	Patients involved with 3Rs whether open or closed case and their spouses	NR Semi-structured focus groups, field notes	Template and edit organising approach. 1) General broad codes related to each semi-structured questions developed. 2) Editing approach to analysis derived from grounded theory
Eastwood 1998a (77)[NR]	Same as Eastwood 1998b			
Eastwood 1998b (76) [NR]	The court support agency (PACT) provided initial contact with participants & their parents/guardians	Female child complainants of sexual abuse and non-abusive parent	Choice of venue determined by participant: Most interviews at home Semi-structured in-depth interview. Research journal for feelings, observations & "gut reactions"	Constructivist inquiry (Lincoln & Guba, 1985): identification of units of meaning, categorisation, identification of patterns and member checks. Credibility of data established via: prolonged engagement, observation, triangulation peer debriefing, negative case analysis, referential adequacy and member checking
Englebrecht 2014 (58) [2011]	Facilitated by: president of a homicide support group through enabling authors attend meetings & letter forwarding to absentees; director of a university center on campus that focused on women's issues; archives of newspapers	Families known to have experienced the death of a loved one to domestic violence, families of homicide victims	University campus 3 semi-structured FGDs centred around three topic areas	Grounded theory approach used to analyse data. Authors individually reviewed the transcripts, met as a group to discuss and reached consensus on the dominant themes that emerged

Author, Date Year of data collection	Recruitment method	Inclusion criteria [patients, participants]	Data collection setting Data collection technique	Type of analysis performed (name/brief description)
Etchegaray (31) 2014 [2010-2011]	Participants identified through Consumers Union. Clinicians & administrators recruited by risk managers at hospitals affiliated with the Uni of Texas	Patients and family members who reported that they or a loved one had experienced an AE while in a hospital	6 University of Texas institutions Interviews were conducted either face-to-face or via telephone	Research members reviewed the interviews, individually identified themes and reached consensus about which themes to retain
Fisher 2016 (32) [2013-2014]	Identified patients and their SDM by screening all ICU patients regularly during the week. Participants contacted via telephone	Patients with age >18 years, acute respiratory failure requiring mechanical ventilation for at least 48h, lack of decision-making capacity with need for a SDM	Over the telephone In-depth interviews. 2 SDMs declined to be recorded in which case detailed notes were taken at the time of the interview	Directed content analysis - Initial coding framework created using interview domains. Codes were added and refined through an iterative process of transcript review, coding, and discussion until consensus was reached
Gallagher 2009 (33) [NR]	NR	NR	NR Case review, interview	NR
Hagensen 2018 (34) [2013-2014]	Ombudsmen obtained sample by performing non-random search in their archives and posted 60 invitation letters	Adults (20-70yrs), AE linked to surgical, medical/orthopaedic treatment at hospital at least 1yr post event	Participants homes/desired place Individual interview using interview guide, Notes & discharge reports	Inductive qualitative content analysis, supported by Malterud's approach. 1) Read and rereading 2) Generation preliminary categories 3)Thematic categories 4) Coding of material in papers
Hannawa 2014 (35) [2014]	Recruitment facilitated by quality management staff of 4 university hospitals and 2 public hospitals in the German-, French-, and Italian-speaking parts of Switzerland. Staff distributed recruitment flyers with an attached registration form to current outpatients	Patients that were Swiss citizens, >18 yrs & able to provide written informed consent. Patients - a hospitalisation within the past 3 years, having a chronic illness, or having a regular source of health care	Hospital 10 focus group meetings. 3 held in the French, 3 in the German and 4 in the Italian-speaking cantons of Switzerland	Transcripts coded in original language into context units. Context units translated into English. Translated context units coded line-by-line into recording units. Recording units classified into higher-level MEDC constructs in accordance with codebook based on the theoretical framework

Author, Date Year of data collection	Recruitment method	Inclusion criteria [patients, participants]	Data collection setting Data collection technique	Type of analysis performed (name/brief description)
Hernan 2014 (24) [2012]	Recruitment sources comprised education and support group meetings for type 2 diabetes self-management, cardiac rehabilitation, group exercise & a mothers' group	Rural and regional patients & carers from south-west Victoria who were frequent users of GP e.g., people with a chronic condition, mothers with child	Victorian towns of Balmoral, Hamilton, Merino and Portland 4 semi-structured focus group interview	Data analysed using a thematic and iterative approach. Narrative analysis used to explore and interpret the lived experience of individuals. Transcripts reviewed by two authors and analysed using the constant comparative method to inductively generate a coding structure that outlined themes and subthemes
Hovey 2014 (36) [NR]	Event-coordinators extended open invitation to workshop participants to join research	NR	NR Individual unstructured interviews	Analysis guided by the philosophical hermeneutics of Gadamer. Enables insight into the subtle transition from factual & chronological recounting of events toward new understandings
Iedema 2007 (40) [2007]	Consumers identified by the relevant pilot facilities' project officers and contacted for permission for the research team to be given contact details	NR	Hospital pilot sites Semi-structured In-depth interview	Coded transcripts tabulated and brought together for verification, comparison & further refinement. Transcripts analysed using semantic discourse analysis
Iedema 2011 (39) [2009-2010]	Through advertising in national broadsheet & tabloid print media, with the help of the health services where the incident occurred, through invitations sent out by two internet marketing companies and by consumer orgs	Documentation of patient experience of AE in Australian hospital in 2008–10; Incident severe-very severe; Patient or family were granted/demanded meeting about the AE; Involved in open disclosure	Half of the interviews conducted face to face in participants' homes, rest over the telephone, 1 by email In depth, semi-structured interviews	Transcripts were discourse analysed with identification of overarching theme domains, cross thematic relationships, and thematic hierarchies. After full verification, thematic domains were imported into and managed in QSR NVivo. The resulting NVivo network of thematic nodes, cross links, and hierarchies enabled identification of the overarching domains of concern
Iedema 2012a (38) [2009-2010]	Same as Iedema 2011			Using 'open coding' analysts coded transcripts. Themes were imported into and reconciled in QSR NVivo

Author, Date Year of data collection	Recruitment method	Inclusion criteria [patients, participants]	Data collection setting Data collection technique	Type of analysis performed (name/brief description)
Iedema 2012b (37) [2010]	Same as Iedema 2011	NR	Home of the respondent In depth semi-structured interview	Case constructed using replicated single-case approach, involving checking and correcting interview details with the patient's wife
IPSOS MORI 2016 (41) [2016]	Parents recruited with the assistance of charities & gatekeepers, e.g., solicitors, advertising on online forums, snowballing	NR	NR Interviews	Narrative synthesis-NR
Kamin- Friedman 2021 (25) [NR]	Purposive sampling involving participants from medicine, law, ethics and vaccine recipients who had suffered injuries	Participants from medicine, law, ethics and vaccine recipients who had suffered injuries	NR Documents review, In-depth individual interviews based on predetermined general guidelines	Documents & protocols documenting transcripts read & main issues highlighted. Units of meaning from protocol & document copied into word document. Then organized according to inclusive thematic categories. Rereading according to grounded theory strategy
Kent 2008 (42) [2006- unknown]	NR	NR	NR Semi-structured In-depth Interview, collation of literature & debate articles	Material analysed using recent sociological theory concerned with trust
Kim 2021 (43) [2020]	Notices on one internet community with largest number of members among medical incident-related communities in South Korea	Experienced a patient AE within past five years in hospitals, capable of expressing their experiences. < 18 years excluded	Face to face at location close to participant's residence e.g. cafe or over the telephone Semi-structured interview	Analytical method of Colaizzi: 1) reading and re-reading 2) marking significant words relevant to POI 3) construct meanings 4) collation of meanings with similar content into themes 5) generation of theme clusters 6) generation of fundamental structure related to POI

Author, Date Year of data collection	Recruitment method	Inclusion criteria [patients, participants]	Data collection setting Data collection technique	Type of analysis performed (name/brief description)
Loren 2021 (44) [2011-2012]	At UW, Participants identified by screening new-born medical records based on ICD-9-CM diagnosis and Diagnosis-Related Group codes. Risk managers filtered the list and parents were invited. At Duke, participants recruited through internet message boards frequented by parents with children who experienced birth injuries. At UTHSCH, parents recruited through a local Brachial Plexus Injury clinic	Parents of baby that experienced a birth AE either during delivery/ due to delivery-related decisions occurring 12-36mths prior to the interview. Exclude: event did not result in harm; diagnosis of cerebral palsy was given at any point; parent contacted a lawyer regarding the event or outcome resulted in neo-natal death	In person or via phone Semi-structured interviews	Directed content analysis - Review transcripts, develop coding scheme, code transcripts. Discrepancies reviewed until consensus was reached in coding and theme identification
Maderia 2008 (59) [2005-2006]	Through mailing letters to individuals on the mailing list of Murrah Federal Building Survivors Association; snowballing	NR	Participants' residences/ telephone In depth open-ended interviews	A grounded theory methodology - NR
Maderia 2010 (60) [05-06]	Same as Maderia 2008			
Martin 2021 (45) [2018-2019]	Two routes. 1) Senior-level staff identified by local collaborators, publicly available sources, snowball sampling 2) staff, patients, family members identified by orgs with access to potential participants with interest in the issues	Senior-level staff with remits around openness; Staff, patients & relatives affected by openness initiatives or participated in orgs investigations into problems of safety	NR Data from (1) using topic guide. Interviews for (2) used narrative approach	Grounded theory/Constant comparative approach 1) coding with themes developed priori 2) themes identified inductively from close reading of the data.

Author, Date Year of data collection	Recruitment method	Inclusion criteria [patients, participants]	Data collection setting Data collection technique	Type of analysis performed (name/brief description)
Matthews 2012 (64) [NR]	Family support group for people who experienced work-related death provided participants access	NR	NR In-depth interviews. No set questions	Transcripts managed and coded using a consensus-coding scheme. Themes identified in advance based upon issues addressed in the interviews, and further themes derived from data during coding
Mazor 2010 (26) [2007-2008]	Through print and internet advertisements, flyers, and a booth at a local mall	Parents who believed they had experienced a medical error	NR In-depth interviews	1) Preliminary coding categories generated based on the interview guide and a subset of transcripts. 2) Checked and modified. 3) Finalized codes used for remaining transcripts 4) Review and discussion for discrepancies
Mazor 2012 (47) [NR]	Patients who received treatment for breast cancer (women)/ gastrointestinal cancer (men & women) 6–18 mths prior, but not actively undergoing treatment at time of study identified through health system records, invited by letter; follow up telephone calls attempted 1–2wks later	Identify something went wrong during care; what went wrong was preventable, and caused/could have caused, significant harm. Willingness & ability to participate in a 1h telephone interview in English	Telephone Semi-structured interviews using detailed interview guide and probes	Transcripts coded using directed content analysis. Coding categories created based on interview questions and refined through transcript review, coding, and discussion, until the team concurred that final coding categories captured the major substantive content of all reviewed transcripts
Mazor 2013 (46) [NR]	Same as Mazor 2012			
McQueen 2021 (48) [2021]	Advertising on websites, NHS Scotland AE Network, third sector non-government orgs	Experienced AE / safety event in last 10 yrs, lives in Scotland, >18 years, English speaking. Exclude AE not occur in Scotland, patients/families in investigation/litigation claim	Telephone Semi-structured interviews	Inductive thematic analysis techniques/interpretative phenomenological analysis: 1) Familiarisation with the data reading, 2) re-reading the transcript 3) generation of initial codes, 4) identifying themes, 5) refining and reviewing themes, 6) Naming themes

Author, Date Year of data collection	Recruitment method	Inclusion criteria [patients, participants]	Data collection setting Data collection technique	Type of analysis performed (name/brief description)
Melville 2012 (49) [NR]	Via law firm in northern English city that offers specialist medical malpractice legal representation	Intimated medical malpractice claims Jan 06 - June 09. Exclude: those not responded after initial enquiry, suffering terminal illness/ living with psychiatric condition	NR Interviews, coding sheet to record data from claimant's legal files	Qualitative methods - NR
Moore 2017a (50) [2016]	CRP administrators: identified hospital and insurer staff; and identified patients & families by applying the inclusion criteria to their CRP databases. Family members were invited if the patient was deceased or a minor	Experienced a CRP, spoke English, and could no longer file a malpractice claim because they had accepted settlement, or the statute of limitations had expired	Home, workplace, telephone Semi structured interviews using an interview guide	Data analysed using grounded theory. Thematic content analysis used to form coding scheme from transcripts of 6 interviews. Coding trees discussed in detail, and any differences were resolved by negotiated agreement
Moore 2017b (51) [2015]	Recruited by inviting participation from members of Acclaim Otago, a national support group for injured people open to all ACC claimants and snowball sampling	English-speaking patients/family members; Experience treatment injury and disclosure in a healthcare institution; Made a claim to ACC	Face-to-face at participant's home/ workplace and telephone Semi structured interviews using interview guide	Thematic analysis undertaken using a process of classifying, comparing and refining text to create categories or themes. Discrepancies were discussed and an agreeable interpretation was reached
Myren 2021 (52) [NR]	Patients and consultants, nurses, and registrars who participated in the M&MMs held between 2016 and 2018 were recruited	NR	Patient interview in patient's home. Healthcare professionals in hospital, or phone In-depth techniques: probes, open-ended questions, words appropriate, field notes	Codes generated by conventional content analysis. Open coding used to allow new insights to emerge from the data. Afterwards, codes were clustered into items, themes, and domains; partly based on important topics from the literature, but derived from the data without pre-defined structures

Author, Date Year of data collection	Recruitment method	Inclusion criteria [patients, participants]	Data collection setting Data collection technique	Type of analysis performed (name/brief description)
Ngo 2021 (65) [2014-2015]	(a) advertising in Australian Centre for Grief and Bereavement Journal & Conference; (b) networking with Mates in Construction, A Miner's Promise, Workplace Tragedy Family Support & Creative Ministries Network; (c) Twitter & Facebook page; (d) radio stations; (e) press releases (f) articles on websites e.g., BioPortfolio	Immediate and extended Australian family members bereaved by a fatal work incident	In person and phone interviews Semi-structured interviews using an interview schedule	Framework analysis, as described by Ritchie and Spencer used to code and organize the interview data. Working framework initially developed based on research aims. Framework applied to transcripts to identify sections of data corresponding to each domain. After all transcripts were coded, and themes identified, a process of charting used to map out the data and identify typologies
Ocloo 2010 (27) [2003-2006]	Writing to participants. Empirical evidence from experiences primarily of the MSHSN and participants who attended the Break Through Programme	Individuals affected by medical harm	NR Meeting observation, Analysis of legal documents, websites and reports, Document proceedings, Interviews, Questionnaires	Thematic content analysis applied to data. Entailed comparison of a range of evidence, noting initially emergent patterns, trends and contradictory evidence, before the data was organised into wider overarching themes
Piper 2014 (53) [2009-2011]	Recruited via health services and advertisement in the national print media and Internet research company	Rural patients &/or families from - a selected subset of the 100 Patient study	NR In-depth, semi structured interviews	Transcripts were discourse analysed by identification of overarching theme domains, cross-thematic relationships & thematic hierarchies
Pyo 2019 (54) [2016-2017]	Participant identified through a sports article on a Korean portal site and contacted via her social network account	Inclusion - Suffered physical disability due to medical AE and experienced litigation. Exclusion - Lost family in medical AE; victim not physically injured from AE; No experience of medical litigation	Participant's house and training facility In-depth interviews, News footage and news reports	Transcripts segmented into meaning unit. Through the units, main experiences apprehended according to the temporal flow of participant. Participant's experiences then categorized into contextual dimension by integrating various data sources and revised after sufficient discussion process when a disagreement was presented

Author, Date Year of data collection	Recruitment method	Inclusion criteria [patients, participants]	Data collection setting Data collection technique	Type of analysis performed (name/brief description)
Saco 2018 (80) [NR]	Compiled list of experts through Internet research of groups and orgs in the USA. Contacted experts through emails or telephone calls. Snowball sampling expanded reach	Expert - community, academic, or criminal justice professional who works/previously worked on homicide; or studies/ previously studied homicide/ homicide survivors	Telephone, one grp interview and one individual face-to face interview In-depth qualitative interviews using interview guide	Grounded theory used to analyse data:1) Initial read-through of transcripts and interview note 2) Coding the interviews (2) comparing and sorting the codes; (3) using the codes to create larger thematic categories; and (4) developing analytic interpretation from categorizations
Shaw 2007 (74) [NR]	Unclear	Families of persons who died in custody	Unclear Casework, surveys and questionnaires	NR
Sorensen 2010 (55) [NR]	Convenience sampling. Obtained a list of clinician, patients or family members involved in Open Disclosure from participating health services	Patients or family members involved in Open Disclosure	Face-to-face in the health service or persons home, or over the telephone Semi-structured open-ended interviews	Transcripts supplemented by interviewer summary reports of the interview coded. Then grouped, tabulated, and consolidated for verification, comparison and refinement. Grounded theory used to analyse data
Wiig 2021 (56) [2017-2018]	Participating next of kin recruited by project manager at the county governor's office	NR	County governor's office Focus group interviews, Field notes, Observation of meetings & interviews	Transcribed data and observations analysed using thematic content analysis. Researchers read the total material and discussed the themes to agree and refine analysis

3Rs = Recognize, Respond, Resolve; ACC = Accident Compensation Corporation; AE = Adverse Event; CRP = Communication-and-Resolution Programs; CPSW - Chicago Patient Safety Workshop; FGD- Focus Group Discussions; Grps- Groups; GP – General Practices; Orgs – Organisations; MHSN - Medical Harm Self-Help Network; Mth – Month; NR – Not Reported; PACT - Protect All Children Today; POI – Phenomenon of Interest; SDM – Surrogate Decision Makers; UTHSCH – University of Texas Health Science Center at Houston; UW – University of Washington; Wks – Weeks

Quality of the evidence

Ratings on the modified Wallace checklist for each of the prioritised papers can be seen in *Table 5*. Checklist items on which most studies scored positively included clear research question (n=38),(21, 22, 24-26, 28-32, 34-36, 38-60, 64, 65, 68, 69, 76, 77, 80) appropriate study design (n=38),(21, 22, 24-26, 28-32, 34-53, 55-60, 64, 65, 68, 69, 76, 77, 80) adequate and appropriate sample (n=40),(21, 22, 24-32, 34-41, 43-52, 54-60, 64, 65, 68, 69, 74, 76, 77, 80) adequately described data collection (n=35),(21, 24, 25, 28-32, 34-36, 38-40, 43-46, 48, 50-52, 54-58, 64, 65, 68, 69, 76, 77, 80) confidence in data collection (n=32),(21, 22, 24-26, 28, 30, 31, 34-36, 38-40, 43, 44, 46-58, 64, 65, 68, 69, 76, 77, 80) confidence in data analysis (n=32),(21, 22, 24, 26, 28-32, 34-40, 43-48, 50-57, 64, 65, 68, 69, 76, 80) finding substantiated by data (n=38),(21, 24-26, 28-34, 36-46, 48-60, 64, 65, 68, 69, 74, 76, 77, 80) consideration of limitation (n=35),(21, 22, 24, 26, 28-32, 34, 35, 37-58, 64, 65, 68, 69, 76, 77, 80) generalisability (n=40),(21, 22, 24-32, 34-60, 64, 65, 68, 69, 74-77, 80) and ethics (n=31).(21, 22, 24-32, 34, 35, 37-40, 43-54, 56, 57, 65, 68, 69, 76, 77) Across the remaining items on the checklist, 12 studies (13 papers) provided a theoretical or ideological perspective of authors/funders,(22, 27, 29, 34-36, 42, 43, 45, 57, 59, 60, 76) and 11 (12 papers) on its influence on study design, methods and findings.(22, 27, 29, 34-36, 42, 43, 45, 59, 60, 76) Also, 20 studies (24 papers) described the data collection setting,(24, 28, 31, 32, 34, 35, 37-39, 43, 46-48, 50-52, 54, 56-60, 69, 76) and 17 studies described the justice-seeking process investigated.(21, 22, 25, 30, 31, 35, 37, 42, 48-52, 54, 57, 65, 69)

The majority of the studies scored positively on at least 8 of the 14 checklist items (range 2,(33) to 13.(34, 35, 43, 57, 76) Exceptions to this were three medical studies which scored positively in 2, 5 and 6 out of 14 items respectively.(27, 33, 41) One non-medical study also scored positively on only 5 out of 14 items.(74) Of the 11 studies (12 papers) which did not score positively on the ethics item, six were non-medical studies.(58-60, 64, 74, 77, 80) Negative scores on ethics items were often due to a lack of clarity in reporting which meant it was difficult to determine if authors sought ethics approval from a legislated institution before beginning data collection.

Table 5: Quality appraisal

Study author/ date	1-Research question clear?	2-Theoretic/ ideological perspective explicit?	3-Has it influenced study design, methods, findings?	4-Study design appropriate to question?	5-Setting adequately described?	6-Sample drawn from appropriate population?	7-Data collection adequately described?	8-Data collection rigorous to ensure confidence in findings?	9-Data analysis rigorous to ensure confidence in findings?	10-Findings substantiated by data?	11-Consideration given to limitations that may affect results?	12-Claims to generalisability follow from data?	13-Ethical issues addressed confidentiality respected?	14-Justice seeking process clearly described?
Bakhbakhi 2017 (28)	Y	N	CT	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N
Biddle 2003 (68)	Y	N	CT	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	N
Bouwman 2018 (21)	Y	N	CT	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
Burns 2006 (57)	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Butler 2019 (22)	Y	Y	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y	Y
Chapple 2012 (69)	Y	N	CT	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Chiu 2010 (29)	Y	Y	Y	Y	N	Y	Y	CT	Y	Y	Y	Y	Y	N
Duclos 2005 (30)	Y	N	CT	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
Eastwood 1998a (77)	Y	N	CT	Y	N	Y	Y	Y	N	Y	Y	Y	CT	N
Eastwood 1998b (76)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N
Englebrect 2014 (58)	Y	N	CT	Y	Y	Y	Y	Y	N	Y	Y	Y	N	N
Etchegaray 2014 (31)	Y	N	CT	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Fisher 2016 (32)	Y	N	CT	Y	Y	Y	Y	CT	Y	Y	Y	Y	Y	N
Gallagher 2009 (33)	N	N	CT	CT	CT	Y	N	CT	CT	Y	CT	CT	CT	N
Hagensen 2018 (34)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N
Hannawa 2017 (35)	Y	Y	Y	Y	Y	Y	Y	Y	Y	CT	Y	Y	Y	Y
Hernan 2014 (24)	Y	N	CT	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N
Hovey 2014 (36)	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	N	Y	CT	N
Iedema 2007 (40)	Y	N	CT	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	N
Iedema 2011 (39)	Y	N	CT	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N
Iedema 2012a (38)	Y	N	CT	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N
Iedema 2012b (37)	N	N	CT	CT	Y	Y	Y	CT	Y	Y	Y	Y	Y	Y
IPSOS MORI 2016 (41)	Y	N	CT	Y	N	Y	N	CT	CT	Y	Y	Y	CT	N

Study author/ date	1-Research question clear?	2-Theoretic/ ideological perspective explicit?	3-Has it influenced study design, methods, findings?	4-Study design appropriate to question?	5-Setting adequately described?	6-Sample drawn from appropriate population?	7-Data collection adequately described?	8-Data collection rigorous to ensure confidence in findings?	9-Data analysis rigorous to ensure confidence in findings?	10-Findings substantiated by data?	11-Consideration given to limitations that may affect results?	12-Claims to generalisability follow from data?	13-Ethical issues addressed confidentiality respected?	14-Justice seeking process clearly described?
Kamin-Friedman 2021 (25)	Y	N	CT	Y	N	Y	Y	Y	CT	Y	N	Y	Y	Y
Kent 2008 (42)	Y	Y	Y	Y	N	CT	N	CT	CT	Y	Y	Y	CT	Y
Kim 2021 (43)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N
Loren 2021 (44)	Y	N	CT	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	N
Maderia 2008 (59)	Y	Y	Y	Y	Y	Y	N	CT	CT	Y	N	Y	N	N
Maderia 2010 (60)	Y	Y	Y	Y	Y	Y	N	CT	CT	Y	N	Y	N	N
Martin 2021 (45)	Y	Y	Y	Y	N	Y	Y	CT	Y	Y	Y	Y	Y	N
Matthews 2012 (64)	Y	N	CT	Y	N	Y	Y	Y	CT	Y	Y	Y	N	N
Mazor 2010 (26)	Y	N	CT	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	N
Mazor 2012 (47)	Y	N	CT	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	N
Mazor 2013 (46)	Y	N	CT	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N
McQueen 2021 (48)	Y	N	CT	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Melville 2012 (49)	Y	N	CT	Y	N	Y	N	Y	N	Y	Y	Y	Y	Y
Moore 2017a (50)	Y	N	CT	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Moore 2017b (51)	Y	N	CT	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Myren 2021 (52)	Y	N	CT	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Ngo 2021 (65)	Y	N	CT	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
Ocloo 2010 (27)	N	Y	Y	CT	N	Y	N	CT	CT	N	N	Y	Y	N
Piper 2014 (53)	Y	N	CT	Y	N	CT	Y	Y	Y	Y	Y	Y	Y	N
Pyo 2019 (54)	Y	N	CT	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Saco 2018 (80)	Y	N	CT	Y	N	Y	Y	Y	Y	Y	Y	Y	N	N
Shaw 2007 (74)	N	N	CT	Y	N	Y	Y	CT	CT	Y	N	Y	N	N
Sorensen 2010 (55)	Y	N	CT	Y	N	Y	Y	Y	Y	Y	Y	Y	CT	N
Wiig 2021 (56)	Y	N	CT	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N

CT=Can't tell, N=No, Y=Yes

Framework synthesis: Part 1 - overview of main findings

We included 41 studies (47 papers) in the framework synthesis; the majority of these studies reported evidence from the health field (n=31),(21, 22, 24-56) and a subsample representing evidence from people seeking justice following bereavement from homicide (n=3),(57-60) work accidents (n=2),(64, 65) suicide(n=2),(68, 69) and death in police custody or following contact with police (n=1).(74) or people seeking justice following sexual abuse (n=2).(76, 77, 80)

The synthesis identified four main themes: 1) The need for Transparency, 2) Person-centredness, 3) Trustworthy and 4) Restorative Justice. The full framework synthesis in Part 2 of this report details the number of studies which contribute towards each of these themes. We have separated the four themes into two groups. The first group explores what a fair process **looks** like according to justice seekers and contains the themes Transparency, Person-centred and Trustworthy. The second group explores what a fair process **feels** like and focuses on the theme of Restorative Justice. Within each theme, we consider how the stage of the justice-seeking process experienced by the participants paper may influence the concepts discussed. The proposed relationship between these four themes, and their subthemes, is represented within Figure 2 below and explored further at the end of this section.

22: Relationship between themes and subthemes

None of these studies reported experiences of individuals who were still actively seeking justice following a non-recent, or “historical”, medical event. *Framework synthesis: Part 2* – relating the findings to historical cases of this section will consider how the points of learning arising from this synthesis could be applied to these historical cases.

Below we provide an overview of the main themes and subthemes developed through the framework synthesis. For the full detail of these findings, please see *Framework synthesis: Full results*.

What does a fair process look like?

Theme 1: Transparency

Thirty-eight studies (44 papers), (21, 24-30, 32-60, 64, 65, 68, 69, 74, 76, 77) 29 of which explored experiences of redress and reconciliation following a medical event, (24-30, 32-56, 76, 77) contribute towards this theme. Different factors which may influence the transparency of the process are discussed within four subthemes; an account, information required publicly available, consideration of systemic factors and provision of a clear rationale for decisions.

Subtheme 1.1 : An account

Thirty-one studies (35 papers) contributed towards this subtheme, which outlines the perceived value that individuals affected by a life-changing event and their families placed on gaining a comprehensive, accurate account of the life-changing event and its consequences. (21, 24, 26, 27, 29, 30, 32-41, 43, 44, 46-53, 55-57, 59, 60, 64, 65, 69, 74) Overall, people seeking redress and reconciliation wanted a comprehensive account of the life-changing event, the circumstances leading up to it, what was being done to investigate it and what was being done to ensure it could not happen again. Being able to meet with those directly involved with the life-changing event to discuss what happened may enhance the perceived trustworthiness of the account received. If people are unable to access this information early within the redress-reconciliation process, it could cause them to pursue more formal litigation.

Subtheme 1.2: Information required publicly available

Thirty-two studies (35 papers) contributed towards this theme which explores the difficulties people seeking redress-reconciliation had in obtaining information. (21, 26-30, 32, 34-45, 48-52, 54-57, 60, 64, 65, 68, 74, 76, 77) People seeking redress-reconciliation would like the information they require to be easily accessible. This information is not just restricted to the circumstances surrounding the life-changing event, but also encompasses the need for signposting to information and support on how to access the redress-reconciliation process itself and their rights within it. Perceptions that individual staff members and/or organisations are trying to avoid contact with those who had been harmed and withholding information reduce the transparency of the process and induce feelings of anger and uncertainty.

Subtheme 1.3: Consideration of systemic factors

Sixteen studies (16 papers) contribute towards this subtheme, aimed at highlighting systemic factors which may influence decision-making within, and thus the perceived transparency of, the justice-seeking process, and if outcomes are perceived to be fair. (25, 27, 36, 41-43, 45, 48-51, 57, 58, 64, 74, 76) The availability of funding for both the individuals seeking justice and those responsible for awarding compensation is one factor which may influence the redress-reconciliation process. Other

factors may include the ease with which the process of redress-reconciliation can record and respond to the individual concerns and experiences of people who have been harmed and consider their views as equal to other stakeholders, such as medical professionals or those who have caused harm. To enhance the transparency of the redress-reconciliation process for justice-seekers, factors which may influence the decisions made during the redress-reconciliation process should be explicitly discussed between all the stakeholders involved in the process.

Subtheme 1.4: Clear rationale for decisions

Seven studies (9 papers) contributed towards this theme.(21, 41, 49, 54, 58-60, 76, 77). Four studies explored experiences of redress-reconciliation processes following non-medical life-changing events,(21, 58-60, 76, 77) whilst three studies included participants who had experienced medical harm.(41, 49, 54) This subtheme focuses on the need for a clear rationale to be given to those seeking redress-reconciliation regarding the decisions made during the inquest or formal litigation process. Overall, these studies indicate that the reasons behind the decisions made during the justice-seeking process are not always transparent to patients and their families, despite attempts made by professionals and justice-seekers themselves to clarify these. Lack of transparent decision-making may contribute to perceptions of bias and lack of consistency in the justice-seeking process and leave patients and their families feeling unheard.

Theme summary: Transparency

People seeking redress and reconciliation following a life-changing event seek a comprehensive account of the harm which they have experienced and what is being done to ensure that it does not happen again. The ease with which this information is made available to them and the extent to which they are signposted to the information and support they need can enhance the perceived transparency of, and trust within, the redress-reconciliation process. Any perception of bias in favour of medical professionals, or that professionals are not being open and transparent, can lead to feelings of anger and suspicion on the part of the people seeking redress-reconciliation and the perception that their needs and views are not valued. People seeking justice appreciate being provided with a clear rationale for the decisions made as part of the process. It may be helpful for all stakeholders involved with the redress-reconciliation pathway to discuss systemic factors such as funding and the rules of the legal system to ensure the rationale for decisions remains explicit and that the resulting processes and outcomes are perceived as fair.

Theme 2: Person-centred

Thirty-nine studies (45 papers) contributed to this theme, which contains two subthemes.(21, 24, 26-60, 64, 65, 68, 69, 74, 76, 77, 80) The first subtheme “Shared rules” explores how the redress and

reconciliation processes can be centred around the needs of patients and their families. The second subtheme “Meaningful goals” discusses some of the different outcomes people may seek following a life-changing event.

Subtheme 2.1: Shared rules

Twenty-four studies (26 papers) contributed towards this subtheme.(21, 28-31, 33, 35-37, 39-41, 43, 45, 46, 48-51, 55, 57, 58, 68, 74, 76, 77) The studies contributing to this subtheme where participants had experienced a medical life-changing event predominantly represented views of the early stages of the redress and reconciliation process. Overall, patients and their families desired the reconciliation process to be based on a shared understanding of what had occurred, their needs as justice-seekers and consideration of what they, themselves wanted to achieve. The process should consider whether the timing, method of involvement and location are convenient for participants and should have a clearly defined end point, which all stakeholders agree upon.

Subtheme 2.2: Meaningful outcomes

Thirty-eight studies (43 papers) contributed towards this subtheme, which focuses on what people perceive as fair or meaningful outcomes following a redress or reconciliation process.(24, 26-60, 64, 65, 68, 69, 74, 76, 80) Twenty-eight of these studies represent experiences of seeking justice following perceived medical harm.(24, 26-56) Key outcomes included receiving answers to their questions and receipt of an apology, which incorporated expressions of remorse and an admission of responsibility, accompanied by actions to assure them that the harm would not happen again and receiving assurance that future health care and financial needs will be met. Other concepts explored include the desire for appropriate sanctions against those perceived to be responsible and the need to ensure the final verdict reflects the evidence provided and incorporates the views of those who have been harmed. The outcomes people seeking redress and reconciliation sought were individual to their own needs and were influenced by the responses they had from the institution or individual whom they perceived to have done them harm.

Theme summary: Person-centred

People who had been harmed sought a redress-reconciliation process which was centred around an assessment of their own, individual needs. This begins with a shared understanding of the life-changing event and its immediate and longer-term impact on the physical, mental and financial wellbeing of those seeking justice. Consideration of the extent to which people seeking redress-reconciliation wish to be involved may increase perceptions of transparency and trust in the process, and in turn the perception of fairer outcomes. Outcomes that are perceived to be meaningful are likely to be unique for everyone, which requires justice-seekers to be consulted at the early stages of the

redress-reconciliation process on what they need and how they can be supported to be able to close this chapter of their lives. The processes needed to achieve this necessitate an ongoing rapport between the different stakeholders throughout the duration of the redress-reconciliation pathway.

Theme 3: Trustworthy

Thirty-seven studies (42 papers) contributed to this theme, which contains four subthemes. (21, 25-43, 45, 46, 48-60, 64, 65, 68, 69, 74, 76) The first subtheme 'A reasonable and consistent process' discusses different features of the redress-reconciliation pathway that may enhance the perceived fairness of the process and outcomes. The second subtheme 'Ongoing support' details the financial and emotional support justice-seekers require. The third subtheme 'Mechanisms for challenge and dispute resolution' explores the importance that opportunities for those who have been harmed to challenge both the process and outcomes following redress and reconciliation are incorporated into the pathway. The final subtheme 'Objective input' addresses the need for people who are perceived to be independent of the institution where the harm has occurred to contribute to the redress-reconciliation process.

Subtheme 3.1: A reasonable and consistent process

Thirty studies (34 papers) contributed to this subtheme, which explores components of redress and reconciliation that may make it more likely that the process will be perceived to be fair by those seeking justice. (21, 28-42, 45, 46, 48-53, 55-58, 64, 65, 68, 74, 76, 77) This subtheme describes how perceived trust in the redress-reconciliation process may be enhanced through the use of a formal pathway which promotes a two-way dialogue between professional stakeholders and those who have experienced harm. Justice-seekers appreciated their experiences and views being actively sought to inform the process and outcomes, as well as the involvement of the individuals they perceived as being responsible for the harm. Finally, those seeking redress-reconciliation wanted the process to be conducted in a timely manner, to limit the negative emotional impact of ongoing uncertainty, grief and fatigue associated with a lengthy, ongoing investigation.

Subtheme 3.2: Ongoing support

Twenty-five studies (27 papers) support this subtheme, which details the ongoing support people seeking redress and reconciliation may require to access and maintain their involvement throughout the process. (26, 28, 30, 33-35, 37, 39-43, 45, 49-56, 58, 59, 64, 65, 74, 76) Assistance with accessing information, as well as emotional and financial support is important and can be fulfilled by advocates and/or family members. A consistent point of contact within the institution or external organisation is also useful. Provision of this support may increase the perceived trustworthiness of the redress-

reconciliation process by demonstrating the desire to engage them with, and thus incorporate their views within, the justice-seeking process.

Subtheme 3.3: Mechanisms for challenge or dispute resolution

Fifteen studies (17 papers) contributed towards this subtheme, which predominantly represents views of redress-reconciliation processes following non-medical adverse events.(21, 37, 38, 41, 42, 49, 54, 57-59, 64, 65, 68, 69, 74, 76, 77) People seeking redress-reconciliation appreciate opportunities to present their views throughout the process. This may be through opportunities to correct formal accounts of the life-changing events, or by pursuing formal litigation processes through the courts and/or having their views incorporated within the final verdict. The appeals process represented an important opportunity to challenge final decisions they did not agree with, although many people did not find this an easy process to access. The appeals process was one factor which could contribute towards unanticipated delays in the resolution of the redress-reconciliation process which, alongside perceived bias in favour of those perceived to have done the harm, can increase the emotional trauma experienced and reduce trust in the process and final outcomes.

Subtheme 3.4: Objective input

Twelve studies (13 papers) supported this subtheme, which explores the importance of individuals and/or organisations who are perceived to be independent of the institution where the harm occurred or the redress-reconciliation process itself.(27, 30, 35, 38, 40, 41, 50, 56, 59, 60, 65, 74, 76) They can help provide information and emotional support to justice-seekers as well as offer oversight of the ongoing investigation. Having individuals or organisations who are perceived as being independent within the formal redress-reconciliation process may enhance the perceived trustworthiness of the process and final outcomes. However, mechanisms need to be in place to ensure that they are provided with the correct information and support to enable them to fulfil their role without being seen to compromise the process or final outcomes.

Theme summary: Trustworthy

To enhance the perceived trustworthiness of the redress-reconciliation pathway, justice-seekers need to be supported to access and maintain engagement with a pre-planned, consistent process that centres around their needs. A process which does not fully account for the needs, views, and experiences of those who have been harmed may be met with formal challenges from justice-seekers, as they seek to have their perceptions accurately reflected in formal accounts of the life-changing event and represented within the final outcome of the redress-reconciliation process. A process which does not support this or is seen to be biased in favour of the individuals/organisations associated with the original harm, may not be experienced as trustworthy, which may in turn influence how fair the

outcome is considered to be. Input from people external to organisations where the harm occurred, or which are hosting the redress-reconciliation process may play a role in mitigating any perceptions of bias. However, these individuals should be given the appropriate information, training, and support to fulfil their role and ensure they remain focused on supporting the needs of justice-seekers or ensuring due process is carried out correctly within the redress-reconciliation process.

What does a fair process feel like?

Theme 4: Restorative Justice

Thirty-eight studies (44 papers) support this theme which consists of two subthemes. (21, 22, 25-27, 29, 30, 32-60, 64, 65, 68, 69, 74, 76, 77, 80) The earlier three themes discuss procedural issues which need to be in place for the redress-reconciliation process, and its outcomes, to be experienced as fair. To complement the procedural aspects of the redress-reconciliation process, this theme considers how the relationships developed between the stakeholders within the redress-reconciliation process can influence the procedural aspects of the process, and also how the process is emotionally experienced by justice seekers, which may in turn influence perceptions of its fairness. The first subtheme, 'Humanising process', explores key features of the redress-reconciliation process which are needed to prevent it from being experienced as emotionally harmful, bureaucratic and insensitive to the needs of those seeking justice. The second subtheme 'Closing a chapter' discusses how the process of redress-reconciliation can support individuals to transition from a position where they are overwhelmed by the trauma they have experienced, through to a position of acceptance and being able to move on with other areas of their life.

Subtheme 4.1: Humanising process

Thirty studies (33 papers) contributed towards this subtheme, which discusses the need for redress-reconciliation procedures to embody the principles of respect, empathy, and good communication and acknowledge the individuals who have experienced harm as equal participants in the justice-seeking process. (21, 25-27, 29, 30, 32-37, 40-44, 46, 48-53, 55-58, 65, 68, 74, 76, 77) This can help to humanise a process that, if too overly focused on its procedural elements, risks minimising the concerns and emotions of those who have been harmed in order to achieve a resolution.

Subtheme 4.2: Closing a chapter

Thirty-four studies (39 papers) contributed towards this subtheme which considers the trauma experienced by those seeking justice, both as a result of the life-changing event and the process of seeking redress-reconciliation afterwards. (21, 22, 26, 27, 29, 30, 32-41, 43, 45-48, 50-52, 54-60, 64, 65, 68, 69, 74, 76, 77, 80) Following this harm, closure may not be achievable, or acceptable, but some

people may be supported to reach a place of acceptance. The procedurally orientated nature of redress-reconciliation processes as documented within themes 1-3 may sometimes overlook the emotional needs of justice-seekers. Developing a shared narrative could provide those who have experienced harm the opportunity to integrate fractured information from multiple sources to construct a thorough understanding of what has happened to them or their loved ones and for this to be reflected in the public account of events. It also allows them to have their say and receive validation of the hurt they have experienced by those they perceive to be responsible for the harm. This validation, alongside being able to express their emotions, and receive support to process these, can be very cathartic for those seeking justice. As a complement to this, individuals can also appreciate opportunities for involvement in the justice-seeking system, through pursuing accountability from individuals and/or organisations and identifying learning points going forwards. This action can help give meaning to the harm they have experienced and provide an end point to the narrative documenting their experiences.

Theme summary: Restorative justice

This theme highlights the importance of developing a mutually empathic relationship between those seeking justice and those perceived as being responsible for the harm, within which patients and their families feel supported, respected and valued. This can create a space where they can integrate the different fractured accounts of what has happened, its impact on them and how the redress-reconciliation process has been concluded into one coherent narrative. We propose that it is the combination of developing a cathartic narrative and opportunities to take therapeutic action which may help some individuals process their trauma and move through to a place of acceptance, and thus feel able to close this chapter of their lives. The process of developing this narrative, telling it and it being heard can be cathartic, especially when accompanied by action which gives meaning to the loss they have experienced. The relationship reduces the distance between the people who have been harmed and other stakeholders involved in the process, creating opportunities to resolve misunderstandings or inaccuracies and acknowledge/validate the pain experienced. This may reduce feelings of isolation, overwhelm and anger and thus increase perceptions of fairness of the redress-resolution process and its outcomes.

Summary of main themes

The three themes 'Transparency', 'Person-centred' and 'Trustworthy' represent the procedural elements of redress-reconciliation which should be established in order to support a fair and objective process. The elements within these three themes are inter-dependent on one another, with each element influencing others within the redress-reconciliation process. For example, it is likely that if

the process is conducted using a person-centred approach that this will increase the transparency and trustworthiness of the process.

If the redress-reconciliation process is conducted in a way which is consistent with the procedural elements identified by this synthesis, it may support the development of a supportive, empathic relationship between justice-seekers and individuals seen as responsible for the harm. This relationship may support those seeking redress and reconciliation to develop a coherent narrative about the trauma they have lived through. This presents the opportunity for them to express their emotions whilst telling their own story and receive acknowledgement for the hurt they have experienced. During this process, those seeking redress and reconciliation can be supported to take part in action which gives meaning to their loss. The combination of experience arising from a humanising process and opportunity to develop a cathartic narrative and participate in meaningful action provides the foundation for the final theme, 'Restorative justice' which encapsulates how a fair process feels to those who have experienced a life-changing event.

It is within the context of the humanising and cathartic relationship between these stakeholders that the procedural elements of the redress and reconciliation process can be worked through, the harm and the impact on the individual can be explored, meaningful outcomes agreed upon and the emotional impact diffused, as people accept what has happened and learn how to incorporate the consequences of the event into their lives going forward. Thus, we propose that a fair process is dependent on both its procedural elements and the quality of the relationship developed between the different stakeholders. The latter has important implications for how those seeking redress and/or reconciliation are made to feel and the extent to which they can feel heard, and their experiences can inform the process. This in turn can influence how fair they perceive the redress and reconciliation process and its outcomes to be.

Framework synthesis: Part 2 – relating the findings to historical cases

This section will consider how the key elements identified by the framework synthesis could be applied retrospectively to appraise if those seeking redress and reconciliation following a historical medical life-changing event have experienced a fair process. These elements are described in the order in which they were presented within the original themes and should not be taken as an indication of their relative importance. The content of this section is drawn from the full synthesis presented in *Framework synthesis: Full results*.

Key elements of a fair redress-reconciliation process

Opportunity to develop a comprehensive account of the life-changing event and redress-reconciliation process

Supporting subthemes: 1.1, 2.2 and 4.2

A fair redress-reconciliation process will provide the opportunity for individuals who have experienced harm to develop a comprehensive account of the life-changing event. This should encompass detail on the circumstances leading up to the event, the event itself, the immediate and long-term impact of the event on those who were harmed and their family and systemic factors related to the occurrence of the event. People seeking justice following a historical life-changing event may also benefit from an account of the redress-reconciliation process to date, including the stages they have been through, the outcomes from these, the reasons for continuing to pursue justice and the impact of this on themselves and others who may also have been affected.

A fair redress-reconciliation process will also present the opportunity for those seeking justice to discuss their own experiences of what has happened, including the redress-reconciliation processes they have been through, and for this to have been developed into a shared understanding of the life-changing event and redress-reconciliation process to date. People seeking justice may appreciate their account being incorporated into formal documentation which is referred to within each stage of the justice-seeking process.

Key information made available

Supporting subthemes: 1.2, 1.4, 2.2, 4.1 and 4.2

Patients and their families appreciate access to key information regarding the life-changing event, including medical records and documentation detailing the process and results of any subsequent investigations. For historical cases, documentation which informed or recorded any formal litigation processes and outcomes could also be made available where appropriate. In cases where this

documentation cannot be made available, a fair process would include providing a clear rationale as to why this is the case, with families given the opportunity to express any concerns or receive answers to any questions they may have. A fair process also involves providing access to documentation regarding any key decisions made throughout the redress-reconciliation process, and the rationale for these. This information may be key in supporting individuals to develop a narrative around the life-changing event and subsequent redress-reconciliation process.

Joint Reflection on systematic factors which may have influenced the redress-reconciliation process

Supporting subthemes: 1.3, 3.2 and 4.1

A fair process will include joint reflection between all key stakeholders involved with the redress-reconciliation process on systemic factors which may have influenced the process and outcomes. Patients and families also appreciate when they feel that their views and experiences are considered to be equal to those of any professionals involved. A fair redress-reconciliation process will also include efforts to overcome or mitigate the influence of these factors on the redress-reconciliation process and outcomes. Examples of this could include the provision of additional emotional and/or financial support to patients and/or their families or providing access to alternative processes which could address their assessed needs and help them fulfil the outcomes they have identified as being meaningful to them.

Assessment of needs and provision of ongoing support

Supporting subthemes: 2.1, 3.2, 4.1 and 4.2

Patients and their families wished for their financial and emotional needs to be assessed and considered within the redress-reconciliation process. For historical cases, patients and their families could be asked what support they feel they require to support their physical and emotional wellbeing outside of the redress-reconciliation process.

A fair process would ensure that people seeking justice have access to appropriate legal support during their ongoing justice-seeking process and provide, or signpost towards, the support required to meet these needs. This assessment needs to be regularly reviewed and updated throughout the redress-reconciliation process. For redress-reconciliation conducted over a prolonged time-period, this may require the identification of an individual or organisation responsible for organising or conducting regular follow-up meetings, whom patients and their families can contact if needed. The people pursuing redress-reconciliation for historical patient events may particularly appreciate regular updates on the process. This regular contact may help develop a relationship between stakeholders

involved with the process and reduce the sense of isolation, anxiety, and anger experienced by patients and their families.

An apology

Supporting subthemes: 1.1, 2.2, 4.1 and 4.2

For those seeking redress-reconciliation for a historical event, the perceived value of an apology may vary across individuals. Factors which may influence the perceived value of an apology may include the time since the life-changing event until the apology is received and whether it is delivered in person by the individual/organisation perceived as being responsible for the harm. The value of an apology may also be affected by whether it is accompanied by sincere expressions of remorse, acceptance of accountability and assurance that the event will not happen again. To prevent an apology from being perceived as procedural, it may be helpful to ensure that it reflects the individual and unique circumstances of the life-changing event and acknowledges the immediate and long-term impact on the individuals who have experienced harm.

Assumptions that the previous apologies which have been offered have met the above criteria may not always be helpful. Patients and their families may find it helpful to be asked about the perceived acceptability of any apologies that have been offered. If unsatisfactory, the reasons as to why this is the case could be ascertained and attempts made to address these if this is still desired by the patients/family.

For patients and families with experience of redress-reconciliation processes which, upon examination did not meet the standards of a fair process, an additional apology may be required to acknowledge the harm this may have caused.

Identifying and addressing points of learning

Supporting subthemes: 1.1, 2.2, 4.1 and 4.2

Closely related to the value of receiving an apology as detailed above, is a demonstration of the desire to learn from the event to ensure it does not happen again by those perceived to be responsible for the harm. Patients and families of historical cases may value evidence that their views have been incorporated into plans to prevent further harm and that these plans have been actioned. Some individuals may want to play a role in educating or informing wider staff groups about how similar harms may be prevented in the future. Follow-up after an agreed period of time may also be useful to reassure all stakeholders that the proposed changes have been implemented effectively.

The above learning points could also be used to address any distress and/or trauma which developed through redress-reconciliation processes which were not procedurally fair, and/or did not fully consider the emotional needs of patients and/or their families. Individuals seeking redress-reconciliation may welcome the opportunity to feedback on the processes they have experienced and for any learning to be incorporated into practice.

Achievement of other meaningful outcomes

Supporting subthemes: 2.2, 4.1 and 4.2

In addition to admissions of accountability, apology and service improvement, other outcomes that people seeking redress and reconciliation may wish to achieve may centre around their financial, health and emotional needs. Some people may also wish to achieve a sense of retribution against those who have done them harm, but this is not always the case. Instead, some individuals may wish to protect and/or reassure the professionals who were involved with the life-changing event and only seek to ensure the harm will not be repeated.

As the desired outcomes being pursued through redress-reconciliation systems are likely to be unique to the people seeking justice, it could be useful to consider if their desired outcomes have been assessed, before establishing if the redress-reconciliation process has then addressed these. Even if the desired outcome has been achieved, the patient and/or their family may benefit from being asked if they feel the outcome reflects the nature and degree of harm experienced. For example, financial compensation may have been an initial goal for some people seeking redress and reconciliation, and it may have been awarded following completion of the process. However, the sum of money awarded may not necessarily reflect the value of a life lost in the eyes of the bereaved, or fully compensate for the financial harms experienced following the event. Follow-up meetings during the redress-reconciliation process may help establish whether the needs of patients and/or their families have changed over time.

Access to a reasonable and consistent process

Supporting subthemes: 1.1, 2.1, 3.1 and 4.1

A fair process will consider whether the people seeking redress-reconciliation had access to processes which reflect the criteria listed at the start of this section. In brief, this encapsulates a formal process which encourages a two-way dialogue between all relevant stakeholders. This process consists of several stages; firstly the development of a shared agreement of what had happened, the severity of the event and its impact on those who have been harmed. Secondly, patients and their families appreciate support to prepare for key stages in the redress-reconciliation process and offered

appropriate support throughout. Finally consistent, regular communication between stakeholders is also important, along with follow-up appointments to update justice-seekers on progress and establish their ongoing support needs with regard to their finances, emotional and physical health and access to the redress-reconciliation process.

Mechanisms in place to support the challenge of institutional accounts and/or decisions made

Supporting subthemes: 3.3, 4.1 and 4.2

A fair redress-reconciliation process will provide the opportunity for patients and their families to challenge the institutional accounts of the life-changing event and any decisions arising out of a redress and reconciliation process they do not agree with. In addition, individuals with experience of extremely protracted redress-reconciliation processes may appreciate the opportunity to challenge aspects of the process that they perceive to be unfair or do not address their concerns.

The process will also incorporate mechanisms to support the resolution of disagreements between stakeholders. What constitutes 'resolution' may differ between individuals involved, indicating that patients and/or their families may appreciate being asked for their views before an issue is declared to be resolved.

Formal inquest and judicial processes do provide one method to support the above processes. However, they can be experienced as adversarial and traumatic for patients and families. Alternative methods which support respectful, empathic dialogue and dispute resolution between stakeholders could also be considered.

Opportunities for objective oversight or input

Supporting subthemes: 3.2 and 3.4

Involvement of individuals who are perceived to be external from the institution where the harm had occurred may increase the perceived fairness of the process. These individuals may provide independent advice and support to patients and families whilst they are seeking redress-reconciliation, or alternatively may provide an oversight to the process itself and/or directly influence the findings. Individuals who are seen to be independent of the people associated with the harm can include solicitors, members of the jury, support workers and the patient liaison office. Some people may prefer this input to be completely independent of the NHS, whilst others are satisfied with supporting individuals to be separate from the institution or department where the harm occurred.

Opportunity to meet those perceived to be responsible for harm

Supporting subthemes: 1.1, 2.1, 2.2, 3.1, 4.1 and 4.2

Having the opportunity to meet with those perceived as being responsible for the harm can provide people seeking redress and reconciliation with the opportunity to achieve restorative justice, through giving their perception of the life-changing event and its impact on them, ask and receive answers to their questions and express their emotions. In turn, this provides other stakeholders with the opportunity to listen to their experiences and validate their emotions as well as offer an apology which reflects the individual needs of the patients/family. This reduction in the distance between these two different groups of stakeholders can allow for the development of a mutually empathic and respectful relationship, which can support the resolution of disputes and identify a shared, more collaborative way forward.

People seeking redress-reconciliation following a historical event may appreciate opportunities to meet with the people involved in making decisions/deciding outcomes of the redress-reconciliation process. It may help increase the transparency of the decisions that have been made and offer an opportunity for reflection as to whether the process experienced to date has been fair.

Validation of experiences

Supporting subthemes: 3.2, 4.1 and 4.2

Acknowledgement and validation of the trauma they have experienced can be very emotionally powerful for individuals who have experienced harm. The ability of an organisation to do this sets the scene to build an empathic, respectful relationship with patients and families and can signal that they are willing to take appropriate accountability for the harm. Patients and families may also feel listened to and valued. As a result, the redress-reconciliation process may be experienced as less adversarial and more collaborative for all stakeholders, potentially creating further opportunities to be satisfied with the processes they have been through.

Meaningful action

Supporting subthemes 2.2, 3.1 and 4.2

Patients and families may appreciate opportunities to create meaning from their loss through being involved in undertaking meaningful action. The type of action needed to achieve this will be individual to each person, but may include; opportunities to improve and develop services, or involvement in training staff. For some, their involvement in the redress and reconciliation process itself represents meaningful action as they pursue efforts to hold those they perceive as being responsible for the harm

to account and bid to witness this accountability being upheld. Others may wish to give a voice to the experiences of those who have been harmed, or ensure that they are remembered in some way.

Summary

Within this section, we have described key elements of a fair process identified through the framework synthesis. These could be applied to the redress-reconciliation process experienced by those seeking justice for a historical life-changing event to establish if the process has been conducted in a way which is procedurally fair.

Discussion

The aim of this report was to identify and synthesise primary qualitative research evidence regarding the experiences of those seeking justice following a life-changing event, with a view to addressing two research questions. The first research question focuses on identifying which aspects of the processes and outcomes of redress and reconciliation following a life-changing event lead the individual and/or family to feel that they were/were not treated fairly and appropriately. Through using framework synthesis to bring the findings The second research question was concerned with how these perceptions varied over time following the initial event.

Following the search and screening methodology detailed earlier in this report, we included 41 studies (47 papers) relevant to these two research questions in the framework synthesis. The majority of these studies explored patients and/or their families' experiences of redress-reconciliation processes following a medically life-changing events (n=31).(21, 22, 24-56) We also included studies where the life-changing event included homicide (n=3),(57-60) sexual abuse (n=2),(76, 77, 80) suicide (n=2),(68, 69) working place accidents (n=2),(64, 65) or death in police custody/contact with police (n=1).(74) We included all of the studies detailing adverse events within the health field for framework synthesis alongside a sample of studies which included experiences of redress-reconciliation following non-medical events (n=10).(57-60, 64, 65, 68, 69, 74, 76, 77, 80)

In relation to the first research question, the framework synthesis identified four key themes relating to key features people perceive as relating to a fair process and fair outcomes. These themes indicated that firstly, the process and final outcomes should be transparent to those taking part in the redress-reconciliation process. Secondly, the process and outcomes should be person-centred, focusing on the shared needs and goals of individuals seeking justice. Thirdly, the redress-reconciliation process should be conducted in a way which makes it trustworthy to stakeholders taking part through the use of a formal process, incorporating support for patients and their families, mechanisms to challenge processes and/or outcomes and incorporating input from individuals independent of the institution or individual who is responsible for the harm. The final theme encompasses the principles of restorative justice, which requires that the redress-reconciliation process is conducted in a way to reduce the distance between the stakeholders involved and that this relationship is conducted on a basis of empathy and respect. The theme explores the value of supporting those who have been harmed to talk about their experiences from their point of view and take part in the action which gives meaning to their loss. Part 2 of the framework synthesis results section details how the content of these themes could be used to consider the redress-reconciliation processes for those seeking justice following a historical life-changing event, to determine if they have experienced a fair process.

In relation to research question 2, none of the included studies explored the views of justice-seekers seeking redress-reconciliation for a historical life-changing medical event. Thus, it was not possible to directly explore how their views or approach to justice-seeking changed over time. However, all of the themes are supported by evidence from across the different stages of the redress-reconciliation pathway. This indicates the components identified within the themes could be considered relevant to all stages of the redress-reconciliation pathway. The content of each theme considers how the underlying concepts included within the theme are related to these different stages and, where appropriate, where escalation in the redress-reconciliation process can occur if the process is not perceived as transparent, person-centred and/or trustworthy. In addition, the theme 'Restorative Justice' explores how some people seeking redress-reconciliation can be supported to move from a position of grief/overwhelm to one of acceptance over time. We propose that the inter-relationship between the procedural aspects of the justice-seeking process and the emotional/relationship orientated aspects facilitate one another, with this relationship evolving and strengthening over time (see Figure 2). Part 2 of the framework synthesis provides additional reflection on how the findings from this review could be applied to individuals seeking justice for historical life-changing events.

The content of the first three themes, Transparency, Person-centred and Trustworthy closely aligns with the concepts of publicity, relevance and legitimacy proposed by Daniels & Sabin (1997;1998;2000).(5-7) The 'Trustworthy' theme within this review also incorporates some concepts related to the opportunity to appeal and enforcement conditions also proposed by Daniels et al., (1997; 1998;2000).(5-7) However, Daniels & Sabin indicate that the involvement of members of the public within the redress-reconciliation process is not necessary in order for it to be procedurally fair, thus the content of our final theme, Restorative Justice, is not represented by their work and was not captured in the initial iteration of our framework (Appendix B: Stages of framework synthesis Table 22). This may reflect the fact that their work focused primarily on resource allocation rather than individual trauma. Instead, as indicated by its name, our fourth theme closely relates to the restorative justice literature, which instead emphasises the importance of the humanisation of all parties involved with the redress-reconciliation process, through establishing respectful relationships which encourage listening and emotional expression.(85) We propose that it is perhaps through encouraging these types of relationships that can lead to a reduction in anger and resentment, thus reducing the desire for revenge and retribution on the part of those seeking redress-reconciliation following historical life-changing events. The value of a restorative approach to justice-seeking following a medical life-changing events in healthcare has been proposed by Wailling et al., (2022).(94) Active participation by all stakeholders within a procedure designed by all parties, which encourages everyone affected by the adverse event to meet with a facilitator to have restorative conversations which aim to restore

trust, meet justice needs and promote repair for all concerned.(94) This approach recognises that human relationships are essential to wellbeing and necessary for healing, something also captured within subtheme 4.1 'Humanising Process' of this synthesis.

Another key concept identified by the framework synthesis is the need for an apology, and that it should encompass expressions of remorse, accountability, assurances the event will not happen again and details for an explicit plan to ensure this. These elements of an apology were represented extensively within the studies prioritised for framework synthesis. The importance of taking accountability, and the limits of this, is recognised within Open Disclosure policies which informed health policy reform across several countries, including the UK.(27, 95) The premise of this policy was to promote openness after an adverse event and prevent the cycle of avoidance and defensiveness by professionals which can prevent learning from occurring and lead to individuals seeking legal action in a bid to attain accountability.(96) These concepts were identified through our framework synthesis, particularly amongst the studies illustrating experiences of the earlier stages of the redress-reconciliation pathway. However, they still represent the core needs of justice-seekers across all stages of the justice-seeking process.

Another core need for justice-seekers was to receive reassurance that the mistakes that led to the life-changing event they or their family member had experienced would not happen again. Whilst it is important that the circumstances for the events are thoroughly reviewed and used as an opportunity for learning and to improve practise where possible, we acknowledge that healthcare systems are continually evolving and that applying learning from past mistakes to current and future practice can be challenging. Within such complex healthcare systems, there are many different factors influencing the care of any individual patient, from a variety of potential multi-component interventions implemented across and multiple clinical and non-clinical systems, with a variety of different stakeholders who must working according to different sets of regulations and guidelines. Thus, implementing and maintaining change, and identifying patients to whom this change may be relevant, can be difficult.(97)

Strengths and limitations

This systematic review of qualitative evidence has been rigorously conducted in accordance with systematic review methodology and reporting guidelines. The results section highlights the key elements of the redress-reconciliation process which are associated with fair processes and outcomes and how these are reflected within different stages of the review process. To ensure that the review remained manageable and could be delivered within the agreed time-period, we were unable to include all studies in the framework synthesis. However, by prioritising the studies which reflected the

experiences of individuals following medically adverse events, we assured that the synthesis was led by the views of those most useful in addressing our research question. Our purposive sampling approach ensured that views of redress-reconciliation processes following non-medically adverse events were also fairly represented and that learning from these papers which could potentially inform practice within the health field could be incorporated into the final synthesis. Data from these papers also helped to inform weaker subthemes within the synthesis. Whilst it is possible that the papers not included in the synthesis may have contributed additional ideas, which would have added nuance to the synthesis, it is unlikely to have altered the final four themes which were identified. Thus, we feel that this approach helped ensure a balance between the conceptual breadth and depth within the final synthesis. We acknowledge the limited involvement of patients and members of the public with experiences of seeking redress-reconciliation following medically life-changing events in this review. We would welcome the opportunity to share our work with more people with experiences of these events and to incorporate their feedback into the findings.

In terms of the primary qualitative evidence included within this review, none represented the views of individuals seeking redress-reconciliation following a historical medical life-changing event. To ensure that our findings fully addressed the needs of the commissioners of this review, we considered how the findings from the framework synthesis could be applied retrospectively to historical cases, to consider whether those involved had experienced a fair process.

As a whole, the subthemes contributing towards each of the four main themes were supported by a evidence from a large number of papers of at least adequate quality, representing justice-seeking processes for medical and non-medical adverse events. The exceptions to this were subthemes 1.4 and 3.4, which were supported by nine and 13 papers respectively. Overall, there was less evidence available to inform the later parts of the justice-seeking pathway following medical adverse events. This is particularly pertinent to subthemes 1.2, 1.4, 3.1 and 3.3. This reflects our purposive sampling strategy, and whilst the learning identified through these studies may be useful to consider within the context of redress-reconciliation processes following a medical event, this may limit the extent to which justice-seekers within healthcare settings may be able to identify with their findings and should be interpreted with caution.

The majority of primary studies included in this review did not contain information which allowed us to explore how structural determinants, such as the ethnicity and gender of those seeking justice, may have influenced the perceived fairness of the process. This represents a vital gap in the learning that can be achieved from this review.

Implications for policy, practice and future research

The results from this framework synthesis are intended to support professionals involved with the redress-reconciliation system to establish if those seeking redress-reconciliation following a **historical** medically life-changing event have experienced a fair process, or not. The features of a fair process highlighted in part 2 of the framework synthesis could be used to support this. Whilst investigations have been the primary mode of resolution (as exemplified by the main literature base for this report), we can extrapolate learning from this area to non-investigatory approaches which include, but may not be limited to, redress-reconciliation meetings.

The elements of a fair redress-reconciliation process identified by the framework synthesis could also be used to inform the work of individuals supporting investigations into **more recent** patient safety events. Patients and their families seeking redress-reconciliation may also find the results of this framework synthesis informative. Our findings may help them know what to expect in terms of a fair process and could be used to help them articulate their needs at different stages throughout their journey

In terms of further research, it would be useful to establish to what extent the findings of this review reflect the experiences and needs of patients and families seeking redress and reconciliation following a historical medical event. This could be achieved through sharing the findings of this review with individuals who have experienced medical harm, or other individuals, groups and organisations who represent them. Alternatively, a separate piece of qualitative primary research could be commissioned to explore the experiences and needs of this group, with particular emphasis on their reflections on the need for a clear rationale for decisions made and their views on the resources available to support them to challenge findings/processes or resolve disputes. Particular importance should be placed on seeking the views of individuals from minority ethnic groups who may find it harder to access a fair redress-reconciliation process. This would help address the weaknesses of the findings of this synthesis as acknowledged above.

Once this work has been completed to validate the findings of this review, primary research to evaluate the extent to which existing structures and processes utilised within the NHS to promote redress-reconciliation reflect the components of the fair process as outlined within this report could be beneficial. This would provide insight into whether the processes currently being used are perceived as fair, with a view to reducing the number of people who remain unsatisfied with the process they have experienced and whose needs remain unmet for prolonged periods of time.

This review and any subsequent primary research have the potential for identifying areas in current practice which are not meeting the needs of people seeking redress and reconciliation and where

changes need to be made. Some of these changes may initially be challenging to incorporate into the procedure-based systems used within healthcare settings and by other organisations supporting the redress-reconciliation process. Thus, further research regarding the most effective way to implement any proposed changes would also be required.

Dissemination strategy

In addition to sharing this report with the commissioners of this review, we would also like to share our findings with patients and/or families who have experienced medically life-changing events. This would likely be through sharing plain language summaries via organisations that support these individuals.

We will also be creating a Briefing Paper to summarise the contents of this report to share with policy makers and clinical professionals. In addition, we will be writing up our findings for publication in a journal article intended to reach audiences with an interest in redress and reconciliation and/or patient safety.

Conclusions

This report highlights key features of redress-reconciliation which should be considered to ensure the process and outcomes are experienced as fair. The nature of these findings considers the procedural aspects of a fair process and the context in which these need to occur in order that fairness can be achieved. Our findings may be used in relation to processes to investigate recent patient safety events as well as those where the life-changing events are historical.

Acknowledgements

We would like to acknowledge the input of members from the PenARC Patient Engagement Group and Exeter PRP Evidence Review Facility Patient and Public Involvement Group for their input. Thank you also to Sue Whiffin for administrative support and proof-reading, alongside Rebecca Abbot, for proof-reading during this review.

Part 2: Full description of methods and framework synthesis results

Methodology

Our review protocol was prospectively registered on PROSPERO.(3) The methods used to conduct and report the findings of this review were consistent with the best practice approach for the conduct of systematic reviews and reporting of qualitative evidence synthesis.(17-19) Below, we provide full methodological details of how we identified, quality appraised and synthesised the findings from the primary qualitative studies included within this review.

Search strategy

The search for studies used a combination of bibliographic databases, checking reference lists, forward citation searching, and web searching. Our approach was iterative, in view of the diffuseness of the literature and the well-documented challenges of pre-specifying all the relevant search terms and sources when searching for qualitative studies.(86) Furthermore, our searches spanned both health and social care, and criminal justice, in order for us to draw on a breadth of research on justice seeking which would facilitate a richer synthesis than one or two fields of research alone.

Our initial bibliographic database search strategy was developed by two information specialists (SB and MR) in consultation with the review team and stakeholders. The search terms were empirically derived from the titles, abstracts and indexing terms (e.g. MeSH in MEDLINE) of potentially relevant journal articles identified in our scoping searches. Stakeholders indicated which of our pre-identified set of relevant studies were most relevant to their research question, which helped us to tailor our searches to identify the most useful studies. We also applied a validated qualitative study type filter to which we added additional search terms based on our pre-identified set of journal articles.(20) The MEDLINE search strategy for the Ovid platform is reported in *Appendix A: Search strategies*. The final search was translated for use in six bibliographic databases:

ASSIA (via ProQuest);

MEDLINE (via Ovid);

CINAHL (via EBSCO);

HMIC (via Ovid);

Social Science Citation Index (via Web of Science);

International Bibliography of the Social Science (IBSS) (via ProQuest).

References were managed using Endnote X8.2 (Clarivate Analytics).

All included primary studies and systematic reviews of interest identified by the bibliographic database searches were used as source studies for forward citation searching using Web of Science, with key studies of interest including those with the richest qualitative data. We manually inspected the reference list of all included studies. Web searches were carried out using the Google Scholar search engine and a selection of topically relevant websites. We also searched the HeinOnline database which indexes a variety of legal materials (see *Appendix A: Search strategies*).

Iterative searching

We carried out two additional searches using the IBBS (ProQuest) bibliographic database which specifically targeted studies on family members experiences of inquests or negligence. We selected the IBBS database as this was where the few studies we knew about on these topics were indexed. The search strategies for these searches are also reported in *Appendix A: Search strategies*. We also checked the reference lists and carried out forward citation searches of relevant studies which were identified via these follow up searches.

Inclusion criteria

Key definitions

Redress: To make amends for or give payment for a wrong which has been done.(87)

Reconciliation: A process which presents the opportunity for the sides of a conflict to express concerns about a past event, have these concerns validated and seeks to move beyond these in a renewed relationship. The reconciliation process also incorporates opportunities for redress.(88)

Life changing event: draws upon the definition of “serious adverse event” (SAE) used within medical settings, which is any “*untoward medical occurrence(s) that at any dose results in death, hospitalisation or prolongation of existing hospitalisation, persistent or significant disability/incapacity or a congenital anomaly or birth defect.*”(89) However this definition can also be applied to events which occur outside of medical settings, examples of which are listed within the ‘*Context*’ section below.

Population

Include

Individuals who have experienced a life changing event. These individuals may include:

- The person who has experienced the event;
- Family or carers who are seeking justice on behalf of the person who experienced the event.

Exclude

- Staff about whom the complaint has been made;
- Staff working within the redress/reconciliation system.

Phenomenon of Interest

Include

- Experiences and/or views of redress and reconciliation processes following a life changing event;
- Experiences and/or views on what is perceived to be a fair/unfair outcome following a life changing event.

Exclude

- Experiences of justice seeking processes where this is against individual members of staff, not system/facility as a whole;
- Experiences and/or views of redress and reconciliation processes following life changing event where primary outcome/phenomenon of interest is impact on grief and/or bereavement

Context

Include:

Redress/reconciliation processes occurring within following settings:

- Health or social care systems following life-changing events (e.g. adverse patient safety events);
- Child protection or sudden child death investigations;
- Homicide reviews and restorative justice processes within a criminal context;
- Any other service or professional context identified by our searches where findings are amenable to importing into the health care context, which will be decided on a case-by-case basis in discussion with stakeholders.

Geographical region

High-income countries as defined by the World Bank list with similar procedural justice systems to the UK.

Date of publication

No restriction.

Study design

Include

Any study design collecting the experiences/views of individuals defined within the 'Population' section above'. Examples of eligible study designs include:

- Primary studies collecting qualitative data where data collection based upon interviews and focus groups and using a clearly recognisable qualitative analysis strategy (e.g. thematic analysis, framework analysis);
- Case studies (individual person and service/organisation level).

Study selection

The inclusion and exclusion criteria were applied to the title and abstracts of a sample (n=100) of the bibliographic database search results by four reviewers (GJMT, LS, SB, HL). Preliminary decisions were discussed to ensure the consistent application of criteria.

The Inclusion and exclusion criteria were then applied to the title and abstract of each identified citation independently by two reviewers (GJMT, LS, SB, HL), with disagreements resolved through discussion or referral to a third reviewer as required. The full text of each paper was assessed in the same way. Endnote software was used to support study selection. A PRISMA-style flowchart was produced to detail the study selection process and reasons for exclusion.

Protocol deviation

Study prioritisation

Due to the higher than anticipated number of included studies, we needed to utilise a prioritisation process to identify studies with the highest quantity of data relevant to our research questions for full data extraction, quality appraisal and framework synthesis.

First, two reviewers (LS, HL) extracted summary data for all the included studies. This data included: method by which study was found, first author, date, title, aim, sector/field, country, year of data collection, stage of justice-seeking process represented, participants relevant experience, participants providing views, data collection method and quantity of first/second-order construct data relevant to the research questions of this review.

We then used a matrix to group all of the included studies according to the field (or context) and the stage of the justice, or redress-reconciliation process which was the focus of that paper. The name of the seven fields were as follows:

1. Medical

2. Sexual abuse
3. Suicide
4. Occupational
5. Homicide
6. Death in custody/Police killing
7. Missing persons

The stages of the redress-reconciliation process identified within the matrix reflected the content of all of the included papers and represented key stages from the initial disclosure of an adverse event, through to the post-verdict meeting between key stakeholders involved in the justice-seeking process. The stages of the justice-seeking process represented by included papers were as follows:

1. Raising concerns and disclosure;
2. Investigation of adverse event/Coroner's inquest;
3. Litigation, malpractice or compensation claim: Included active or recently settled cases;
4. Post-investigation or litigation;
5. No ongoing investigation or litigation claim;
6. Post adverse event.

The completed prioritization matrix can be viewed in *Appendix E: Prioritisation matrix*. In the initial stage of prioritisation, studies within the health field with the highest quantity of data relevant to our research question were selected for full data extraction, quality appraisal and inclusion in the framework synthesis. We ensured that all parts of the justice-seeking pathway were represented by this first group of studies. For parts of the pathway where none of the studies which contributed was deemed to have a 'High' quantity of relevant data (two or more pages), we selected those with a 'Medium' quantity of data (approximately 1 page) instead.

The remaining studies from the health field were the second group of studies which underwent full data extraction, quality appraisal and were included in the framework synthesis, as described below. The third and final group of studies prioritised for data extraction and framework synthesis represented a sample of studies from across the non-health fields. These were selected using purposive sampling,⁽⁹⁰⁾ a technique utilised in other health-related evidence syntheses of qualitative research.⁽⁹¹⁾ This technique ensured that parts of the justice-seeking pathway which were under-

supported by research from the health field were more fairly represented within the synthesis. This approach also allowed us to seek additional evidence to support some of the weaker themes within the developing synthesis. This process is described more fully within the 'Framework synthesis' section below.

Data extraction and quality appraisal

Extraction of the descriptive data for prioritised studies was undertaken by one reviewer (HL, LS) and checked by a second (HL, SB, JTC, RG, LS, GJMT) using Microsoft Excel, with disagreements settled by a third reviewer if necessary. The data extracted is outlined in *Table 6: Data extracted from included studies* below.

Table 6: Data extracted from included studies

Data	Description
First author and year of publication	For example, Burns 2006
Type of publication	Is the study a journal article, dissertation, government or website publication
Country of data collection	For example, the Netherlands, the UK
Focus/Aim of review	The primary/secondary aims of each study relevant to the aims and objectives of the review
Field, type and consequence of life-changing event	The field the life-changing event occurred within (medical, sexual, police/prison, employment, CSA, suicide) Type of life-changing event (e.g. medication error, delayed treatment) and consequence (e.g. disability, death)
Participants and age	Eligible participants as stated within our review's inclusion criteria, their mean age & age range
Other stakeholders and age	Other participants in the study who have not experienced AE and their mean age & age range
Redress-reconciliation process	Describes the stage of the redress and reconciliation pathway participants are providing their views on
Year of data collection	Year in which each study collected data from participants
Recruitment strategy	How participants were recruited for the study
Inclusion criteria	Criteria implemented by each study to determine eligible participants
Setting and method of data collection	Where the research was conducted (e.g. home, hospital) and how data was collected (e.g., focus group, interviews)
Data analysis	The type of data analysis method used (eg thematic analysis, grounded theory)
Quality rating	Quality rating as indicated by modified Wallace checklist

AE=Adverse Event; CSA=Child Sexual abuse

We extracted first and second-order construct data from the results and discussion sections of studies prioritised for synthesis into a framework. This was carried out by one reviewer (LS) and checked by a second (HL). Further detail on the framework synthesis is provided in the next section.

We appraised the quality of all studies prioritised for inclusion in the framework synthesis using the Wallace Checklist (2004) using the same process as described for descriptive data extraction.(4)

Framework synthesis

Summary descriptive data from all included studies were tabulated and described narratively, in addition to key features of the sample, methods and quality appraisal from studies prioritised for inclusion in the framework synthesis.

Development of the best-fit framework

Selection and adaption of an initial framework drew upon a 'Best-fit' framework synthesis approach.(92, 93) We developed the first version of our best-fit framework based on the 'Accountability for Reasonableness' work carried out by Daniels and Sabin (1997;1998;2000), which proposes four conditions that priority setting within healthcare has to meet in order to be considered fair and legitimate: (1) publicity, (2) relevance, (3) appeals and (4) enforcement.(5-7) These conditions became the basis of our preliminary themes. Key concepts relevant to the 'Accountability for Reasonableness' were identified by one reviewer (LS) and, where possible, mapped onto these four conditions.(5-7) These formed the basis of early sub-themes within the framework. Key concepts not easily mapped onto the four conditions described by Daniels et al. (1998) were listed separately. Finally, we added a theme within the 'publicity' condition to reflect the inclusion of papers where the main focus was how the disclosure of an error was conducted. This first version of the framework was shared with other members of the team for discussion and revision (GJMT, HL) whilst piloting the framework on 4 of the prioritised medical studies. The first version of our framework can be viewed in *Appendix B: Stages of framework synthesis: Table 24*.

During the piloting process, two researchers (LS, HL) extracted first and second-order construct data from the results and discussion sections of four studies from the health field with a high quantity of information relevant to the research question of this review. Each researcher carried out data extraction for two papers, and then checked the two papers extracted by the other reviewer. This ensured that the framework was suitable for the purpose of the initial data extraction and allowed the reviewers to check they shared an understanding as to what constituted relevant data for the purposes of this review.

Once we completed the piloting process, reviewer one (LS) extracted the remaining medical studies from the first stage of the prioritisation process into the framework using Nvivo. The second reviewer (HL) checked the data extracted from each study to ensure we had captured all data relevant to our research questions. Upon completing this checking, reviewer one conducted some inductive, descriptive coding of the content coded under each of the sub-themes and grouped similar concept

together. This involved moving groups of codes across different subthemes and helped to ensure that the developing subthemes remained conceptually distinct from one another. Reviewer 1 discussed the placement of descriptive codes within each subtheme with reviewer 2, before receiving feedback on the developing framework from members of the wider team (RG, SB, JTC, MN). This process meant that the medical studies with the greatest quantity of conceptually rich data had the greatest influence in shaping the developing framework, ensuring it best reflects the content of the papers most relevant to the research question of this review.

One reviewer (LS) then coded the remaining medical studies using the descriptive codes from the revised framework. Additional descriptive codes were added as required and applied to previously coded studies within an iterative process. Key concepts identified by reviewer one from this second group of papers were used to revise how certain descriptive codes were grouped, resulting in the generation of a new theme containing two new subthemes. The names and positions of other existing subthemes were also changed to reflect their content. The names of some of the existing theme names were then changed to ensure they accurately reflected the content, and relationship between, the subthemes within them.

Reviewer one discussed the revised framework with reviewer two and received suggestions for amendments. The wider team (GJMT, RG, JTC, SB) were consulted for their input regarding the names of themes within the revised framework and the proposed relationship between the different themes and subthemes. Their feedback was incorporated into the synthesis, and the revised framework was then shared with review stakeholders for comment.

In the final stage of the framework synthesis, studies from non-health fields were selected using purposive sampling and coded to the framework. Reviewer one and reviewer two each read half of the non-medical studies, and recorded the names of descriptive codes represented within each study, as well as any novel concepts not yet captured by the synthesis within a table. Each reviewer independently made a decision as to whether each study should be included in the framework synthesis (see Appendix E: Prioritisation matrixTable 27: Matrix for prioritising non-medical studies). Disagreements were resolved through discussion. Studies were included in the synthesis if they specifically spoke to experiences of post-disclosure elements of the justice-seeking process and contained information relevant to sub-themes within the existing synthesis which were not supported by many studies from the health field.

Stakeholder involvement

Representatives of the DHSC involved with commissioning this review were involved throughout the review process. The impact of this involvement on the review is summarised in *Table 7* below.

Table 7: Stakeholder engagement and impact on the review

Stage of review	Stakeholder, mode of contact	Influence on review process
Protocol development	Three representatives from DHSC – remote meeting, email	<ul style="list-style-type: none"> - Defining our research question - Developing the project protocol, specifically enabling us to identify key populations and phenomenon of interest - Finalising search terms for bibliographic database searches
Screening	Two representatives from DHSC – remote meeting, email	<ul style="list-style-type: none"> - Providing clarification on review inclusion criteria - Reviewing the list of included reviews following full-text screening - Providing feedback on studies to include via purposive sampling
Synthesis/ Presentation of findings	Three representatives from DHSC – remote meeting	<ul style="list-style-type: none"> - Providing feedback on preliminary findings - Ensuring our findings are accessible to our intended audience

DHSC=Department of Health and Social Care

We were unsuccessful in our efforts to contact people with direct or in-direct experience of seeking redress-reconciliation following a medically adverse event. Organisations we approached to ask for volunteers to contribute towards this review included: Making Families Count, National Voices, Inquest, and the Health Service Investigation Branch. We were able to consult with two individuals from two existing patient and public involvement groups from the Faculty of Health and Life Sciences at the University of Exeter. These two individuals had lived experience of medically adverse events and were able to provide insight on the results of our review. Their input corroborated our findings, particularly around the need for an apology, to feel heard and be treated with respect and empathy. Their involvement also supported us to develop our thinking regarding the implications of our findings on future research and practise, especially with the need to seek the views of people from ethnic minorities.

Framework synthesis: Full results

We included 41 studies (47 papers) in the framework synthesis; the majority of these studies reported evidence from the health field (n=31),(21, 22, 24-56) and a subsample representing evidence from people seeking justice following bereavement from homicide (n=3),(57-60) work accidents (n=2),(64, 65) suicide(n=2), (68, 69) death in police custody or following contact with police (n=1),(74) or people seeking justice following sexual abuse (n=2).(76, 77, 80)

The synthesis identified four main themes: 1) The need for Transparency, 2) Person-centredness, 3) Trustworthy and 4) Restorative Justice. *Table 8* below outlines the four themes and the number of studies which support them, separated according to the stage of the justice-seeking process represented by the participant views reported within them.

Table 8: Studies contributing to each theme

Theme name	Theme 1: Transparency	Theme 2: Person-Centred	Theme 3: Trustworthy	Theme 4: Restorative Justice	
Studies (N)	38	39	37	38	
Stage of Redress-Reconciliation Process	Disclosure/ Communication	Duclos 2005(30) Fisher 2016(32) Hagensen 2018(34) Hannawa 2017(35) Hernan 2014(24) Hovey 2014(36) ledema 07(40) ledema 2011; 2012a; 2012b; Piper 2014(37-39, 53) Kent 2008(42) Kim 2021(43) Loren 2021(44) Martin 2021(45) Mazor 2010(26) Mazor 2012; 2013(46, 47) Sorensen 2010(55)	Duclos 2005(30) Fisher 2016(32) Hagensen 2018(34) Hannawa 2017(35) Hernan 2014(24) Hovey 2014(36) ledema 07(40) ledema 2011; 2012a; 2012b; Piper 2014(37-39, 53) Kent 2008(42) Kim 2021(43) Loren 2021(44) Martin 2021(45) Mazor 2010(26) Mazor 2012; 2013(46, 47) Sorensen 2010(55)	Duclos 2005(30) Fisher 2016(32) Hagensen 2018(34) Hannawa 2017(35) ledema 07(40) ledema 2011; 2012a; 2012b; Piper 2014(37-39, 53) Kent 2008(42) Kim 2021(43) Loren 2021(44) Martin 2021(45) Mazor 2010(26) Mazor 2012; 2013(46, 47) Sorensen 2010(55)	Butler 2019(22) Duclos 2005(30) Fisher 2016(32) Hagensen 2018(34) Hannawa 2017(35) Hovey 2014(36) ledema 07(40) ledema 2011; 2012a; 2012b; Piper 2014(37-39, 53) Kent 2008(42) Kim 2021(43) Loren 2021(44) Martin 2021(45) Mazor 2010(26) Mazor 2012; 2013(46, 47) Sorensen 2010(55)
	Review or inquest	Bakhbakhi 2017(28) Biddle 2003(68) Bouwman 2018(21) Chapple 2012*(69) McQueen 2021(48) Myren 2021(52) Ngo 2021(65) Shaw 2007*(74) Wiig 2021(56)	Bakhbakhi 2017(28) Biddle 2003(68) Bouwman 2018(21) Chapple 2012*(69) Etchegaray 2014(31) McQueen 2021(48) Myren 2021(52) Ngo 2021(65) Shaw 2007*(74) Wiig 2021(56)	Bakhbakhi 2017(28) Biddle 2003(68) Bouwman 2018(21) Etchegaray 2014(31) McQueen 2021(48) Myren 2021(52) Ngo 2021(65) Shaw 2007*(74) Wiig 2021(56)	Biddle 2003(68) Bouwman 2018(21) McQueen 2021(48) Myren 2021(52) Ngo 2021(65) Shaw 2007*(74) Wiig 2021(56)

Theme name	Theme 1: Transparency	Theme 2: Person-Centred	Theme 3: Trustworthy	Theme 4: Restorative Justice	
	Litigation Process	Burns 2006* Eastwood 1998a;1998b Englebrecht 2014 Ipsos-MORI 2016* Maderia 2008;2010 Matthews 2012 Melville 2012 Moore 2017a Moore 2017b Ocloo 2010 Pyo 2019	Burns 2003 Eastwood 1998a; 1998b* Englebrecht 2014 IPSOS 2016* Melville 2012 Maderia 2008; 2010 Matthews 2012 Moore 2017a Moore 2017b* Ocloo 2010 Pyo 2019	Burns 2003 Eastwood 1998a; 1998b Englebrecht 2014 Ipsos-MORI 2016* Maderia 2008;2010 Melville 2012 Matthews 2012 Moore 2017a Moore 2017b* Ocloo 2010 Pyo 2019	Burns 2003 Eastwood 1998a; 1998b Englebrecht 2014 Ipsos-MORI 2016* Maderia 2008;2010 Melville 2012 Matthews 2012 Moore 2017a Moore 2017b* Ocloo 2010 Pyo 2019
	Post-litigation process/	Chiu 2010*(29) Gallagher 2009*(33)	Chiu 2010 (29) Gallagher 2009(33) Saco 2018(80)	Chapple 2012*(69) Chiu 2010*(29) Gallagher 2009(33)	Chapple 2012*(69) Chiu 2010*(29) Gallagher 2009(33) Saco 2018(80)
	Other	Kamin-Friedman 2021(25)	NA	Kamin-Friedman 2021(25)	Kamin-Friedman 2021(25)

*Contributes insight towards multiple stages of redress and reconciliation process; Green text=study from non-health field; NA – Not Applicable

We have separated the four themes into two groups. The first group explores what a fair process **looks** like according to justice seekers and contains the themes *Theme 1: Transparency*, *Theme 2: Person-centred* and *Theme 3: Trustworthy*. The second group explores what a fair process **feels** like and focuses on the theme of *Theme 4: Restorative Justice*. Within each theme, we consider how the stage of the justice-seeking process experienced by the participants may influence the concepts discussed. The proposed relationship between these four themes, and their subthemes, is represented within *Figure 3* below and explored further at the end of this section.

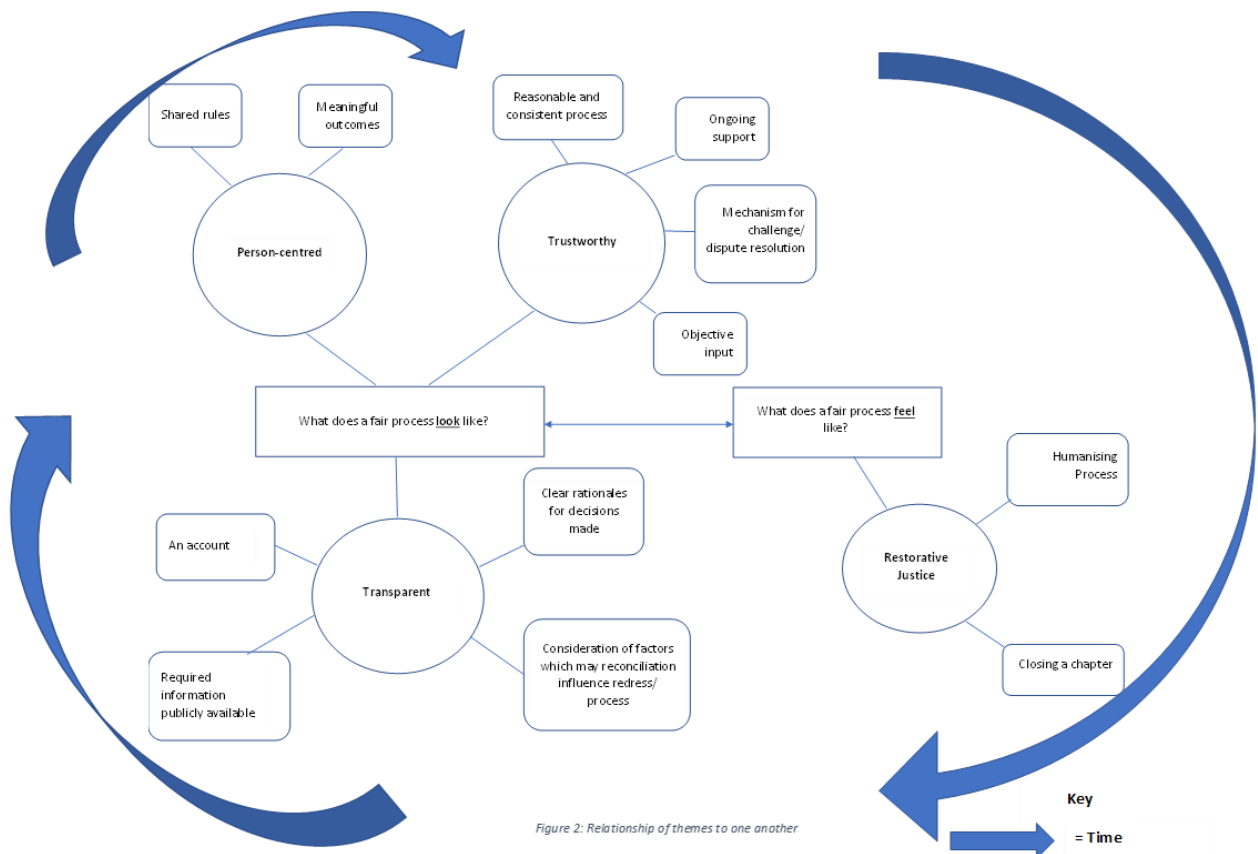


Figure 2: Relationship of themes to one another

Figure 3: Relationship between themes and subthemes

None of these studies reported experiences of individuals who were still actively seeking justice following a non-recent, or “historical”, medical event.. See the ‘*Framework synthesis: Part 2 – relating the findings to historical cases*’ section within the first part of this report on how the points of learning arising from this synthesis can be applied to historical cases.

What does a fair process look like?

Theme 1: Transparency

Thirty-eight studies (44 papers), (21, 24-30, 32-60, 64, 65, 68, 69, 74, 76, 77) 29 of which were from the Health field,(24-30, 32-56, 76, 77) contribute towards this theme (see *Table 8*). Different factors which may influence the transparency of the process are discussed within the four subthemes; an account, information required publicly available, consideration of systemic factors and provision of a clear rationale for decisions.

Subtheme 1.1 : An account

Thirty-one studies (35 papers) contributed towards this subtheme, which outlines the perceived value that individuals affected by a life-changing event and their families placed on gaining a comprehensive,

accurate account of the life-changing event and its consequences.(21, 24, 26, 27, 29, 30, 32-37, 39-41, 43, 44, 46-53, 55-57, 59, 60, 64, 65, 68, 69, 74) These experiences were consistent across the different stages of the justice system, as shown below in *Table 9*:

Table 9: Studies supporting subtheme 1.1

	Stage of Redress-Reconciliation Process					
	Disclosure/ Communication	Review inquest	or	Litigation Process	Post-litigation process/ desired outcomes	Other
Supporting studies	Duclos 2005 (30) Fisher 2016 (32) Hagensen 2018 (34) Hannawa 2017 (35) Hernan 2014(24) Hovey 2014(36) Iedema 07(40) Iedema 11(39) Iedema 2012a(38) Piper 2014(53) Kim 2021(43) Loren 2021(44) Mazor 2010(26) Mazor 2012(47) Mazor 2013(46) Sorensen 2010(55)	Biddle 2003(68) Bouwman 2018(21) McQueen 2021(48) Myren 2021(52) Ngo 2021(65) Shaw 2007(74) Wiig 2021(56)		Burns 2006(57) IPSOS 2016*(41) Maderia 2008(59) Maderia 2010(60) Matthews 2012(64) Melville 2012(49) Moore 2017a(50) Moore 2017b(51) Ocloo 2010(27)	Chiu 2010* (29) Chapple 2012*(69) Gallagher 2009(33)	

*Contributes insight towards multiple stages of redress and reconciliation process; **Green text**=study from non-health field

Twenty-seven studies (30 papers) spoke to the desire of those seeking redress-reconciliation to have a clear, accurate account of what had happened with regard to the life-changing event, including the events leading up to it and wider contextual or systemic factors which may have contributed to its occurrence.(21, 24, 26, 27, 29, 30, 32-34, 36, 37, 39-41, 43, 44, 46-49, 51, 52, 55, 57, 59, 60, 64, 65, 68, 74) Twelve studies (thirteen papers) discussed the importance of accurate information around the time the life-changing event occurred, (24, 30, 33-37, 39-41, 44, 48, 52) as illustrated by the experience of patients participating in a morbidity and mortality meeting within a surgical department:(52)

We wanted to see what happened, because we experienced a lot of stress and therefore we have missed some information and what exactly happened. [Female patient, Myren et al., 2021 p47]

Two mothers within a rural general practice setting who had experienced harm had the following

conversation:(24)

P1: Like, I feel like you need an explanation and why everything went chaotic. I think they should explain this is what happened. They can't tell you at the time because it's all happening.

P2: No, nobody was telling me anything.

P1: But afterwards I think you definitely need a, your doctor should debrief you and say this is what is happening; this is why we did this and that. [Female patient, Hernan et al., 2014 p562]

The above two quotes acknowledge the stress associated with the fast-paced nature of life-changing events can make it difficult for patients to understand what is happening and for clinicians to provide an explanation at the time. This may have disrupted their ability to form a coherent narrative of what had happened, the importance of which is discussed in *Subtheme 4.2: Closing a chapter*. This represents a potential source of dispute, as patient and/family recollections of what occurred may differ from those of professionals involved. This may influence the perceived accuracy of the account provided (see *Subtheme 2.2: Meaningful outcomes*), and thus the trustworthiness of the disclosure process (*Theme 3: Trustworthy*). Seven studies (7 papers) expressed how valuable it was for the people affected by the event to receive an in-person explanation as to what had occurred:(33, 41, 46, 51-53, 56):

Some things were explained briefly [after the AE], it was explained very well again the next day . . . and during the meeting. When that happens, you have nothing to complain about. [Female patient, Myren et al., 2021 p347](52)

In addition to information about the event itself, justice-seekers also sought information on what was being done to investigate the event and reassurance in terms of the impact of the event for themselves and future treatment:(43)

When this kind of problem occurs, the doctor should state the facts precisely and suggest a response, and if it is difficult for him to complete treatment, he should promptly refer the patient to another hospital. Nurses should explain this situation in more detail. They should tell the patient what precautions to take in the future, and reassure the patient that everything will be okay [Patient or family member, Kim et al, 2021 p2507]

Even in the early stages of the redress-reconciliation pathway, individuals also sought assurance that such a thing would not happen again and requested evidence that lessons had been learned going forward. These concepts are discussed further within *Subtheme 2.2: Meaningful outcomes* below.

Five studies (6 papers) indicate that patients and family within the early parts of the disclosure or event review process found formal written documentation of meetings which they could refer back to useful, particularly as the stress associated with the life-changing event or justice seeking process, and grief associated from loss, could make it difficult to remember important information.(35, 37, 39, 52, 56, 74) Written documentation also provided justice-seekers with the opportunity to correct any information they perceived to be inaccurate,(56) and presented an opportunity to develop a two-way dialogue between clinicians and justice-seekers, and involve them in the justice-seeking process, the importance of which is explored further within *Subtheme 3.1: A reasonable and consistent process*.

As illustrated below in *Subtheme 1.2: Information required publicly available*, the early stages of the justice-seeking process do not always provide a clear account of the life-changing event. Data from three studies indicate that the inquest process can provide access to accurate information people had previously been unable to obtain:(49, 60, 65)

I just was blown away by how far a scope - even to the point where there were text messages on [worker's] phone. Now for all those years nobody had bothered to look at them and yet there he was getting the police in, just like that we had them in print. So, we could show that [worker] had gone in there to work on the machine before he died [Family member of individual who died following work accident, Ngo et al., 2021 p456](65)

I needed to find out everything that went on, how it went on, how they was [sic] able to prosecute or catch him and all these things. The more I knew about what was going on and in that case the better off I was ... [Participant in interviews regarding Oklahoma City bombing, Maderia et al., 2010 p1500](60)

However, four studies, three documenting justice processes following non-medical life-changing events, indicated that information given during inquest/trial hearings did not always present a comprehensive account of the event in the eyes of the justice seeker:(41, 68, 69, 74):

There was lots of evidence that though I told them was never brought out at the inquest they had quite obviously made up their minds and not even bothered to read it and when I gave evidence the coroner just scribbled on his pad and brought in the suicide verdict. As far as I'm concerned the official hearing didn't listen (Family member bereaved by suicide, Biddle et al., p1040)(68)

This quote also illustrates the importance of ensuring the views of justice-seekers are incorporated into the summing up of information during inquests/trials, and thus the final verdict or outcome (see *Subtheme 3.1: A reasonable and consistent process*).

Ten studies (eleven papers) indicated that people seeking redress-reconciliation would like to receive an account of what happened from those they perceived to be directly involved with the life-changing event as it gave them the opportunity to seek the answers they needed from someone who knew what had happened (see subthemes *Subtheme 3.1: A reasonable and consistent process* and *Subtheme 4.1: Humanising process*). (32-34, 39, 40, 50, 51, 53, 55, 65, 74) This opportunity to meet face-to-face has been associated with feelings of transparency and opportunities to build trust. (56)

Overall, people seeking redress and reconciliation wanted to obtain a comprehensive account of the life-changing event, the circumstances leading up to it, what was being done to investigate it and what was being done to ensure it could not happen again. Being able to meet with individuals that were directly involved with the life-changing event to receive this account may enhance the perceived trustworthiness of this account, through providing answers to issues that were unknown and providing reinforcement to people’s own memory of the event. If people were unable to access this information early within the redress-reconciliation process, or if information received conflicted with what was already know, it could cause them to pursue more formal litigation.

Subtheme 1.2: Information required publicly available

Thirty-two studies (35 papers) contributed towards this theme which explores the difficulties people seeking redress-reconciliation had in obtaining information and how of professionals supporting the process may hinder or facilitate the exchange of information required. (21, 26-30, 32, 34-45, 48-52, 54-57, 60, 64, 65, 68, 74, 76, 77) *Table 10* below presents the stages of the justice-seeking process supported by the papers contributing to this theme.

Table 10: Studies supporting subtheme 1.2

	Stage of Redress-Reconciliation Process					
	Disclosure/ Communication	Review inquest	or	Litigation Process	Post-litigation process/ desired outcomes	Other
Supporting studies	Duclos 2005(30) Fisher 2016(32) Hagensen 2018(34) Hannawa 2017(35) Hovey 2014(36) Iedema 07(40) Iedema 2011(39); 2012a(38); 2012b(37) Kent 2008(42)	Bakbakh 2017(28) Biddle 2003(68) Bouwman 2018(21) McQueen 2021(48) Myren 2021(52) Ngo 2021(65) Shaw 2007(74)		Burns 2006(57) IPSOS 2016*(41) Eastwood 1998a(77) Eastwood 1998b(76) Maderia 2010(60) Matthews 2012(64)	Chiu 2010*(29)	

	Kim 2021(43) Loren 2021(44) Martin 2021(45) Mazor 10(26) Sorensen 2010(55)	Wiig 2021(56)	Melville 2012(49) Moore 2017a(50) Moore 2017b(51) Ocloo 2010(27) Pyo 2019(54)		
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*Contributes insight towards multiple stages of redress and reconciliation process; **Green text**=study from non-health field

The people seeking redress-reconciliation represented in the prioritised studies often found it difficult to obtain the information they required. Ten studies (10 papers) predominantly representing experiences of processes early on in the process, reported on the difficulties individuals experienced when trying to gain access to information about the life-changing event:(30, 34, 39-41, 43, 49, 56, 64, 74):

I thought, as her next of kin and as the executor, I could just walk up and get her files and show them to my doctor ... because my brothers and sisters were so angry about the whole thing, and I wanted someone to explain it to us in our terms, and they said, 'No no because of the system or whatever we can't do that, we can't release them [Bereaved daughter, ledema et al., 2011 p10](39)

The above quote suggests that some individuals may not realise they are not entitled to receive information regarding the adverse. It also illustrates how the need to maintain the confidentiality of the patient experiencing the life-changing event may be perceived as system bureaucracy, a concept discussed further in the *Subtheme 1.3: Consideration of systemic factors*.

Five studies (six papers) indicated that even when obtained, medical records may not always provide an account of the life-changing event which agrees with the justice-seekers experience:(34, 37, 39, 42, 43, 56)

... there is a note [in the medical record] that says, '3am patient feels worse Endo Registrar contacted and Cortisone given.' And it makes it sound like it was an immediate thing, and it wasn't; there is no mention of the other five times she was called into my room. ... There is nothing there. ... So it covers them legally as well [Participant, ledema 2011, p11](39)

Here it appears the participant believes that some information has been withheld in the formal record of the life-changing event, acting as a barrier to starting the redress-reconciliation process. Difficulties accessing information were not limited to the initial disclosure process. One individual was still seeking an account of what had led to the death of their family member after three years of investigations:

We still don't know what happened. We don't know whether anybody was held responsible. We don't know whether they were charged. Nothing like that [Family member of person killed during work accident, Matthews et al., 2012 p23](64)

Not only does this point to the difficulty in accessing information for justice seekers, it highlights that this needs to be done in a timely manner (see *Subtheme 1.3: Consideration of systemic factors*). In addition, it emphasises the need of those who had been harmed to hold someone account to account what they had experienced (see *Subtheme 2.2: Meaningful outcomes*).

Participants in nine studies perceived that the individuals responsible for the medical error were avoiding communicating with them and/or answering their questions.(26, 29, 34, 35, 41, 43-45, 47) This perception occurred both during, (41)(IPSOS, 2016) and after the event:(26, 29, 34, 35, 43, 45)

At first, I felt that they just didn't want to communicate with us, and had been attempting to hide the true information from us. and [they] postponed the meeting again and again [Participant, Chiu et al., 2010 p706](29)

They just seem to want to fob us all off and hope we'll go away. They don't seem to be taking the complaint serious enough and being proactive about doing something about it. They just seem to be wanting to avoid the issue completely, and thinking, 'Well, not many women complain' [Patient – complained about treatment following painful invasive investigation, Martin 2021, p4] (45)

This perceived avoidance led some patients and/or their families to believe that clinicians did not care or were guilty.(26) In addition, patients/families in nine studies believed that some professionals took part in more active defence of themselves, their colleagues and/or institution.(27, 34, 39, 42, 48, 54-56, 74) They felt that information could go missing,(48, 54, 56)(Pyo, McQueen, Wiig) that clinicians acted in defence or cover up for their colleagues,(34, 42, 56)(Hagensen, Kent, Wiig) and 'closed ranks' against those expressing their concerns:(27, 48)

Complaining...gets me nowhere, people shut down, notes go missing, people close ranks. And then you're not heard, and you're not believed and actually they put the blame on me and say, oh, no, you're paranoid or whatever. I've had the whole works and also ...people are only human, we're dealing with human beings that are stressed out often [Participant McQueen 2021 p7](48)

I do think they're just so protective. Frightened of anybody suing, and that's their first priority, not 'Can we do this any better?' [...] They're so defensive. And bat off these complaints back at the people, [...] like when you have a car accident and they say, 'Never say it's your fault'

[Relative complained about poor outcomes following surgical procedure, Martin et al., 2021 p4](45)

The above quotes indicate that people seeking redress-reconciliation experienced this as an attempt to avoid being blamed for the life-changing event. Some participants perceived that attempts were made instead to shift the blame onto themselves, the people who had been harmed. They saw this as a barrier to individuals and organisations from taking responsibility for the error and moving forward into a place of learning, important outcomes for justice seekers. This is discussed below in subtheme 2.2. Sixteen studies reported on the importance of the perceived honesty of clinicians, With one patient co-chair for patient safety providing insight into the emotional impact of this for patients:(27, 30, 34, 35, 39-43, 45, 49, 52, 55, 57, 65, 68)

When patients and families sense that information is being withheld, we lose trust, and we are more anxious, fearful and angry [Co-chair for patient safety in Canada, Hovey et al., 2014 p267](36)

The above quote suggests that lack of perceived openness by professionals reduced trust in the redress-reconciliation process and could reinforce the need for people to make formal complaints or pursue litigation.(27, 41, 43, 49) Four studies presented data from participants who sought support from external organisations to access information about exactly what had occurred,(38, 49, 64, 74) including one participant who sought support from a solicitor to instigate legal action against an NHS Trust:

I'm glad that I went that far, I knew I wouldn't win I had no intentions of winning, I just wanted to get to the bottom of things if I could to a certain extent... (Female family member of patient who died, Melville et al., 2012 p45)(49)

Here the need for answers (*see Subtheme 2.2: Meaningful outcomes*) represents a clear motivation for instigating the litigation process.

Eight studies (10 papers) indicated that over the course of the redress-reconciliation process, patients and families had difficulty understanding the medical and legal information they were given.(30, 37, 39, 40, 49, 52, 56, 74, 76, 77) Concerns focused on the use of technical language,(49, 52, 76, 77) the complex nature of medical decision-making (39, 40), organisational structures and/or professional roles (40, 56, 74) and confusion surrounding justice seeking processes.(12, 49, 56, 74) This highlights the need for patients and their families to receive adequate information and support through the justice-seeking process to ensure they gain full insight into the life-changing event itself and can fully participate, concepts which are explored more fully in the *Subtheme 3.2: Ongoing support*.

Eight studies (nine papers), four from the health field,(26, 32, 34, 39, 40) and four from the non-health field, (57, 64, 74, 76) indicated that patients and/or their families can find it difficult to know how to proceed with making a complaint and/or negotiate the litigation process or where they could access support:

...wanted to know details ... they wouldn't tell us anything ... I wanted to know what was going on, it was really important to me [Female survivor of CSA, Eastwood et al., 1998b p201](76)

Information should be disseminated rather than the family having to search for it. Put families in touch with lobbying groups as it is a great help [Family of a man who died in prison, Shaw 2007, p36](74)

The above quotes illustrates how those involved with the litigation process appreciate information on how to access support and highlight the need for more active signposting by services.(30, 50, 74)

Four studies (five papers) indicate that people seeking redress and reconciliation needed to be kept informed of their rights within formal legal proceedings, firstly to initiate legal proceedings and obtain legal representation,(39, 50, 51) but also their rights regarding providing a victim impact statement,(57) or accessing a second post-mortem:(74)

I regret not getting a lawyer sooner...It was really helpful that the hospital said I could have help from a lawyer, because I hadn't thought of that and he really helped to explain stuff to me [Patient, Moore et al., 2017b p793](51)

Being signposted to appropriate information and support may help those seeking redress-reconciliation feel that their involvement in the process is being actively sought and is valued, this increasing the perceived trustworthiness of the justice-seeking process (see *Theme 3: Trustworthy*). Four studies also highlighted the importance of informing patients about their options regarding how they wish to be involved in the redress-reconciliation process in the future.(21, 28, 68, 74) Three studies indicated that patients and their families could appreciate person-centred information, both in terms of the quantity and level of detail.(28, 35, 44)

This subtheme highlights how those seeking redress-reconciliation desire that the information they require is easily accessible. This information is not just restricted to the circumstances surrounding the life-changing event, but also encompasses the need for signposting to information and support regarding how to access the redress-reconciliation process itself and their rights within this. Increased ease of accessing information can enhance the transparency, and thus trust in, the justice-seeking process. Conversely, attempts made by individuals and organisations to avoid contact with those who

had been harmed and to withhold information induce feelings of anger and uncertainty, which may contribute to people's pursuit of answers via more formal litigation processes.

Subtheme 1.3: Consideration of systemic factors

Sixteen studies (16 papers) contribute towards this subtheme, aimed at highlighting systemic factors which may influence decision making within, and thus the perceived transparency of, the justice-seeking process, and if outcomes are perceived to be fair.(25, 27, 36, 41-43, 45, 48-51, 57, 58, 64, 74, 76) Specific factors which justice-seekers felt affected the process included access to funding and processes which were overly procedural or bureaucratic. *Table 11: Studies supporting subtheme 1.3* provides further detail of the studies contributing towards this subtheme

Table 11: Studies supporting subtheme 1.3

	Stage of Redress-Reconciliation Process					
	Disclosure/ Communication	Review inquest	or	Litigation Process	Post-litigation process/ desired outcomes	Other
Supporting studies	Hovey 2014(36) Kent 2008(42) Kim 2021(43) Martin 2021(45)	McQueen 2020(48) Shaw 2007(74)		Burns 2006(57) Eastwood 1998b*(76) Englebrecht 2014(58) IPSOS 2016*(41) Matthews 2012(64) Melville 2012(49) Moore 2017a(50) Moore 2017b*(51) Ocloo 2010(27)		Kamin- Friedman 2021(25)

*Contributes insight towards multiple stages of redress-reconciliation process; Green text=study from non-health field

Nine studies highlighted the importance of funding within the justice seeking process.(25, 27, 41, 43, 45, 49, 50, 64, 74) The availability of funding influenced decisions made throughout the process, beginning with the decision to pursue litigation. Four studies highlighted how lack of, or difficulty accessing, available funding could prohibit the initial instruction of a solicitor or pursue a claim once their initial approach to a solicitor had been declined.(27, 49, 51, 74) This is illustrated by two people who had withdrawn from pursuing claims via a solicitor following a medical error:(49)

...there was nothing else that the solicitor could do because you only get Legal Aid for a certain amount of money and once I'd been to that lawyer [barrister] and they'd said "no", that was

the money used up and I would have to pay, which would go to tens of thousands of pounds, and I haven't got tens of thousands of pounds to take it any further, like to the High Court. I could have done, had I had the money but I didn't have that sort of money at the time, my children were all pretty young and you know you can't do it can you, unless you've got a lot of money saved? So that was it, basically it was squashed sort of thing [Bereaved female relative, Melville et al., 2012 p34]

Because of the funds, he said, if you cannot offer to continue its better for you to stop at the stage and leave the case and I said okay. But I was fighting all the way, if I had the money I would continue actually (Bereaved male relative, Melville et al., 2012 p35)(49)

Three studies highlighted the limitations associated with legal aid, including difficulty in applying, limited eligibility criteria and the fact it did not completely cover legal or travel costs:(27, 49, 74)

I was not eligible for legal aid and was initially quoted costs of a minimum of £5000. Fortunately it has been possible to reach an agreed cost I can afford without getting into a large debt [Family of a man who died in prison, Shaw et al., 2007 p93](74)

'I got legal aid but had to pay for the barrister myself [Family of a man who died in prison, Shaw et al., 2007 p93](74)

These examples also indicate that it is important that the limitations to financial support, and potential implications for this, are explained to participants before they begin seeking justice. Two studies indicated how limitations in government funding or insurance coverage may limit the compensation amount successful complainants receive.(41, 43) This can influence claimants decision to settle for a lump sum, rather than accept a series of small payments over time once the full impact of the life-changing event is known. An example below is provided by the parent of a child who suffered an injury during birth:(41)

As a claimant, my concern is that political will changes...so from a claimant's perspective there's more security in having this lump sum model, you know what you've got [Parent, Ipsos-MORI, 2016 p39]

In this study, the participant is aware that government policy may change over time, influencing the money they receive. For justice-seekers who may require long-term health or social care support following an life-changing event, their decision on what constitutes a fair outcome and desire to pursue this via an appropriate justice-seeking process may conflict with their need to ensure their future health and social care needs will be fulfilled (see *Subtheme 2.2: Meaningful outcomes*).

Eight studies exploring patient/family views on organisational responses following an life-changing event highlighted aspects of the system they perceived as 'bureaucratic'.(27, 36, 43, 45, 48, 49, 51, 57) Four studies highlighted how the procedural nature of the complaints system felt constraining to patients/families, by requiring them to reduce their complex concerns into a format which could be process:(36, 45, 48, 51)

Perhaps have a bit more thought about how families should be engaged with might only need a short conversation, is there anything we need to know? Anything over and above what we have gathered that we [the NHS] need to know? They would have been able to gather from us very quickly that these are the key risks. I think that they could have drawn a lot more information from us [family] but basically that is lost because it is all very transactional - here is the response, this is what we are [Participant, McQueen et al, 2021 p5](48)

Five studies indicated that justice-seekers may not always understand how best to communicate their complex concerns in the format which was required by hospital complaint processes, or felt that existing procedures were limited 'box ticking' exercises.(36, 45, 48, 51, 57) These processes also prevented families from being able to provide clarification regarding their specific concerns and individual circumstances (an important aspect of delivering person-centred justice, as discussed in the theme Person-Centred) and resulted in a narrow, non-personalised response which some individuals felt to be a 'box-ticking' exercise:(45, 48)

I felt as though it minimised it really, and for us, obviously we didn't really have the chance to complain down the normal route because it was superseded by this investigation, and it feels— although we have had our input and communicated our feelings and our experience—a little bit like one-way traffic. I understand it is being done so they can ensure that the learning happens [Family member of child detained for over 24 hours under the Mental Health Act, Martin et al, 2021 p5]

She said "we've decided that we're going to do...a serious adverse incident review...and that I'm going to send you a leaflet"; no communication, no time to explain, we'll just send you a leaflet... I've just lost my son...we'll send you a leaflet, it didn't feel helpful at all [Bereaved parent, McQueen et al., 2021 p5]

The second quote suggests that the nature of the response to this parent's complaint left them confused as to the next stage of the justice-seeking process and minimized the nature of their loss. Overall, some procedural processes limited the extent to which the system could respond to the needs of justice-seekers.

Other aspects of justice-seeking processes that people found frustrating were the time limits associated with instigating or concluding an investigative or litigation process,(45, 49) and the need to prove causality.(27, 43, 49). The rationale behind these requirements may not have always made clear to patients and their families, which appeared to result in the perception of bias towards the opinion of medical professionals within the redress-reconciliation system. Two studies indicated that those seeking redress-reconciliation felt that greater weight was given to the views of medical professions, over the views and experiences of those seeking redress-reconciliation.(42, 51)

Four studies also highlighted the perception that procedures within the courtroom appeared to prioritise the needs and rights of offenders over those of victims and their families: (57, 58, 74, 76)

They said that 'justice is not served until the victims are.' I thought, 'that's a hollow statement.' You know, that's true, but nobody has seemed to want to serve the victims [Family member bereaved by homicide, Burns et al., 2006 p70](57)

I thought it would be about me and my son. It's not [Parent bereaved by homicide, Englebrecht et al., 2014 p415](58)

We feel you cannot win against a government institution [Family of a young man who died in prison, Shaw et al., 2007 p100](74)

The limitations of the legal system could also impede mutual goal setting between those who had been harmed and those representing them and prevent those seeking redress-reconciliation from achieving their desired aims:(25, 57)

We met with the DA's office on a regular basis, and I feel like had we not been relentless, we would not have gotten the outcome we got. [The townspeople] called his office the 'Let's Make a Deal' show. And, we found out why real quick. He wanted to cut a deal. He said he didn't have everything he needed to get the death penalty on both of them, and he said if we got one of them to turn evidence, the main guy who orchestrated it all would definitely get the death penalty. We did not agree, by Oklahoma laws, they have to talk to the families about this now, and we did not agree to it. We never agreed to it. We wanted the death penalty for both of them, and we really went head to head over it. There was a lot of yelling. My mom and I were there one day with the district attorney, and he was screaming at us. It was very bad [Family member bereaved through homicide, Burns et al., 2006 p78](57)

In summary, to enhance the transparency of the redress-reconciliation process for justice-seekers, systemic factors which may influence the process should be discussed by all the stakeholders involved in the process, alongside how these factors may influence any decisions being made. The availability

of funding for both the individuals seeking justice and those responsible for awarding compensation, is one factor which may influence the redress-reconciliation process. Other factors may include the ease with which the process of redress-reconciliation can record and respond to the individual concerns and experiences of people who have been harmed and consider their views as equal to other stakeholders, such as medical professionals or those who have caused harm.

Subtheme 1.4: Clear rationale for decisions

Seven studies (9 papers) towards this them (see *Table 12: Studies supporting subtheme 1.4*). (21, 41, 49, 54, 58-60, 76, 77) Four studies explored experiences of redress-reconciliation processes following non-medical life-changing events, (21, 58, 60, 76, 77) whilst three studies included participants who had experienced medical harm. (41, 49, 54) This subtheme focuses on the need for a clear rationale to be given to those seeking redress-reconciliation regarding the decisions made during the inquest or formal litigation process.

Table 12: Studies supporting subtheme 1.4

	Stage of Redress-Reconciliation Process					
	Disclosure/ Communication	Review inquest	or	Litigation Process	Post-litigation process/ desired outcomes	Other
Supporting studies		Bouwman 2018(21)		IPSOS 2016*(41) Eastwood 1998a(77) Eastwood 1998b(76) Englebrecht 2014(58) Maderia 2008(59) Maderia 2010(60) Melville 2012(49) Pyo 2019(54)		

*Contributes insight towards multiple stages of redress-reconciliation process; Green text=study from non-health field

In terms of seeking support to pursue a legal claim against the NHS, patients and their family are dependent on the need for causality to be proved before a solicitor will take on their case (see *Subtheme 1.3: Consideration of systemic factors*). One study described how solicitors will often seek advice from an independent medical expert to ascertain if there is merit in proceeding and suggests

that some justice-seekers found it hard to understand why these independent experts did not agree that negligence had occurred:(49)

And [the expert report] came back saying, “well actually we can’t really say anyone was at fault as such”... this medical expert seemed to miss the point... (Patient with serious injury, Melville et al., 2012 p28]

The same study highlights how attempts were sometimes made to mitigate this by providing opportunities for patients and their families to meet with the medical experts to hear their explanation and ask questions. However, resolution of different opinions was not always possible and sometimes this lack of agreement was attributed to bias towards the opinion of medical professionals (see *Subtheme 1.3: Consideration of systemic factors*):(49)

...an independent report supposedly but I think it was done in collusion with each other, one isn’t going to criticise another one is he? Even though he might have been retired he’s certainly not going to criticise another eye surgeon (Patient with moderate injuries, Melville et al., 2012 p28)

The above individual appears to feel that the medical profession are ‘closing ranks’. This perception(see *Subtheme 1.2: Information required publicly available*) could be partially influenced by the complex nature of medical decision making, which can sometimes be difficult for those outside of the medical context to understand.(49)

In terms of decisions regarding compensation, parents whose children had suffered a birth injury highlighted the need for the panel responsible for determining eligibility to provide a fair and transparent outcome, based on the child’s needs.(41) They also highlighted the need for this process to be carried out independently of any process to determine negligence on the part of the NHS, a concept discussed further in *Subtheme 3.4: Objective input*.

Four studies exploring views of inquests or trials following non-medical life-changing events.(54, 58, 60, 76) One study indicates that some family members desire to attend inquest/court proceedings in person in order to better understand the final verdict:

...desire to see that, that justice was served and witness it so that if it didn't come out the way I knew it should've I could understand why it didn't [Participant, Maderia et al., 2010 p1501](60)

However, data from the other three studies indicates that this understanding was not always achieved:(54, 58, 76)

I don't understand how if somebody admits to doing what they did and they say it was with consent, that they can get away with it. I just don't know how you can do that [Parent of CSA survivor, Eastwood et al., 1998b p240](76)

Why is that murder different from somebody else's, it should all be consistent. You kill somebody, ten years. But I see them some get four years, some get six, some get eighteen. It's not consistent and it should all be consistent [Mother of a murder victim, Englebrecht 2014 p415](58)

One of the quotes above illustrates how the perceived lack of consistency in decision-making surrounding the final verdict can cause confusion,(58) which may be linked to the final verdict being perceived as unfair, or non-representative of the crime (see *Subtheme 2.2: Meaningful outcomes*).

Overall, these studies indicate that the reasons behind the decisions made during the justice-seeking process are not always transparent to patients and their families, despite attempts made by professionals and justice-seekers to clarify these. Lack of transparent decision-making may contribute to perceptions of bias and lack of consistency in the justice-seeking process, leaving patients and their families feeling unheard.

Theme summary: Transparency

People seeking redress and reconciliation following a life-changing event seek a comprehensive account of the harm which they have experienced and what is being done to ensure that it does not happen again. The ease with which this information is made available to them and the extent to which they are signposted to the information and support they need can enhance the perceived transparency of, and trust within, the redress-reconciliation process. Any perception of bias in favour of medical professionals, or that professionals are not being open and transparent, can lead to feelings of anger, suspicion and that their needs and views are not valued. People seeking justice appreciate being provided with a clear rationale for the decisions made as part of the process. It may be helpful for all stakeholders involved with the redress-reconciliation pathway to discuss systemic factors such as funding and the rules of the legal system to ensure the rationale for decisions remains explicit and that the resulting processes and outcomes are perceived as fair.

Theme 2: Person-centred

Thirty-nine studies (45 papers) contributed to this theme, which contains two subthemes.(21, 24, 26-60, 64, 65, 68, 69, 74, 76, 77, 80) The first subtheme "Shared rules" explores how the redress and reconciliation processes can be centred around the needs of patients and their families. The second

subtheme “Meaningful goals” discusses some of the different outcomes people may seek following a life-changing event. Table 8 illustrates the studies which support this theme.

Subtheme 2.1: Shared rules

Twenty-four studies (26 papers) contributed towards this subtheme and their distribution across the redress-reconciliation pathway is described below in Table 13.(21, 28-31, 33, 35-37, 39-41, 43, 45, 46, 48-51, 55, 57, 58, 68, 74, 76, 77) The contents of this subtheme reflect patients and families desire for the justice-seeking process to be centred around a shared understanding of the life-changing event and consideration of their needs as justice-seekers. This theme also considers the need for shared goals between the professionals involved in facilitating the justice-seeking process and those who have experienced the life-changing event.

Table 13: Studies supporting subtheme 2.1

	Stage of Redress-Reconciliation Process					
	Disclosure/ Communication	Review inquest	or	Litigation Process	Post-litigation process/ desired outcomes	Other
Supporting studies	Duclos 2005(30) Hannawa 2017(35) Hovey 2014(36) ledema 2007(40) ledema 2011(39); 2012b(37) Kim 2021(43) Martin 2021(45) Mazor 2013(46) Sorensen 2010(55)	Bakhbakhi 2017(28) Biddle 2003(68) Bouwman 2018(21) Etchegaray 2014 (31) McQueen 2021(48) Shaw 2007*(74)		Burns 2006(57) Eastwood 1998a(77) Eastwood 1998b*(76) Englebrecht 2014(58) IPSOS 2016*(41) Melville 2012(49) Moore 2017a(50) Moore 2017b*(51)	Chiu 2010(29) Gallagher 2009(33)	

*Contributes insight towards multiple stages of redress-reconciliation process; Green text=study from non-health field

Eight studies (nine papers) indicated that in order to facilitate a person-centred process, centred around the needs of parents and families, all stakeholders taking part in the redress-reconciliation process should have a shared understanding of the life-changing event and its consequences (reflecting content in *Subtheme 1.1 : An account*). (21, 31, 37, 40, 41, 43, 50, 68, 76) Two studies contained data which underlined the importance of an agreement between different stakeholders as

to what constitutes an adverse, or sentinel event,(21, 51) and three studies highlighted the need to establish the severity and/or impact of the event on the patient/family:(41, 43, 51)

That is so necessary and it never happened with us, we were left believing that, yes, he'd been through a traumatic birth but we weren't told there was any permanent damage or that there might be permanent damage, we were told nothing. And that is important [Parent of child with birth injury, Ipsos-MORI, 2016 p14](41)

Data from three studies indicated the need to determine the key features of the case from both perspectives:(49, 68, 76)

They said in the courtroom that apparently she could really recollect the acts of oral sex, but she had blocked out the attempted rape and they had to keep reminding her that attempted rape is the more serious charge ... We were told she lost because she couldn't remember the attempted rape as well. [Mother of CSA survivor, Eastwood et al., 1998b p244](76)

It wasn't just the facts it was far more. He (the coroner) queried me about our marriage breakdown which wasn't necessary, it wasn't even relevant and this all happened in front of my sons too. They had to go through all this when I had to answer things that the coroner had in front of him, I mean I had to say out loud perhaps he had a drink problem—why should me and my sons be subjected to that? [Wife bereaved through suicide, Biddle et al., 2003 p1038](68)

The above two quotes represent family members seeking justice for non-medically related life-changing events and illustrate how the absence of a shared understanding of the key features of the event from the perspectives of the justice-seekers vs the law can result in justice-seekers not being prepared for the line of questioning during trial/inquest processes, which may cause distress and potentially influence the later verdict. The second quote from Biddle et al., also illustrates the importance of those questioning family/patients to be sensitive to their emotional needs. This concept is supported by a further six studies where participants expressed how important it was that people involved in conducting the justice process considered the emotions of patients and their families, starting from those involved in initial disclosure and delivery of care itself,(28, 30, 36, 39, 55) through to those in the litigation process (see Subtheme 3.2: Ongoing support and Subtheme 4.2: Closing a chapter).(51)

Eleven studies highlighted the importance of understanding and directly addressing the needs of patients and/or their families within the redress-reconciliation process.(29, 33, 35, 40, 41, 46, 48, 49, 55, 57, 58)

Six studies highlighted the importance of professionals assessing what justice-seekers need during the process:(33, 46, 48, 51, 55, 58)

What can we do to fix this? How can we make this right? [Patient, Mazor et al., 2013 p6](46)

I loved that [the hospital] asked me 'How can we address this for you [Participant, Moore et al 2017b p792](51)

Data from five studies indicated that some individuals were keen to access financial compensation based on their assessed needs.(30, 41, 50, 51, 55) However this was not always the sole motivation for seeking justice, as illustrated by two individuals talking about their experiences during a healthcare life-changing event review:(48)

I was never asked about what mattered to me or what type of method of communication worked best. If they had, they'd have known I wasn't interested in the serious life-changing event review, their longwinded report, or monetary compensation, I just wanted answers and to move on [Participant life-changing event review, McQueen et al. 2021 p5](48)

I just feel that the medical profession is so scared of being sued that it closes down...if they listened to people, and tried to rectify the mistakes, in a way that people actually wanted, there would be less compensation and it's less confrontational (Participant life-changing event review, McQueen et al., 2021 p8](48)

The second quote supports the observation record above in *Subtheme 2.2: Meaningful outcomes*; that organisational defensiveness can impede learning, and their lack of engagement result in patients and families escalating their attempts to achieve justice.

Data from fourteen studies highlighted the importance of establishing a shared set of goals and/or agreed agenda between professionals supporting the redress-reconciliation process and those seeking justice.(35, 39, 40, 45, 48-51, 55-58, 68, 76) although one study acknowledged that justice-seekers may find it difficult initially to know what justice-looks like for them.(29)

Data from ten studies (11 papers) indicated that it is important patients and their families were provided with choices regarding how they wished to participate in the redress-reconciliation.(21, 28, 35, 39, 40, 45, 50, 58, 74, 76, 77) Participants in five studies highlighted that patients and their families seeking justice preferred a choice as to when their involvement was sought, particularly early on when they were still coming to terms with what had happened:(21, 28, 40, 45, 51)

It needs to be very clear to people that you have the right to say, 'Not now' [Daughter - experience open disclosure meeting, Iedema et al., 2011 p4](45)

If the idea is to learn, how much is lost in the learning when people are pushed at times when they actually can't mentally or physically do any more other than survive what has happened? [Relative of child detained for over 24 hours under Mental Health Act – event review, Martin et al., 2021 p6](45)

The meeting was about 4 weeks after my baby passed. ... [That timing] worked for me. It was all too much to process in the beginning ... [Bereaved mother, Moore et al., 2017b p792](51)

The above quotes indicate that the emotional needs of the patients and families should be considered, and supported, by professionals during the process (see [Subtheme 2.1: Shared rules](#)) and that people made aware of their rights within the institutional review procedures. Having a choice in the timing of their involvement gives patients and families time to prepare and seek legal representation,(40, 74) and may also help provide a meaningful role and sense of control within a process predominantly initiated and delivered by others.(58, 76) This is illustrated by a female child, describing her experiences of being interviewed by police:(76)

They kept telling me that I was running the show and if I wanted to stop they would stop. I could do what I wanted - it was up to me ... it made me feel in control [CSA survivor, Eastwood 1998b p199](76)

Data from three papers highlighted that people preferred to be communicated with in different ways.(35, 51, 74) Some people viewed written communication as impersonal, but others recognised that by approaching people in this manner gave people time to prepare and process information. People also valued the opportunity to meet face-to-face with those they perceived to be directly responsible for the life-changing event, as it gave them the opportunity to ask questions and give their views on what had occurred and the impact of the event on them. This is discussed further in subthemes [Subtheme 3.1: A reasonable and consistent process](#) and [Subtheme 4.1: Humanising process](#).

People had different preferences regarding the location,(35, 39) and presence of other people during the initial disclosure and further meetings.(35) One mother describes how meeting in a hospital made her feel deeply uncomfortable:(39)

That's what it was like, going to school and going to the headmaster's office, that's what it felt like ... Even if it was at the other hospital, somewhere totally away from the clinic maybe [Mother – Experience of open disclosure, Iedema et al., 2011 p4](39)

Here, the importance of considering power dynamics within the professional-patient relationship is indicated. Disclosure of a life-changing event, and subsequent processes, represent a time when

patients and family members are particularly vulnerable. Meeting at a location of their choosing, or at least removed from the site of the life-changing event, may help them feel comfortable and better able to ask the questions they need in order to develop a clear narrative regarding what has happened to them (see subthemes *Subtheme 1.1* : An account and *Subtheme 4.2*: Closing a chapter).

Finally, five studies indicated that it is not always the patient or their families who decide when a fair outcome has been achieved or that an investigation or litigation process is over.(40, 41, 49, 57, 76) Aside from the impact of limited funding as discussed in *Subtheme 1.3*: Consideration of systemic factors, people also withdrew from the litigation process due to the emotional impact of the intrusive, and often disrespectful, nature of the questioning (see *Subtheme 4.2*: Closing a chapter):(76)

I was sick through the whole thing - they had to bring a doctor in - I was vomiting and everything. It was nerves - because I was fine as soon as I walked out of the courtroom. Every time I walked back in I was sick. . . On Thursday I was really sick - I got worse and that is when I withdrew. I just couldn't go on anymore ... When I said I was going to withdraw they said he would be finished by the end of the afternoon - that was at about 1.30 pm and they wanted me in there for another four hours ... But I just couldn't do it. I couldn't even have done another hour [CSA survivor, Eastwood 1998b p217](76)

Data from two studies indicate that people perceived it was often the health service who determined whether an investigation was over:(39, 49)

There has been no follow-up. No one has come to us or written to us. And as far as I'm concerned there has to be a finalisation of everything. And this is not final [Family member, ledema et al., 11 p3](39)

...when that [expert report] comes back and says no, he died of a stroke, that's the end of it then [the law firm] can't take it any further [Bereaved female claimant, Melville et al., 2012 p28](49)

The studies contributing to this subtheme where participants had experienced a medical life-changing event predominantly represented views of the early stages of the redress and reconciliation process. Overall, patients and their families desired the process be based upon a shared understanding of what had occurred and consideration of what they themselves wanted to achieve. The process should consider whether the timing, method of involvement and location are convenient for participants and should have a clearly defined end point, which all stakeholders agree upon.

Subtheme 2.2: Meaningful outcomes

Thirty-eight studies (43 papers) contributed towards this subtheme, which focuses on what people perceive as fair or meaningful outcomes following a redress or reconciliation process (see Table 14).(24, 26-60, 64, 65, 68, 69, 74, 76, 80) Twenty-eight of these studies represent experiences of seeking justice following perceived medical harm.(24, 26-56) This subtheme considers how, following a life-changing event, patients and families seek answers about what had happened and an apology from those directly involved. There is also a desire to look to the future, both to learn from what had occurred and prevent it from happening again and receive assurance that future health care and financial needs will be met. Other concepts explored include the desire for appropriate sanctions for those perceived to be responsible and the need to ensure the final verdict reflects the evidence provided and incorporates the views of those who have been harmed.

Table 14: Studies supporting subtheme 2.2

	Stage of Redress-Reconciliation Process					
	Disclosure/ Communication	Review inquest	or	Litigation Process	Post-litigation process/ desired outcomes	Other
Supporting studies	Duclos 2005(30) Fisher 2016(32) Hagensen 2018(34) Hannawa 2017(35) Hernan 2014(24) Hovey 2014(36) Iedema 2007(40) Iedema 2011(39) Iedema 2012a(38); Iedema 2012b(37) Piper 2014(53) Kent 2008(42) Kim 2021(43) Loren 2021(44) Martin 2021(45) Mazor 2010(26) Mazor 2012(47); 2013(46) Sorensen 2010(55)	Bakhabakhi 2017(28) Biddle 2003(68) Chapple 2012*(69) Etchegaray 2014(31) McQueen 2021(48) Myren 2021(52) Ngo 2021(65) Shaw 2007(74) Wiig 2021(56)		Burns 2003(57) Eastwood 1998b(76) Englebrecht 2014(58) IPSOS 2016*(41) Melville 2012(49) Maderia 2008(59); 2010(60) Matthews 2012(64) Moore 2017a(50) Moore 2017b*(51) Ocloo 2010 (27) Pyo 2019(54)	Chiu 2010*(29) Gallagher 2009(33) Saco 2018(80)	

*Contributes insight towards multiple stages of redress-reconciliation process; Green text=study from non-health field

Reflecting the need of people seeking redress and reconciliation to receive an account of what happened and develop a shared understanding of events as outlined in subthemes *Subtheme 1.1 : An account* and *Subtheme 2.1: Shared rules* respectively, fifteen studies (17 papers) spoke to people's need to receive answers.(27-29, 35, 37, 39-41, 48, 49, 55, 57, 64, 65, 68, 69, 74) People wanted the opportunity to receive answers to questions about what they didn't know and receive confirmation about their own perceptions of what had occurred.(49, 68) Studies from the health field contributing towards this subtheme predominantly represented the early stages in the process, such as disclosure and inquests, demonstrating the need to provide these answers early in the investigative process. One family member reflects on their experience of the Open Disclosure process, and the sense of acceptance (see *Subtheme 4.2: Closing a chapter*) once they realised that there were no more questions that could be usefully asked:(37)

The first bit, I think anybody would get to, but it was at the last bit [last disclosure meeting] where we got the actual answers; and there are still holes in that, but you have to get to a point where you say, "I know as much as I'm going to know out of something." So, not everybody gets answers, but I got more answers than I would have if we hadn't have done it... You have to get to a point and say "Okay. I've got as much as I'm going to get and I have to put it in a box [Family member, Iedema et al., 2012b p440](37)

The above quote suggests that, whilst the reconciliation process may not be able to provide an exhaustive response to queries raised, it is possible to give answers which are "good enough" to satisfy the needs of patients and their families.

Data from 20 studies (21 papers) highlighted the key role an apology played in the process of reconciliation.(24, 26-29, 32-36, 39, 40, 43, 46-48, 50-52, 55, 57) Participants interviewed regarding their experience of the early stages of the reconciliation process following a medical life-changing event emphasised the emotional impact of an apology:(36, 46)

The doctor, the radiologist, I have to say that he became ill and he contacted us and he offered...we met and he did apologize. The apology ...in one sense was very short. It meant so much. I was amazed at how my feelings could change [Participant, Hovey et al., 2014 p270](36)

And she [the PCP] was sad, too, but she was in congruence with my emotions. She wasn't trying to pretend that nothing had happened...That made a huge difference. She was just very sincere and authentic [Patient, Mazor et al., 2013 p5](46)

Study participants emphasised that an apology was more than words.(26, 46, 48) Key features of a

sincere apology included the verbal apology itself, the person or organisation perceived as being responsible admitting accountability and providing assurance that the event would not happen again through identifying and communicating the lessons learned following the event and developing an explicit plan to implement proposed changes to practice and support the future care of the individual who had experienced harm.

Eleven studies indicated that expressions of regret or remorse were highly valued by participants.(29, 33, 35-37, 41, 46, 50, 51, 55, 59) One participant who met with a doctor following the death of their baby describes their experience thus:(51)

There were lots of silences. But they were helpful spaces where I was given time to process what was said... I could see in [the doctor's] eyes that he was genuinely remorseful about the loss of my baby...that he really meant it when he apologized. I went into the meeting devastated. I came out feeling like I could move on. ...[W]e actually eventually had another child and she was delivered at the same hospital [Bereaved parent, Moore et al., 2017b p800](51)

Patients and families appear to value some indication that those responsible for the error had been emotionally affected by it as well and this in turn influenced perceptions of the sincerity of their apology. The above quote illustrates how a sincere apology can aid the re-establishment of trust between those who had experienced harm and the clinician/organisation taking responsibility.(33, 51) However, the value of an apology appeared to be significantly diminished if it was not delivered by an individual closely associated with the error:(26, 40, 47, 51, 53)

... an apology is one thing [but] this is coming from the patient safety officer, not coming from the doctor who decided not to scan my spine further [Patient with experience of Open Disclosure process, ledema et al., 2007 p98](40)

Fourteen of the 20 studies which contained data expressing participants desire for a sincere apology represented the early stages of the redress and/or reconciliation process.(24, 26, 28, 32, 34-36, 39, 40, 43, 46-48, 52, 55) However, the need to receive an apology was not confined to the disclosure or early investigation of a life-changing event, as illustrated below by a patient who had successfully litigated against an NHS trust:(49)

It would have been just nice at the end of the legal process just to get a letter saying we apologise for everything that you've been through and we will learn lessons from it, but no that doesn't happen, you don't get that you just get money. I got a letter from my solicitor saying they're now settled out of court and it got quite business like with the costs and all of

that and then eventually I got a cheque and that was the end of it (Patient, moderate injuries, Melville et al., 2012 p44)(49)

Participants from 31 studies (33 papers) discussed their desire for, and difficulty achieving, an admission of accountability for the life-changing event.(24, 26-30, 33-35, 37, 38, 40-43, 45-49, 51, 53-57, 60, 64, 65, 69, 74, 76, 80) Perceptions that there was an avoidance of taking responsibility for the life-changing event was associated with individuals pursuing a more formal litigation process:(27, 48)

Right from the very beginning, people had said to go straight to a solicitor, but I didn't want to do that. I wanted just to make sure it never happens to anybody else. However, in the end, I thought that I've got nowhere, I really don't feel that they are taking much responsibility, so I just decided I would take it further [Participant, McQueen et al., 2021 p8](48)

Above the admission of responsibility is presented as a necessary precursor to preventing the harm from occurring again. Data from 21 studies (23 papers) from across the redress-reconciliation pathway indicated that individuals wanted assurances that the harm they had experienced would not happen to anyone else:(24, 26-30, 35, 38-40, 45-51, 55-57, 65, 74, 76)

What happened cannot be undone, sadly. But it is possible to do your best to prevent the same mistakes from happening again. Then there has to be a willingness to look into what happened. And looking back to our next of kin meeting at the hospital, there were no signs of willingness, not one millimetre, although there were obvious mistakes (laughter). So, it feels kind of hopeless, I have to admit... So, it is rather a question if they try to protect themselves and then send someone (to the meeting) that is not willing to admit anything [Participant, Wiig et al., 2021 p1715](56)

Data from 16 studies (17 papers) indicated that people seeking redress and reconciliation wanted to hear about the lessons that had been learned following the event,(28, 33-35, 37, 39, 41, 45, 46, 48-52, 56, 64, 74) and 12 studies (13 papers) explored views on the importance of translating these lessons into organisational change.(31, 36, 38, 39, 43, 44, 46, 49-52, 55, 56) This is illustrated by patients and family members who took part in the inquest processes following a medical life-changing event:(48, 50)

They're all about 'Hospital of the Future,' but it's like, 'Don't forget about your hospital of the past'....I just want to know how they've learned from it and if they've put any measures in place... or if they have forgotten [Patient, Moore et al., 2017a p1598](50)

The hospital administrator risk guy...said, 'We're doing a full report on this. We'll give it to you before you leave the hospital'.... We never got anything. That was very disappointing." [Patient,

Moore et al., 2017a p1599](50)

In terms of proper engagement...it would have been good to see what actually changed as a result ...we don't know, and we will never know, actually, because the complaint was closed at that point because essentially we were satisfied that the complaint was upheld [Participant, McQueen et al., 2020 p7](48)

These quotes illustrate the importance of communicating the key changes which have been made to organisational policy and practice following the life-changing event. Some individuals also wished to be directly involved with informing/implementing organisational changes.(38, 39, 52, 56) It may be that this involvement may increase the transparency of, and trust within, the redress-reconciliation process, and also support individuals to identify meaning from the harm they had experienced (see subthemes *Subtheme 1.2: Information required publicly available*, *Subtheme 3.1: A reasonable and consistent process* and *Subtheme 4.2: Closing a chapter* respectively). This indicates the necessity of development and maintenance of an ongoing, two-way rapport between those who had been harmed and those they perceive as responsible to support these processes throughout the redress-reconciliation pathway. This is explored in *subtheme Subtheme 4.1: Humanising process*.

Whilst financial compensation wasn't the core goal for many people seeking redress and reconciliation,(48, 49, 56) it did appear to serve two key purposes. Firstly, it acted as a symbol or recognition that harm had occurred, and secondly to achieve financial security for themselves and their family in the future. Seven studies (9 papers) contributed to the concept of financial security, which also encompasses the need to compensate for earnings lost following injury.(33, 35, 41, 43, 46, 47, 50, 51, 64). One study spoke of the importance of achieving this to account for the escalation in care needs for their child following the birth injury:(41)

I've been able to take time off work [and] become his carer. It's also meant that we've been able to move house, have accommodation that we're all comfortable in, accommodation that allows Jimmy to be looked after safely and far more easily. Also means that we can have holidays with him...they're not easy but they're easier [Parent of child with a birth injury, Ipsos-MORI, 2016 p35](41)

One study exploring views of participants seeking financial compensation following the death after a work accident indicates that that compensation was one way in which families could achieve retribution against those responsible for the harm.(64)

The judge didn't take away their licence. They continued to operate and they only got a fine of \$65,000. That is how much his life was worth – \$65,000 – when they are able to hand down

finer of \$200,000. That is why we continue to have workers die, because builders know that they can get away with it [Family member, Matthews et al., 2012 p19](64)

The above quote indicates that the amount of compensation should reflect individuals perceptions of the harm done to them.(50, 64) Overall, participants in 12 studies expressed a desire for retribution against those perceived as responsible for the crime:(29, 35, 43, 48, 54, 55, 57, 58, 60, 64, 76, 80)

You know, that apology was really great at the time; it's not going to help me in future if I have to cease work or...or whatever. So, you know, I'm out, out for blood. ...I'm not out for any individuals blood, but I think there is a problem with the system. And the system has messed me up, um...potentially, and I think the system should pay for it (Patient with experience of disclosure, Sorensen et al., 2010 p152)(55)

However, data from five studies indicated some individuals wished to reassure or protect people involved with the care in which they sustained harm, suggesting the desire for retribution or punishment of the persons perceived as responsible is not a universally desired outcome.(26, 40, 43, 47, 48) One potential explanation for this is that the anger and hurt experienced by people who do not receive an admission of responsibility, an apology, evidence of learning and adequate compensation may motivate them to seek retribution against the individuals and organisations they see as responsible for causing them harm.

Overall, the outcomes people seeking redress and reconciliation sought were individual to their own needs and were influenced by the responses they had from the institution or individual whom they perceived to have done them harm. Key outcomes included receiving answers to their questions and receipt of an apology, which incorporated expressions of remorse and an admission of responsibility, accompanied by actions to assure them that the harm would not happen again.

Theme summary: Person-centred

People who had been harmed sought a redress-reconciliation process which was centred around an assessment of their own individual needs. This begins with a shared understanding of the life-changing event and its immediate and longer-term impact on the physical, mental and financial wellbeing of those seeking-justice. Consideration of the extent to which people seeking redress-reconciliation wish to be involved may increase perceptions of transparency and trust in the process, and in turn the perception of fairer outcomes. Outcomes that are perceived to be meaningful are likely to be unique for everyone, which requires justice-seekers to be consulted at the early stages of the redress-reconciliation process on what they need and how they can be supported to be able to close this chapter of their lives. The processes needed to achieve this necessitate an ongoing rapport between

the different stakeholders throughout the duration of the redress-reconciliation pathway.

Theme 3: Trustworthy

Thirty-seven studies (42 papers) contributed to this theme, which contains four subthemes.(21, 25-43, 45, 46, 48-60, 64, 65, 68, 69, 74, 76, 77) Table 8 provides information on how the studies included in this theme represent individual stages of the redress-reconciliation pathway. The first subtheme ‘a reasonable and consistent process’ discusses different features of the redress-reconciliation pathway that may enhance the perceived fairness of the process and outcomes. The second subtheme ‘ongoing support’ details the financial and emotional support justice-seekers require. The third subtheme ‘Mechanisms for challenge and dispute resolution’ explores the importance that opportunities for those who have been harmed to challenge both the process and outcomes following redress and reconciliation are incorporated into the pathway. The final subtheme ‘Objective Input’ addresses the need for people who are perceived to be independent from the institution where the harm has occurred to contribute to the redress-reconciliation process.

Subtheme 3.1: A reasonable and consistent process

Thirty studies (34 papers) contributed to this subtheme (see Table 15), which explores components of redress and reconciliation which may make it more likely that the process will be perceived to be fair by those seeking justice.(21, 28-42, 45, 46, 48-53, 55-58, 64, 65, 68, 74, 76, 77) This subtheme also addresses the importance of using a formal process, which promotes dialogue between all key stakeholders.

Table 15: Studies supporting subtheme 3.1

	Stage of Redress-Reconciliation Process					
	Disclosure/ Communication	Review inquest	or	Litigation Process	Post-litigation process/ desired outcomes	Other
Supporting studies	Duclos 2005(30) Fisher 2016(32) Hagensen 2018(34) Hannawa 2017(35) Hovey 2014(36) ledema 2007(40) ledema 2011(39); 2012a(38); 2012b(37); Piper 2014(53) Kent 2008(42)	Bakhabakhi 2017(28) Bouwman 2018 (21) Biddle 2003(68) Etchegaray 2014(31) McQueen 2021(48) Myren 2021(52) Ngo 2021(65)		Burns 2003(57) Eastwood 1998a(77) Eastwood 1998b(76) Englebrecht 2014(58) IPSOS 2016*(41) Melville 2012(49)	Chiu 2010*(29) Gallagher 2009(33)	

	Martin 2021(45) Mazor 2013(46) Sorensen 2010(55)	Shaw 2007(74) Wiig 2021(56)	Matthews 2012(64) Moore 2017a(50) Moore 2017b*(51)		
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*Contributes insight towards multiple stages of redress-reconciliation process; Green text=study from non-health field

Nine studies (10 papers) suggest that patients and their families desired a clear, formal process, starting with the full and ready acknowledgement that an error had occurred via a formal disclosure process:(28, 39-41, 45, 53, 55, 56, 64, 74)

... the other ladies in the bed in the room told us [family members] exactly what happened [Family member, ledema et al., 2007 p23](40)

When I saw the doctor at X hospital, it wasn't an arranged meeting. I went up there with a urinary tract infection and I got him. He went away and he'd got [name of patient] report, so we read through it [Patient, Piper et al., 2014 p202](53)

Patients and families described various informal routes to disclosure, including communications from other health professionals not immediately involved with their care, either immediately after the incident or during follow-up, or other patients and their families. Sometimes disclosure did not happen at all, with patients or their families having to pursue answers for themselves.(53)

When face-to-face disclosure did occur, sometimes patients were left confused as to whether the meeting constituted a formal disclosure, indicating the importance that clarity be given regarding meeting purpose and intended outcomes.(55) Patients also wanted clarity regarding when their case was going to be looked into, as illustrated by a patient who had submitted a complaint about delays to their rehabilitation process:(45)

The original e-mail just says, 'We'll send to you in due course', or something similar to that. Which I was starting to be anxious and thinking, 'Well it's six weeks next week, when is this going to be? Is it going to be weeks, is it going to be months? And so that's when I got on to PALS, and they were absolutely brilliant, within two hours I had an appointment date (Patient, Martin et al., 2021 p4](45)

The above quote also indicates how important it is that NHS trusts respond promptly to patients concerns and that they provide access to advocates who can provide information and support to

patients initiating the redress and reconciliation process, as discussed below in *Subtheme 3.2: Ongoing support*.

Eight studies (nine papers) indicated that having the opportunity to prepare prior to meetings and/or attending inquest/court proceedings is also beneficial.(39, 40, 52, 55, 56, 68, 74, 76, 77) Such preparation could include both face-to-face and written communications and encompass, in the first instance, notifying patients and/or their families that a life-changing event would shortly be disclosed and the nature of the information that would be shared:(39, 40)

I was visited once by the obstetrician when I was in hospital...she came to visit me then, but it wasn't a planned [meeting]... she just popped up to see me... so I didn't have any questions planned or anything [Patient, Iedema et al., 07 p94](40)

The above quote illustrates how the patient lost an opportunity to ask questions about what had happened to them. This may increase the risk that patients will instigate formal processes to gain the answers they require. After the initial disclosure, information regarding the next stage of the justice-seeking process can be useful, especially regarding how the meeting/future meetings will be conducted, the setting these will be conducted within and how the information the patient/family has provided will be used, particularly when information may be released to the media:(68)

Well I think that they could call me in advance and explain that when there is an unexpected death they would investigate it. Then you are a bit prepared when you receive the letter [Participant, Wiig et al., 2021 p1715](56)The courtroom was one of the most stressful things. I wasn't prepared for that at all. I had the idea that we would sit round a table and it would be very informal not that you've got to swear an oath and 'all rise' and then there was the coroner with the coat of arms behind him. [Family member at suicide inquest, Biddle et al., 2003 p1036](68)

For those taking part in inquests or pursuing formal litigation processes through the courts, three studies contain data which indicates that both those providing a testimony and families awaiting the verdict could potentially benefit from preparation regarding the adversarial nature of the overall process and questioning, and/or the timescale of the redress-reconciliation process.(41, 74, 76, 77)

Twelve studies (13 papers) highlighted the value of follow-up by professionals supporting the redress-reconciliation process.(33, 35, 39-41, 45, 48, 50, 51, 57, 74, 76, 77) This follow-up appeared to serve several purposes, from establishing future care needs for those who had sustained life-changing injuries,(41, 45) providing updates on how investigation processes were proceeding,(50, 51, 57, 76, 77) giving the opportunity to ask questions,(33, 35, 39) and acting as a source of emotional

support.(76, 77) This latter point is illustrated by a child sexual abuse survivor discussing the role their support work fulfilled during and after the trial:(76)

It was good that she came, because I didn't have anyone there. Because Mum and Dad had to work and my sister was busy and stuff like that. . . And after she didn't just forget about me, she rang me up a couple of times to see how I was [CSA survivor, Eastwood 1998b p224](76)

This quote highlights how important it is that regular contact with those seeking redress and reconciliation is maintained both during and after the active investigation period (see *Subtheme 4.1: Humanising process*). Those who had been the victims of harm and their families valued this continuity and support in the investigation process (40, 74). It ameliorated the frustration associated with feeling ignored (77) and prevented them from feeling abandoned and left alone with the error (See *Subtheme 4.1: Humanising process and Subtheme 4.2: Closing a chapter*):(33, 35, 39, 55, 74)

Next day, the prison offered to send a chaplain but we declined. We were given INQUEST's number then left alone and had no further support from the prison or social services and little help from the police. Prison staff are offered support in these circumstances but families are totally disregarded [Family of a child who died in a young offender institution, Shaw et al., 2007 p25](74)

Maintaining frequent contact may help maintain a working relationship between all stakeholders involved with the redress-reconciliation process, which in turn may help the injured parties maintain trust in the health care and/or justice systems.(35)

Data from seven studies (eight papers) highlighted the importance of a two-way dialogue between individuals seeking redress and reconciliation and those representing people perceived to have done them harm.(37, 39, 43, 45, 52, 55, 58, 65) Such an approach presented opportunities during the open disclosure and review process for both parties to share their perception of what had occurred and voice their concern, and for this to be incorporated into documented accounts, learning points and care going forward.(37, 39, 43, 52) However, care needs to be taken that such a process does not become too procedural (see *Subtheme 1.3: Consideration of systemic factors*), as it can prevent those whose views are being sought from providing their full input, as illustrated by a relative of a child detained over twenty-four hours under the Mental Health Act:(45)

I felt as though it minimised it really, and for us, obviously we didn't really have the chance to complain down the normal route because it was superseded by this investigation, and it feels—although we have had our input and communicated our feelings and our experience—a little bit like one-way traffic. I understand it is being done so they can ensure that the learning

happens [Family member, Martin et al., 2021 p5](45)

Limited opportunity for participation in later stages of the redress/reconciliation processes meant that some justice-seekers felt that their views were not fully considered when final outcomes were being decided:(58)

I was not a part of the plea at all, and that was my right to be part of it. Even though I know it's their final decision, but at least I should know what the plea is before the day of court [Father of a homicide victim, Englebrecht et al., 2014 p413](58)

Limited dialogue between different stakeholders during the redress-reconciliation process can also mean that patients and their families feel that their views have not been listened to (*Subtheme 4.2: Closing a chapter*) and/or that they have not had the opportunity to challenge statements they believe to be false.(65) Thirteen studies (15 papers) provided data that indicated justice-seekers value opportunities to be involved throughout the redress-reconciliation process. Their involvement can provide opportunities for them to ask questions,(21, 31, 33-40, 52, 56, 57, 65, 74) provide insight on the life-changing event itself and/or circumstances surrounding it,(21, 31, 33, 34, 39, 56, 57) and in turn influence learning/improvement processes.(21, 34, 37-40, 52, 56) One mother provided insight into the potential emotional impact informing system change had on those seeking justice:(40)

I could have had counselling until the cows come home, but it would not have had the same effect as talking to those people about improving the way they transport babies [Patient, Iedema et al., 2011 p11](40)

Providing opportunities for direct involvement in the redress-reconciliation process can provide opportunities for individuals to work through their grief and anger associated with the life-changing event, a concept described more fully as 'Therapeutic Action' within *Subtheme 4.2: Closing a chapter*. However, opportunities for involvement were not always fully operationalised:(21, 34, 39, 50, 74)

'The investigation was totally inadequate. I was not involved at all. When a different force took over the investigation was totally different. I was classed as a 'living part' of the investigation and kept fully informed with letters of introduction and contact [Family member, Shaw et al., 2007 p64](74)

My son is...having a hard time. He watched [his sister] go through [the operation]....He said, 'Why am I not invited to talk? I was affected by all this.' I mean, he's 11 [Family member, Moore et al., 2017a p1598](50)

As well as supporting a shared understanding of the life-changing event (subthemes *Subtheme 1.1* : An account and *Subtheme 2.1: Shared rules*) and enhancing learning opportunities (see *Subtheme 2.2: Meaningful outcomes*), involvement of those affected by the life-changing event in the inquest process may increase trust in the redress-reconciliation process, and thus the institution, by reassuring patients and families that system representatives were engaged with their case and cared about establishing what had happened.(56) Conversely, lack of involvement may reduce transparency around what had occurred and/or the inquest process, diminishing trust in the redress-reconciliation process, and potentially fuelling feelings of anger and desire for retribution.

Eleven studies (eleven papers) contained data which highlighted the importance of involving professionals perceived as directly responsible for the harm in the dialogue between justice-seekers and professionals representing the institution in the early stages of the justice-seeking process:(32-34, 39, 40, 46, 50, 51, 53, 55, 74)

One of the nurses actually went and found a doctor to come in and talk to me” but went on to say, “But it wasn’t sort of a person who knew completely about her care. It just happened to be maybe the resident who was on the unit at that time [Family member, Fisher et al., 2016 p1691](32)

One of the major regrets that I have had since this happened is that I never had an opportunity to talk with the fellow who marked the spot—who mismarked the spot. That person never appeared again. When I asked if I could have a chance to speak with the fellow, I was told that the person had already left the hospital and was not around any longer. I thought that was a real missed opportunity, both for the fellow and for me [Patient, Gallagher et al., 2009 p670](33)

In the letter, it started off by saying that they apologised and they’re sorry that our dealings with the hospital hadn’t been positive ones, but I think the wrong person’s apologised, we didn’t want the Area Health to apologise, we wanted the person responsible to apologise . . . It just made it so impersonal... [Family member, Piper et al., 2014 p202](53)

The above quotes illustrate that having the opportunity to speak to those perceived as being responsible for the harm they had suffered could be extremely valuable to people seeking redress and reconciliation. It may reassure them that they were speaking to the persons who could give an accurate account of what had occurred and provides them the opportunity to ask direct questions.(65) It may also increase the merit of any apology offered by ensuring it reflects the personal circumstances of those harmed (see *Theme 2: Person-centred*). That being said, there is not always a clear consensus

as to who should be involved in the process of disclosure,(35) or apology.(46) One participant described how they appreciated an apology given on behalf of the person they perceived to have harmed them:(46)

The fact that other people apologized for her actions made me feel that they felt really bad that that had happened to me [Participant, Mazor et al., 2013 p5](46)

The above quote supports the concept that expressions of remorse are important to those who have experienced harm (see *Subtheme 2.2: Meaningful outcomes*). Here the apology may have acted as external validation of the harm this person has endured, which can be an important part of the healing process (see *Subtheme 4.2: Closing a chapter*).

Three studies indicated that the perceived importance of having opportunities to involve those perceived as responsible for the harm during later stages of the redress-reconciliation process varied.(51, 57, 65) Two studies represented views of justice-seekers who wanted to speak with individuals directly involved with the harm they had received in order to ensure relevant information had been gathered or to obtain closure:(50, 65)

I wanted mediation with the doctor who was responsible...I still can't get closure because I haven't yet spoken to that doctor [Patient, Moore et al., 2017b p793](50)

However, one study represented the views of families of murder victims, who could not see the purpose of meeting with the offender after the trial:(57)

There's nothing in my soul that makes me even want to have a conversation with him because I feel like any conversation I would have with him is full of crap anyway. It's not going to bring my dad back, so what's the point? [Family member, Burns et al, 2006 p106](57)

Here the desire to meet with the offender is influenced by the perceived likelihood of receiving an accurate account of what had occurred and the irreversible nature of the harm that has been done. Overall, it seems that the most sensible course of action would be to ask individuals seeking redress-reconciliation who they wish to be involved.

Finally, twenty-one studies (22 papers) emphasised the value of conducting all aspects of the redress-reconciliation process in a timely manner.(28-31, 34, 39-42, 48-52, 55, 57, 64, 65, 68, 74, 76, 77) Ten studies indicated that this started with the prompt disclosure and/or action following the life-changing event,(30, 34, 39, 40, 42, 49, 55, 64, 74, 76, 77) followed by timely provision of information regarding what had happened and what to expect next:(41, 48, 52, 74)

It wasn't until after the Health Rights Commission had done their formal investigation that I finally got notified. It was about a week later that...the patient safety officer from (named hospital) actually rang me and said: We need to talk to you. We need to have an Open Disclosure (Patient, Sorensen et al., 2010 p152)](55)

[I expected] the full facts surrounding my husband's death to be uncovered in a realistic timescale (six months). Instead it has taken thirteen months to set a date. I have been periodically upset as more sensitive information is gradually released. Prison report was received May 2004! Police report was received July 2004!' [death occurred in August 2003] [Family of a man who died in prison, Shaw et al., 2007 p67](74)

Participants in five studies emphasised the importance of conducting the early stages of the redress-reconciliation as soon as possible.(28, 29, 31, 65, 74) Part of this was to ensure that important details of the event were not forgotten, which has important implications for those who have experienced harm being able to reconstruct a comprehensive narrative of the harm they have experienced (subthemes *Subtheme 1.1 : An account and Subtheme 4.2: Closing a chapter*):(28, 65, 74)

Some interviews (post-death) were done months after my husband died and likely to be inaccurate. The nine months to get the prison report and 12 and a half months to get the police report were NOT acceptable – the delays caused even greater upset [Family of a man who died in prison, Shaw et al., 2007 p67](74)

This quote illustrates the emotional harm experienced by participants who have to wait for long periods of time to receive an account of what happened. Seven further studies (8 papers) acknowledged the difficult emotions experienced by those seeking redress-reconciliation in response to prolonged wait for investigations to start, and then conclude.(41, 48, 57, 65, 68, 74, 76, 77) Delays could prolong grief and exacerbate uncertainty, making it difficult for people to move on with their lives, as illustrated by the quotes below:(57, 68, 77)

It was really hard because I would get a date to go to court and it would get changed. It was adjourned four times - I got so I didn't believe it was ever going to happen [Survivor CSA, Eastwood et al., 1998a p3](77)

It's hard on someone who's the family member of someone who's been murdered to go through the delays and the extensions of dates. It's really, really hard because a week seems like a year. It's hard to get yourself mentally and emotionally ready for something, and then they say that it's been delayed. That's the hardest thing. It's just crushing. It is so unfair. And,

to not know if there's going to be an end to it [Family member of homicide victim, Burns et al., 2006 p82](57)

It (the delay) lead to the most horrendous speculation. I started to wonder and think all sorts of things - was there someone else involved, perhaps he'd not meant to do it, was the coroner looking for some other evidence—something against me? Now the inquest is over I feel 200% better. I can move on without all the guilt and worry hanging over me. [Family member bereaved by suicide – inquest process, Biddle et al., 2003 p1039](68)

The impact of the challenging emotions experienced during the redress-reconciliation process as highlighted may compound the initial trauma of the life-changing event. This is more fully explored within *Subtheme 4.2: Closing a chapter*. One study offered conflicting views on the value of an apology given a long time after the life-changing event. One participant indicated that in such circumstances, the value of an apology is diminished:(51)

An apology this late in the game means nothing. I actually didn't want one at this stage [Patient, Moore et al., 2017b p792](51)

However other patients in the same study indicated that apologies were better received once the patients had had time to process their loss.(51) It appears that those who are responsible for the harm must judge the appropriate time/s to offer an apology according to the needs of those seeking redress-reconciliation. In some circumstances, the need for emotional support and catharsis may limit/outweigh the usefulness of an apology.

Overall, the main message was that the time taken to reach a verdict and/or complete the redress-reconciliation process took far too long and needed to be expediated.(34, 41, 49, 50, 57) This somewhat conflicts with justice-seekers desire or appreciation for a rigorous investigative process,(65, 68) which arguably should not be undertaken too quickly. Here the value of regular communication to support realistic expectations regarding the likely duration of the redress-reconciliation process and reasons for any unexpected delays is highlighted.

This subtheme describes how perceived trust in the redress-reconciliation process may be enhanced through use of a formal pathway which promotes a two-way dialogue between professional stakeholders and those who have experienced harm. Justice-seekers appreciated their experiences and views being actively sought to inform the process and outcomes, as well as the involvement of the individuals they perceived as being responsible for the harm. Finally, those seeking redress-reconciliation wanted the process to be conducted in a timely manner, to limit the negative emotional impact of ongoing uncertainty, grief and fatigue associated with a lengthy, ongoing investigation.

Subtheme 3.2: Ongoing support

Twenty-five studies (27 papers) support this subtheme (see Table 16), which details the ongoing support people seeking redress and reconciliation may require throughout the process.(26, 28, 30, 33-35, 37, 39-43, 45, 49-56, 58, 59, 64, 65, 74, 76) The importance of assistance in accessing information and emotional and financial support is discussed. The important role advocates and/or family members can play alongside a consistent point of contact within the institution or external organisation is also explored.

Table 16: Studies supporting subtheme 3.2

	Stage of Redress-Reconciliation Process					
	Disclosure/ Communication	Review inquest	or	Litigation Process	Post-litigation process/ desired outcomes	Other
Supporting studies	Duclos 2005 (30) Hagensen 2018 (34) Hannawa 2017 (35) ledema 07(40) ledema 11(39) ledema 2012b(37); Piper 2014(53) Kent 2008(42) Kim 2021(43) Martin 2021(45) Mazor 2010(26) Sorensen 2010(55)	Bakhabakhi 2017(28) Myren 2021(52) Ngo 2021(65) Shaw 2007(74) Wiig 2021(56)		Eastwood 1998b(76) Englebrecht 2014(58) IPSOS 2016*(41) Maderia 2008(59) Matthews 2012(64) Melville 2012(49) Moore 2017a(50) Moore 2017b(51) Pyo 2019(54)	Gallagher 2009(33)	

*Contributes insight towards multiple stages of redress-reconciliation process; Green text=study from non-health field

Seven studies (seven papers) highlighted the need for those seeking redress/reconciliation to be supported to access and understand information pertaining to the life-changing event.(28, 35, 39, 40, 51, 52, 74) Three of these studies emphasised the need for healthcare workers to aid patient access to and understand written documentation,(28, 39, 74) from the initial letter describing the event prior to discharge(28) through to the explanation of the post-mortem report.(74) Five studies highlight the need for people to receive support during initial meetings with professionals to ensure that important information is retained during times of distress and allow patients/families to ask questions about any written information that has been provided and request regular updates about the investigation going forwards:(35, 40, 51, 52, 74)

Probably if we had a nurse in there as well and some other support people, that would have made it less clinical. Can I say, we probably would have benefited [and] I personally would have benefited greatly from having some contact with some support from a social worker, for example, just somebody to support us through that time. The nursing staff can't do it. They are too busy. It's not to say that they are not very good, they are, but they can't give the support that I felt we needed [Patient, Iedema et al., 2007 p95](40)

Here the patient expresses a desire for a support person dedicated to their needs. Whilst the person in this study suggested the appropriate person to fulfil this role would be a social worker, other individuals felt that social workers should not be present at early disclosure meetings:(50)

I would have liked to only have the surgeon come in when he first met with us and maybe a resident..., but no hospital administrator and definitely no social worker I assumed my child was dead, because otherwise what do you need a social worker for? [Family member, Moore et al., 2017a p1597](50)

Thirteen studies identified the need for individuals to be supported to access and negotiate the redress-reconciliation system.(25, 30, 34, 35, 37, 42, 43, 45, 49, 50, 54, 64, 74) This encompassed signposting to support available and help to navigate the complex requirements the process entailed:(74)

I reiterate that there needs to be more immediate knowledge of who and what is available for people who find themselves in our position and awareness needs to be raised within the judicial system of what is available to present to us [Family of a man who died in prison, Shaw et al., 2007 p27](74)

Seven studies (7 papers) highlighted the importance of independent advocates to provide support during more formal litigation processes.(41, 49-51, 58, 74, 76) These individuals included solicitors,(25, 41, 49) support workers or liaison officers,(74, 76) and attorneys.(50) Support received included updates regarding progress,(41) help to prepare for what was going to happen,(58) as well as representing their case in court.(25) Another important aspect of the care provided by advocates or intermediaries is the provision of emotional support, something which can often be overlooked:(34, 55)

There has been no real follow-up with me as a person, and I don't feel that I have had any support [Participant, Hagensen et al., 2018, p7](34)

Overall nine studies referenced the need for emotional support during the redress-reconciliation process.(33-35, 49, 51, 55, 56, 74, 76) Often, this was provided by individuals outside of the institution

investigating the harm by professions representing those seeking justice. One study highlighted the importance of peer support:(74)

It was helpful to understand that many families had suffered in a similar way and that there is a pattern of failure by the establishment generally to properly investigate and apportion blame when deaths occur in the care of the state [Family of a man who died following a police vehicle incident, Shaw et al., 2007 p120](74)

This quote indicates that individuals seeking justice may value contact with other families who have experienced similar difficulties with redress and reconciliation processes as it means that, despite their perceptions they have been abandoned by the system, they are not alone (see *Subtheme 4.2: Closing a chapter*) Data from the same study also indicated that individuals may value support from individuals who they perceive to be more independent of the investigative process (see *Subtheme 3.4: Objective input*):(74)

My Liaison Officer was helpful to a certain degree but as she said, she was 'here to help but first and foremost she was a police officer' so I thought, she is here to gather information [Family of a man who died following contact with police, Shaw et al., 2007 p60](74)

Closely linked to the importance of financial compensation (see *Subtheme 2.2: Meaningful outcomes*) was the need for financial support whilst active investigations or litigation processes were underway and/or harms to health were being resolved:(26, 30, 49, 50, 54, 64)

I thought I was out for the count when all them [sic] bills were rolling in. There was a stack of bills like this from my insurance. And they just kept coming because I kept having surgery after surgery [Patient, Duclos et al., 2005 p481](30)

And it's almost to the point where. . . well, if the problem persists for two or three years, how long can it be before I sue the people who were involved to help pay for the problem. I mean, it's bad enough that I have to physically deal with it, but then to have to financially deal with it is a totally different situation [Patient, Duclos et al., 2005 p482](30)

These quotes also illustrate the importance that people receive the physical healthcare necessary to manage the physical consequences of the error. Eleven studies highlight the importance of ensuring continuity of healthcare whilst the redress-reconciliation process is underway:(26, 28, 30, 34, 35, 41-43, 45, 50, 54)

They didn't really monitor her heels. She got a grade two [pressure ulcer], she was discharged, and now she's bedbound, because she can't step out on to her heel. And it's a massive knock-

on effect. She's now bedbound and extremely poorly. Huge quality of life, and she's got 24-hour carers. [Daughter]'s moved in with her. And that, and that's it, so we've got, on an RCA [root cause analysis], lessons learned about we should have got a different mattress earlier and we should have been monitoring it and filling the forms [Relative, Martin et al., 2021 p6](45)

We have bigger fish to fry in that we needed to get our son well. And these people ultimately were going to be our only resource to get that done [Family member, Mazor et al., 2010 p105](26)

The second quote above provides an example of the tension which can exist between the desire to achieve justice and the fear that seeking redress would impact future care received.(26, 43, 53) Preserving or rebuilding the relationship between justice-seekers and those who have harmed them via frequent meetings and permitting two-way dialogue (see *Subtheme 3.1: A reasonable and consistent process*) may help mitigate this. In addition, eight studies (eight papers) contained data highlighting the need for a consistent point of contact through with individuals seeking justice can obtain support.(30, 39-41, 50, 64, 74, 76) These studies represented individuals from different stages of the redress-reconciliation process, from those tired of repeating the story of what had happened during the disclosure process,(39, 40) to those seeking support and continuity of communication during the inquest process.(51, 64)

Finally, seven studies indicated the need to ensure that the individuals and services working as part of the redress-reconciliation process had the required skills necessary to support their work with those who had been harmed.(33, 49, 54, 56, 64, 74, 76) This included the ability to deliver bad news,(33, 74) adapt their approach according to their age,(76) and ability to represent their interests in a court setting.(49, 54, 64)

This subtheme details the support required by those seeking justice so that they can access and maintain their involvement with the redress-reconciliation process. Provision of this support may increase the perceived trustworthiness of the redress-reconciliation process by demonstrating the desire to engage them with, and thus incorporate their views -in justice-seeking process and its outcomes.

Subtheme 3.3: Mechanisms for challenge or dispute resolution

Fifteen studies (17 papers) contributed towards this subtheme, which predominantly represents views of redress-reconciliation processes following non-medical life-changing events (see Table 17). (21, 37, 39, 41, 42, 49, 54, 57-59, 64, 65, 68, 69, 74, 76, 77) The theme explores how existing legal structures

can provide the opportunity for those who have been harmed to seek redress-reconciliation and highlights how mechanisms to challenge information which is perceived to be inaccurate could be improved. The section ends by considering views on the necessity of an appeals process following an initial verdict and reflects on the limitations of this.

Table 17: Studies supporting subtheme 3.3

	Stage of Redress-Reconciliation Process					
	Disclosure/ Communication	Review inquest	or	Litigation Process	Post-litigation process/ desired outcomes	Other
Supporting studies	Iedema 2011(39) Iedema 2012b (37) Kent 2008(42)	Biddle 2003(68) Bouwman 2018(21) Ngo 2021(65) Shaw 2007(74)		Burns 2006*(57) Eastwood 1998a(77) Eastwood 1998b(76) Englebrecht 2014(58) IPSOS 2016*(41) Matthews 2012(64) Melville 2012(49) Pyo 2019(54)	Chapple 2012*(69) Madeira 2008(59)	

*Contributes insight towards multiple stages of the redress-reconciliation process; Green text=study from non-health field

Three studies highlighted how existing legal structures such as the police, external complaint agencies and the inquest process can already provide opportunities for people who have experienced harm to raise complaints about the care they have received or challenge public accounts of the event that they believe to be inaccurate.(42, 65, 68)

Three studies highlight the need for processes to resolve disputes between patients and professionals within the healthcare system during the redress-reconciliation process.(21, 39, 41) The need for this is likely to be exacerbated in processes which support greater involvement of patients and their families.(21, 37) One solution to address differences in opinion regarding future care needs going forwards, and thus prevent a protracted negotiation between claimants and defendants, was for parties to agree to repeat assessments going forwards:(41)

[The ongoing assessments] would be a big time saving, money saving, stress saving, and everything, whereas we went through this thing where we had to have that side visit and that side visit, and those two argue [Parent, experience of birth injury, IPSOS MORI, 2016 p36](41)

Three studies representing experiences of the inquest and litigation stage of the redress-reconciliation pathway identified the need for a mechanism to enable justice-seekers to feedback on the conduct of health professionals or the content of reports detailing the life-changing event which they perceive to be inaccurate.(41, 49, 65) As discussed in *Subtheme 1.3: Consideration of systemic factors*, some of the participants in the study conducted by Melville et al., (2012)(49) who were seeking compensation from an NHS trust were enabled by their solicitor to meet medical professionals to discuss the content of independent medical reports. This was an opportunity to discuss any dissatisfaction with perceived difficulties in determining causality, which informed solicitor decisions on whether to proceed with a particular case:(49)

...she said to us, if they say that before a judge, the judge would listen to the expert witness
[Patient with serious injuries, withdrawn claim, Melville et al., 2012 p27](49)

The above quote illustrates how the legal processes can prioritise the views of medical professions over the concerns of patients and their families when determining the perceived merit of proceeding with a case (see *Subtheme 1.3: Consideration of systemic factors*). This can be a source of frustration for those seeking justice and reduce trust in the redress-reconciliation process.

Six studies highlighted the need for a system to support individuals to challenge a verdict they don't agree with.(54, 58, 64, 69, 74, 76) Whilst one study provides an example of how the views of families of people who had completed suicide were taken into account during the verdict,(69) data from the remaining studies indicates this is not always common practice:(54, 58, 64, 74, 76)

[We felt] empty. We felt that there should be more to do – more questions to be clarified etc., but decisions had already been made. We were advised that we could appeal by judicial review but were aware of the lengthy process – it had taken two years to get to this [Family of a man who died in prison, Shaw et al, 2007 p107](74)

In addition to dissatisfaction with the verdict, perception of lack of support/bias from professionals involved with the process and legal errors within the inquest process were factors which contributed towards people's desire to challenge the final verdict:(54, 74)

I told the judge while crying; If I were your family, would you have done this? How could you only listen to the opponent? Would you have done the same if your family was going through this? Then he said, if it were him, if it were him, he wouldn't have make a case like this. (...) He said I can walk. He would pray for me to walk, so if I try hard, I can walk. So I filed an application to challenge the judge [Patient, Pyo et al., 2019 p7](54)

Four studies indicated that challenging the verdict by pursuing follow-up trial or appeal processes provided a way for people to get their views heard and ensure justice was achieved:(54, 64, 74, 76)

... I have decided that after I have got a bit of money together that I will go for a civil suit, and I am going to get everything done my way. I'm not quitting until I find justice I am determined to get him because he doesn't deserve to be out there [CSA survivor – not guilty verdict, Eastwood 1998b, p241](76)

However, three studies indicated that there is often no clear way for people to challenge or appeal the final verdict, with factors such as money, time and emotional resources acting as barriers to individuals accessing the appeals process:(54, 74, 76)

After five years of trials, I have two years to ask for a retrial. I don't even know if my retrial demand will go through, I don't know if I can go through another trial if my demand is accepted. The lawyers told to me just forget about it, just move on with my life. They said 20% award is a really big deal apparently [Patient, Pyo et al., 2019 p6](54)

The quote above illustrate how exhausted justice-seekers may be following the trial and suggest factors such as lack of support and uncertainty associated with another lengthy process may prevent people from progressing further with their redress-reconciliation process. However, one study exploring the views of family members of murder victims indicates that in cases where a clear determination of guilt has been achieved, a protracted appeals process can cause result in great distress for the families seeking justice:(57)

It just keeps dragging on. It keeps victimizing us. We have to go through the same things over and over, and it's just ridiculous [Family member, Burns et al., 2006 p82](57)

If they weren't the right people [offenders], I would be the first person to say, 'Let's go find the right ones.' But they were. They had confessed up front. But, we had gone through so many trials trying to get them off [Family member, Burns et al., 2006 p84](57)

This instance demonstrates the perception that the legal system was biased in favour of the offender. Whilst the process itself was a fair one, as it supported the offenders right to appeal, it did not consider the emotional needs of the family. Prolonging the trial process through repeated appeals can also be linked to feelings of anger, and distress and delays the opportunity for people seeking justice to close this chapter of their lives (see *Subtheme 4.2: Closing a chapter*).

The contents of this subtheme indicate that people seeking redress-reconciliation appreciate opportunities to present their views throughout the process. This may be through opportunities to

correct formal accounts of the life-changing events, by pursuing formal litigation processes through the courts and having their views incorporated within the final verdict. The appeals process represented an important opportunity to challenge final decisions they did not agree with, although many people did not find this an easy process to access. The appeals process was one factor which could contribute towards unanticipated delays to the resolution of the redress-reconciliation process which, alongside perceived bias in favour of those perceived to have done the harm, can increase the emotional trauma experienced and reduce trust in the process and final outcomes.

Subtheme 3.4: Objective input

Twelve studies (13 papers) supported this subtheme (see Table 18) which explores the importance of individuals and/or organisations who are perceived to be independent of the institution where the harm occurred, or the redress-reconciliation process itself. (27, 30, 35, 38, 40, 41, 50, 56, 59, 60, 65, 74, 76) The role these individuals or organisations can play in terms of providing information, emotional support and oversight of ongoing investigation are discussed below.

Table 18: Studies supporting subtheme 3.4

	Stage of Redress-Reconciliation Process					
	Disclosure/ Communication	Review inquest	or	Litigation Process	Post-litigation process/ desired outcomes	Other
Supporting studies	Duclos 2005(30) Hannawa 2017(35) Iedema 07(40) Iedema 12a(38) Moore 2017a*(50)	Shaw 2007(74) Ngo 2021(65) Wiig 2021(56)		Eastwood 1998b(76) IPSOS 2016*(41) Maderia 2008(59) Maderia 2010(60) Ocloo 2010(27)		

*Contributes insight towards multiple stages of redress-reconciliation process; Green text=study from non-health field

Five studies indicated that having individuals who were perceived to be independent of the institution where the harm had occurred to support patients and/or their families or channel information between different stakeholders may be beneficial during the investigation:(30, 35, 40, 50, 74)

There should be a totally independent organisation that is on hand to speak to families (if the families want to) [to] offer advice, support and keep them fully informed. Family Liaison attached to police are not helpful and not to be trusted [Family of a man shot dead by police, Shaw et al., 2007 p61](74)

In terms of support, having professionals connected with the organisation where the harm had occurred responsible for helping patients introduced suspicion that these individuals were there to help the organisation limit their liability or gather information.(50, 74) Having an external party present during meetings may also help establish a “trusting” environment for open communication.(35)

Two studies highlighted the need for an independent or impartial body to oversee investigations,(41, 56) with suggestions that this could help increase confidence in the findings of the redress-reconciliation process.(41) Both of these studies indicated that “independence” should at minimum signify individuals or organisations who were separate from the healthcare services where the harm had occurred; with one study indicating that patients and families may need some reassurance that this was the case.(56) However, one study highlighted the frustration of patients at the perceived failure of external organisations to investigate issues raised, thus allowing professionals to shift blame from health organisations to patients.(27) In addition, two studies indicated that the absence of independent medical experts, including the coroner’s role, may reduce access to the redress-reconciliation process for individuals who had been harmed.(27, 74)

In two studies, people indicated that if the formal inquest or litigation processes were conducted by an external authority, it may provide reassurance to individuals who had been harmed:(65, 74)

It would have given me peace of mind that another governing body had a look at what happened and then maybe if they deemed it still to be just an accident, that maybe I would feel a little bit more settled about it [Bereaved family member, Ngo et al., 2021 p453](65)

The investigation should be done by a completely independent body with no bias to police or public but just to find out truth and justice and factual knowledge [Family of a man who died in a police vehicle incident, Shaw et al., 2007 p52](74)

However, two studies highlighted the need for robust processes to be in place to ensure that these independent investigations remained trustworthy and protected those who had been harmed.((74, 76) Firstly, the need for intervention by judges, and crown prosecutors to stop intimidatory and/or degrading cross-examination of witnesses was highlighted by two survivors of childhood sexual abuse:(76)

No ... she never got up and objected. And that is what I hated. She just sat there and I kept looking at her - pleading - please say something [CSA Survivor, Eastwood et al., 1998b p237](76)

These studies also discussed the importance of an independent jury,(74, 76) and highlighted that jury

members should reflect both the communities they represented,(74) and the nature of the case being discussed in order to avoid issues such as racism and sexism influencing the verdict:(76)

. . . And about more females on the jury, even though it is easier to talk in front of women, it wouldn't be fair. We are all equal now and it is not always females who are abused [Family member, Eastwood 1998b p246](76)

Some people perceived that members of the jury could get answers to the questions that they needed and act as a valuable source of emotional validation:(74)

Their role was very, very important. [They were] able to ask more direct questions and get the answers [Family of a woman who died in prison, Shaw et al., 2007 p104](74)

[They were] extremely fair. Their reaction at the end of the inquest showed them to be very sympathetic [Family of a man who died in prison, Shaw et al., 2007 p103](74)

The same studies highlighted the importance of providing the jury with adequate support to ensure they can fulfil their role:(74, 76)

Overwhelming for the jury at first but [I] could see that they started to pick up the story and see the many issues as the day went by. They needed an outline of the issues at the beginning so that they knew what it was all about [Family of a man who died in police custody, Shaw et al., 2007 p103](74)

[They] didn't seem to take all the witness statements into account and were rushed to reach their verdict [Family of a young man who died following police pursuit, Shaw et al., 2007 p104](74)

One study also highlighted the vulnerability of the jury to feedback from the judge who, in this instance, cautioned the jury regarding the possible unreliable nature of the evidence provided by CSA survivors:(76)

...the jury had been willing to convict but had been warned off by the Judges' instructions [CSA Survivor, Eastwood 1998b p246](76)

...very disappointed at the direction given to the jury on corroborated evidence [Father CSA survivor, Eastwood 1998b p246](76)

In this instance, both victims and family members perceived that the judge's attempt to ensure the jury undertook a balanced consideration of the evidence cost them a guilty verdict. This highlights the extreme caution with which judges should provide information/opinion to jury members, due to the influence of their position of power within the courtroom. One study suggested that the involvement

of families within the courtroom may act as a reminder to the jury that there were many people concerned with the outcome, and thus act as a source of external influence.(59, 60)

Having individuals or organisations who are perceived as being independent within the formal redress-reconciliation process may enhanced the perceived trustworthiness of the process and final outcomes. Their presence may increase the support available to those who have been harmed and/or act help provide an oversight of the process to ensure it is conducted fairly. However, mechanisms need to be in place to ensure that they are provided within the correct information and support to enable them to fulfil their role without being seen to compromise the process or final outcomes.

Theme summary: Trustworthy

To enhance the perceived trustworthiness of the redress-reconciliation pathway, justice-seekers need to be supported to access and maintain engagement with a pre-planned, consistent process that centres around their needs. A process which does not fully account for the needs, views, and experiences of those who have been harmed may be met with formal challenges from justice-seekers, as they seek to have their perceptions accurately reflected in formal accounts of the life-changing event and represented within the final outcome of the redress-reconciliation process. A process which does not support this or is seen to be biased in favour of the individuals/organisations associated with the original harm, may not be experienced as trustworthy, which may in turn influence how fair the outcome is considered to be. Input from people external to organisations where the harm occurred, or which are hosting the redress-reconciliation process may play a role in mitigating any perceptions of bias. However, these individuals should be given the appropriate information, training, and support to fulfil their role and ensure they remain focused on supporting the needs of justice-seekers or ensuring due process is carried out correctly within the redress-reconciliation process.

What does a fair process feel like?

Theme 4: Restorative Justice

Thirty-eight studies (44 papers) support this theme (see Table 8) and consist of two subthemes.(21, 22, 25-27, 29, 30, 32-60, 64, 65, 68, 69, 74, 76, 77, 80) The earlier three themes discuss procedural issues which need to be in place for the redress-reconciliation process, and its outcomes, to be experienced as fair. To complement the procedural aspects of the redress-reconciliation process, this theme considers how the relationships developed between the stakeholders within the redress-reconciliation process can influence the procedural aspects of the process, and also how the process is emotionally experienced by justice seekers, which may in turn influence perceptions of its fairness. The first subtheme, 'Humanising process', explores key features of the redress-reconciliation process

which are needed to prevent it from being experienced as emotionally harmful, bureaucratic and insensitive to the needs of those seeking justice. The second subtheme ‘Closing a chapter’ discusses how the process of redress-reconciliation can support individuals to transition from a position where they are overwhelmed by the trauma they have experienced, through to a position of acceptance and being able to move on with other areas of their life.

Subtheme 4.1: Humanising process

Thirty studies (33 papers) contributed towards this subtheme, which discusses the need for redress-reconciliation procedures to embody the principles of respect, empathy, and good communication and acknowledge the individuals who have experienced harm as equal participants in the justice-seeking process (see Table 19).(21, 25-27, 29, 30, 32-37, 40-44, 46, 48-53, 55-58, 65, 68, 74, 76, 77)

Table 19: Studies supporting subtheme 4.1

	Stage of Redress-Reconciliation Process					
	Disclosure/ Communication	Review inquest	or	Litigation Process	Post-litigation process/ desired outcomes	Other
Supporting studies	Duclos 2005(30) Fisher 2016(32) Hagensen 2018(34) Hannawa 2017(35) Hovey 2014(36) Iedema 2007(40) Iedema 2012b(37); Piper 2014(53) Kent 2008(42) Kim 2021(43) Loren 2021 (44) Mazor 2010(26) Mazor 2013(46) Sorensen 2010(55)	Bouwman 2018(21) Biddle 2003(68) McQueen 2021(48) Myren 2021(52) Ngo 2021(65) Shaw 2007(74) Wiig 2021(56)		Burns 2003(57) Eastwood 1998a(77) Eastwood 1998b(76) Englebrecht 2014(58) IPSOS 2016*(41) Melville 2012(49) Moore 2017a(50) Moore 2017b*(51) Ocloo 2010(27)	Chiu 2010*(29) Gallagher 2009(33)	Kamin-Friedman 2021(25)

*Contributes insight towards multiple stages of redress-reconciliation process; Green text=study from non-health field

Eleven studies (12 papers) from across the redress-reconciliation pathway indicated that justice-seekers were not always treated with respect by professionals or the organisations they represented, resulting in feelings of shock, hurt and anger:(29, 32, 35, 43, 52, 55, 57, 65, 68, 74, 76, 77)

I felt like they had no conscience. This doctor’s basic character was appalling. He did not even have a conscience. He never showed even a shred of an apology. The thing that most

astonished me was that the doctor acted as if he had stepped in a turd. I was shocked that he thought he was unlucky for getting caught up with a patient like me [Patient – experience of disclosure, Kim et al., 2021 p2506](43)

I've got so much anger around it. The whole thing shouldn't have been dealt with like that. Why can't it be done showing a bit more respect for the family? I'm going to hurt for the rest of my life. It's like being stabbed and having the knife twisted [Family member, suicide inquest, Biddle et al., 2003 p1038](68)

The second quote above suggests that such treatment has the potential to compound the emotional harm experienced following the life-changing event itself. One study indicates that there was little space for the emotions of witnesses or families during court proceedings:(57)

His [offender] lawyers were upset and made us take off all our jewelry that was angels. When we were in the courtroom, I felt like we were treated like Kindergarteners because we were told not to talk, not to speak, no emotions [Parent of homicide victim, Burns et al., 2006 p87](57)

Whilst it is important that the jury is supported to remain impartial (see *Subtheme 3.4: Objective input*), the above quote indicates that this may result in families feeling that their emotional needs are being discounted. The quote also illustrates how families felt they were being talked down to by the legal professionals representing the defendant. Two further studies exploring experiences of the inquest or litigation processes following a non-medical life-changing event indicated that the people being cross-examined, or the families watching, sometimes felt belittled by the way they were treated:(74, 76)

He was an asshole. Not even if you are in trouble at school, in the principal's office, not even the school principal would treat you the way he did. He put my character down and everything [CSA survivor, Eastwood et al., 1998b p218](76)

Participants in six studies spoke about how they were treated as though they were the ones who were “the problem” or to blame for what had occurred:(27, 35, 48, 58, 74, 76)

The whole system requires a full overhaul. The families should be treated with respect, we were made to feel that we had committed crimes ourselves [Family of a man shot dead by police, Shaw et al., 2007 p100](74)

Five studies (six papers) indicated a lack of respect early in the investigative process.(32, 55, 57, 74, 76, 77) Participants in one study suggested they were not treated the same way due to racism within

the disclosure process:(55)

Because maybe they just look at us we're black and they think maybe your mind's black that's how they, they just, well just do like that and live it, they didn't do their best at all like how they do to other people, especially the white people [Family member experience of disclosure process, Sorensen et al., 2009 p154](55)

Participants in four studies indicated that they felt ignored by the professionals conducting the investigation:(32, 48, 57, 77)

I went two years and nine months without ever wanting compensation, and I've made that very clear from day one that was never my goal and I didn't want to profit (from the death of my loved one). But I decided to do this because I was being ignored and I knew that I'd get a reaction [Participant, McQueen et al., 2021 p8](48)

In accounts which support maintaining a two-way dialogue throughout the redress-reconciliation process (as discussed in *Subtheme 3.1: A reasonable and consistent process*), eleven studies highlighted how justice-seekers valued the opportunity to meet with both representatives of organisations who had harmed them and those representing them within the litigation process.(33, 34, 37, 40, 41, 46, 48, 49, 51, 53, 56)

The hospital then did a review which I was really pleased they were open about that...so we saw a report and went into hospital and had a meeting [Parent of child with birth injury, IPSOS MORI, 2016 p18](41)

...and within two weeks of putting in a complaint, I did have a meeting with the associate medical director. But after that, it seemed to me really slow and took almost two years...which is a long time to have it hanging over you. So, there was a lot of time between these meetings and letters where nothing was happening [Participant, McQueen et al., 2021 p6](48)

....A twenty cent phone call sort of looked, made, [name deceased patient] very cheap [Family, Piper et al., 2014 p202](53)

The above quotes illustrate how the willingness to meet with patients and family members may enhance perceptions of the transparency of the process (*Theme 1: Transparency*) and thus help build trust.(56) The quote also illustrates how face-to-face meetings, may help honour and respect the individuals who have died, as well as those who are now representing them. Face-to-face communication may also help reduce opportunities for unresolved conflict during the redress-reconciliation process through the ability to support immediate receipt of feedback and reassurance

for all stakeholders. Eight studies (8 papers) highlighted the adversarial nature of different stages of the justice-seeking pathway:(25, 41, 48-51, 56, 76)

When we tried to ask questions about what happened we were pushed away, and in terms of those very initial days, that was really, we were just so isolated is all I can say.' Parent, experience of a birth injury [Parent with experience of birth injury, IPSOS MORI, 2016 p12](41)

[they] did not even make an offer....they were so frugal and so aggressive with their mediation [Parent, Moore et al., 2017a p1600](50)

Why do I have to confront someone who doesn't want to pay me?...It means that either I have to hire a lawyer at my own expense, which costs more than what I might receive here, or I have to show up alone and face some shark lawyer who'll eat me alive, and that's fine with everyone. What are they actually doing there? [Legal guardian of minor with vaccine injury, Kamin-Friedman et al., 2021 p7](25)

This perception of defensiveness and aggressiveness may act as a barrier to collaborative resolution between different stakeholders in the justice-seeking process and, as illustrated by the quote above, contribute towards justice-seekers feeling that they have been left alone with their anger and grief which also contributes to dehumanising feeling,(36) and that no-one cares (see *Subtheme 4.2: Closing a chapter*).

Seven studies documenting experiences of redress-reconciliation processes within the health field highlighted the need for professionals to exhibit good communication skills.(30, 35, 40, 43, 52, 55, 56) Such skills encompassed both the frequency of communication (see also *Subtheme 3.1: A reasonable and consistent process*) and the skills associated with interacting on a one-to-one basis:(30, 35)

And he was very nice about the whole situation, polite, calm. He wasn't excited about. . . oh you can't be suing, and all that kind of stuff. And he just was you know very professional about it, very professional and gave me the information that I needed [Participant, Duclos et al., 2005 p481](30)

if one of them doesn't look at me, I feel like they don't even know I am here, that is very unkind [Participant, Hannawa et al., 2017 p5](35)

Core communication skills identified within these studies included eye-contact, attentiveness body posture, removal of physical barriers between professional and justice-seeker, appropriate proximity, well-paced, empathic and openness (see *Theme 1: Transparency*). Good communication may be linked to increased perceptions of professionalism, trustworthiness, and empathy.

Twelve studies (12 papers) contained data which indicated people seeking justice really valued it when professionals treated them as a human being, by being caring, compassionate and showing their own “human” side:(26, 29, 30, 34, 35, 46, 48-50, 55, 56, 77)

Our communication with the consultant...was really good...because she was being like a human being, a women who's a mother herself and she kind of slightly stepped back from her professional role and just spoke to you like an adult...it made us feel good because we knew she cared [Parent whose baby died, McQueen et al., 2021 p6](48)

...and when we had to have some quite serious meetings and go into things in-depth he would always say to me if it's getting too much for you if you're getting upset you just have to say so. He was very mindful of my feelings, that we're not talking about an unknown person here, we are talking about my husband and I was married for twenty-five years so it wasn't sort of, he took all of that into account he didn't just go into legal mode, he was actually there's a human being here (Female family member – views of solicitor, Melville et al., 2012 p23](49)

What meant something to us was people, like the resident, who actually cared...He wrote [my daughter] a letter and came to visit her...He wasn't afraid to actually reach out....That meant something to us, more than an apology [Family member, Moore et al., 2017a p1598](50)

Six studies highlighted how professional empathy could inform practise during the redress and reconciliation process through mindful sharing of information, use of language, expressions of sympathy and support activities to aid the family grieving process:(35, 44, 46, 50, 56, 74)

You feel that they see you as a person, and you could feel their empathy. I think that is crucial in such meetings. You are vulnerable, so extremely vulnerable. You can feel the atmosphere, you can look at the persons and notice if they are not interested. Then everything is wrong. But that was not the case at all here in this meeting. They were very empathic and understanding. They said it was nice and well done that we came. Yes, it is those little things, such as saying 'great that you came, we are very grateful for that.' You could think of it as superficial, but it is so important [Participant – experience of inspector, Wiig 2021 p1715](56)

...if I don't get this information, I would feel like the hospital doesn't give a damn [Patient, Hannawa et al., 2017 p5](35)

One study proposed that the establishment of relationships between those participating in the redress-reconciliation process was key to establishing mutual empathy.(35) Given the emotional impact of perceived empathy from professionals on those seeking justice, any reluctance from professionals in terms of meeting or taking responsibility for the harm (see *Subtheme 1.3:*

Consideration of systemic factors) is likely to act as a barrier to developing relationships and empathy, acting as a barrier within the redress-reconciliation process.

Three studies highlighted potential actions professionals could take to support relationship building between stakeholders in the justice-seeking process.(49, 74, 76) Two studies exploring the experiences of individuals taking part in courtroom inquests/trials following non-medical life-changing events indicated that people welcomed the opportunity to meet the professionals involved in a less stressful setting.(74, 76) Participants in the study conducted by Melville et al., (2012) indicated they welcomed efforts made by their solicitor to develop a relationship with them, however this was not always successful:(49)

I think to be honest she was too professional... Very distant, very professional, you couldn't fault her; you couldn't be friendly with her or anything like that... It was all just very cut and dried sort of thing, but very nice [Male claimant, moderate injuries, Melville et al., 2012 p24](49)

The quote above indicates that the professional boundaries enacted on the part of solicitors can impede the development of a relationship perceived as being fully supportive.

Having the opportunity to develop a relationship prior to key stages in the redress-reconciliation process may also help reduce perceptions of bias in favour of the professionals involved.(Shaw) Nine studies highlighted the perception of unequal power dynamics between the justice-seekers and professionals involved in the redress-reconciliation process and/or the importance of treating patients as equals.(21, 26, 27, 35, 37, 42, 51, 52, 55) This is illustrated by one parent discussing how they were dissuaded from pursuing a more formal complaint:(26)

I feel like a bad parent in away by not getting justice, but I don't know. I just don't want to put my daughter through this and I just feel like honestly I feel like what I'm saying and what he's going to say he's a doctor I'm just like a regular, average person and I feel its his word against mine [Parent, Mazor et al., 2010 p105](26)

In contrast, the quote below indicates that actively seeking to involve justice-seekers and incorporate their views within the redress-reconciliation process can promote the development of a mutually empathic, respectful relationship in which justice-seekers feel valued, which could improve the perception of fairness of the process:(52)

I just really appreciated how you [the department] do it now. Be transparent, clear, and honest. That gives you a feeling of...being important. ...That things are discussed in this manner and that you are taken seriously, in your whole story [Patient, Myren et al., 2021 p348](52)

Overall, the people seeking justice valued being treated with empathy and respect and feeling as though their views were held to be equal to those of professionals involved in the redress-reconciliation process. This can help to humanise a process which, if too overly focused on its procedural elements, risks minimising the concerns and emotions of those who have been harmed in order to achieve a resolution.

Subtheme 4.2: Closing a chapter

Thirty-four studies (39 papers) contributed towards this subtheme (see

Table 20).(21, 22, 26, 27, 29, 30, 32-41, 43, 45-48, 50-52, 54-60, 64, 65, 68, 69, 74, 76, 77, 80) The subtheme starts by considering the trauma experienced by those seeking justice, both as a result of the life-changing event and the process of seeking redress-reconciliation afterwards. It then discusses that following this harm, closure may not be achievable, or acceptable, but that some people may be supported to reach a place of acceptance. The procedurally orientated nature of redress-reconciliation processes as documented within themes 1-3 may sometimes overlook the emotional needs of justice-seekers. This subtheme discusses how developing a cathartic narrative supports justice-seekers to develop a comprehensive understanding of the circumstances of the life-changing event, in addition to receiving support to express and manage their emotional needs and involvement in meaningful action may help individuals come to terms with what has happened to them.

Table 20: Studies supporting subtheme 4.2

	Stage of Redress-Reconciliation Process					
	Disclosure/ Communication	Review inquest	or	Litigation Process	Post-litigation process/ desired outcomes	Other
Supporting studies	Butler 2019(22) Duclos 2005(30) Fisher 2016(32) Hagensen 2018(34) Hannawa 2017(35) Hovey 2014(36) ledema 2007(40) ledema 2011(39) ledema 2012a(38) ledema 2012b(37); Kim 2021(43) Martin 2021(45) Mazor 2010(26) Mazor 2012(47) Mazor 2013(46) Sorensen 2010(55)	Bouwman 2018(21) Biddle 2003(68) McQueen 2021(48) Myren 2021(52) Ngo 2021(65) Shaw 2007(74) Wiig 2021(56)		Burns 2003(57) Eastwood 1998a(77) Eastwood 1998b(76) Englebrecht 2014(58) IPSOS 2016*(41) Matthews 2012(64) Maderia 2008(59) Maderia 2010(60) Moore 2017a(50) Moore 2017b*(51) Ocloo 2010(27) Pyo 2019(54)	Chiu 2010*(29) Gallagher 2009(33) Chapple 2012*(69) Saco 2018(80)	

*Contributes insight towards multiple stages of redress-reconciliation process; Green text=study from non-health field

Ten studies highlight how most people seeking redress-reconciliation following a serious life-changing event start the process deeply traumatised and are often experiencing great distress, encompassing strong emotions of shock, grief, anger and guilt.(32, 33, 36, 54, 57, 59, 64, 68, 80) Twenty-three studies (25 papers) indicate that professionals and their organisations representing justice systems do not always acknowledge, and at worst can compound, the trauma justice-seekers have already experienced:(22, 26, 27, 30, 32-35, 37, 41, 45, 47, 48, 50, 54, 57-60, 64, 65, 68, 74, 76, 77)

Oh it was quite traumatic all the way through, and the different things, but we just had to say put on our suit of armour and go and battle the next battle [Parent, experience of a birth injury, IPSOS MORI, 2016 p25](41)

The strain of pursuing the truth, of injustice, of character assassination without a right of reply, of callousness in the face of the trauma caused, has damaged our lives and it hurts and is impossible to forget [Participant, Ocloo et al., 2010 p513](27)

It (the inquest) took me straight back to the night she was found and it put me back I would say that far again you know I felt it really did take me back to square one [Family member – suicide inquest, Biddle et al., 2003 p1039](68)

I'm finding it hard to fit back in and get on with my life sometimes. Sometimes I feel like a failure because I couldn't go all the way, but I'm slowly getting on with things trying to fit in again. I let so much go while I was waiting to go to court that now it's too late to pick everything back up. I go to counselling once a week which is good I s'pose ... there's a lot of stress. . . but it still feels like I'm in that courtroom letting people judge and humiliate me. I s'pose life's like that [CSA survivor, Eastwood et al., 1998b p247](76)

We are drawing this [the review] out longer and longer and longer. And I have to be careful, I don't drown myself in this whole process...I shouldn't have to sacrifice my own health and wellbeing just to get answers [Participant, McQueen et al., 2020 p6](48)

Very upset and sad in fact from day one of our son dying there has been a lot of lies and cover up. We feel that we will never find the truth about how our son died or where all his personal effects are ... all we got back was a few clothes, shoes [Family of a man who died in prison, Shaw et al., 2007 p116](74)

These quotes illustrate how all-consuming the redress-reconciliation process can become for individuals who have experienced harm, and the distress this could cause. Ultimately, some people will still left with a profound sense of loss and lack of answers, with the harm they had experienced inhibiting their ability to continue with their daily lives.

Some of the specific features of the redress-reconciliation process that people found traumatising included difficulty in achieving a response from individuals or organisations they were seeking answers from,(32, 33) professionals minimizing or denying their experiences,(27, 34, 35, 45, 47, 48, 76) and/or making them feel guilty or ashamed,(22, 58, 68, 76) and needing to repeatedly recount traumatic events or witness to graphic witness:(41, 57, 76)

When [the police] kept interviewing me, and asking what happened ... that made me feel like a real arse, because ... I knew damn right... I'm like 'I didn't do anything, I know I didn't'. But that made me feel like crap, and it made me ... feel guilty and blame myself [Bereaved parent – loss of child, experiences of disclosure process, Butler et al., 2019 p43](22)

You look at this [letter] box every few weeks...every letter was traumatic to read. It may only be three or four pages on a letter but there's thousands of letters in there so it was a constant...reminder. You're just trying to cope with a new regime, even three, four years down

the line, and then you suddenly get a report that then goes back [to the birth [Parent, experience of a birth injury, IPSOS MORI, 2016 p25]](41)

Oh, it was the games that they played. When they were trying to get information out of me, I would get myself 'attorneyed up.' [The DA] had spread her [daughter] autopsy pictures all over his desk and was trying to shock me, I guess. I think...he figured that if he could shock me and show me the horrific pictures that they have of her, that somehow or another that I would tell him something that he needed to know... [Family member, Burns et al., 2006 p77]](57)

However, one study indicated that whilst learning about details of the life-changing event and recounting what had happened could be extremely distressing, it could lead to the desired outcomes:(37)

In a way, it was a horrible, horrible [disclosure] meeting that could have gone wrong at any time, but we got a very good outcome. The meeting went very well...As cruel as it was, they went through every step of the way [Bereaved family member, Iedema et al., 2012b p438]](37)

In this study, the family member appreciated the willingness of individuals to work with her to retrace what had happened, highlighting the need for professionals involved to accept responsibility (see [Subtheme 2.1: Shared rules](#)) and support justice-seekers through the investigatory process (see [Subtheme 3.2: Ongoing support](#)).

Overall, ten (11 papers) studies indicated that for some people, achieving 'closure' was not possible.(46, 50, 51, 57, 59, 60, 64, 65, 68, 76, 80) Reasons for this included it being impossible to undo the harm they had experienced,(50, 57, 60) being unable to obtain the answers they needed,(68) or, for bereaved individuals, the phrases was associated with ending their connection with their loved one:(65, 80)

It's not resolved, because I've lost a loved one [Family member, Moore et al., 2017a p1599]](50)

Uh, I don't like the word closure because, people have a tendency to suggest that people should get over it, period and there's a time frame they give 'er that's a grace period then it should all be gone it just don't happen. It all depends on the individual and how they deal with things, and for most people, nobody's ever totally over it they get better. That's all I know. And it's not over for any of us [Family member of homicide victim, Maderia et al., 2010 p1495]](60)

[It's] probably kind of like when you lose a parent. You spend a week going through everything, and you finally lower the casket, and it's ok. Maybe that kind of closure. It'll be a closed chapter. But, when I wake up everyday, it's there, and him being alive or dead isn't going to

change a lot of that. So, I don't believe in the word closure [Family member, Burns et al., 2006 p117](57)

Here the concept of 'closing a chapter' is introduced.(57, 60, 68). Six studies (seven papers) provided insight on how 'closing the chapter' following the life-changing event could be achieved during the redress-reconciliation process, with content that relates closely to some of the subthemes discussed earlier in this synthesis.(57-60, 65, 68, 80) Three studies highlighted the role receiving a comprehensive account (see *Subtheme 1.1* : An account) of the life-changing event in supporting justice-seekers to contextualise and understand their experiences:(59, 60, 65, 68)

It wasn't until I got the coronial inquest that the video in my head went away. I don't know if you believe that but anyway it was nearly like dad or someone was trying to tell me something is not right. You have to find what actually happened [Family member bereaved by work accident, Ngo et al., 2021 p456](65)

Two studies exploring individuals experiences of seeking the death penalty for offenders following homicide highlighted the need for a conclusive end, both in terms of receiving definite reassurance the harm could not occur again,(57, 59) but also the end of the redress-reconciliation process.(57, 59, 60) Two studies highlighted that whilst forgiveness may be possible,(57) this does not mitigate the desire for those responsible for harm to pay for their crime and for the punishment to reflect the severity this harm.(57, 58) However, achieving retribution (see *Subtheme 2.2*: Meaningful outcomes) is not always necessary for those who have been harmed in order to close the chapter on this part of their lives:(57)

The mistake is that everyone thinks that this is closure, but it's not what gets you closure. What gives you closure is yourself. You have to say, 'They're not going to control me anymore [Family member, Burns et al., 2006 p119](57)

About five years later [after the murder] I decided I am not going to let them tell me what to think every morning. It's one more day since it was overdue. 'I am not going to let them make my life miserable. I have two beautiful boys. They're growing up, and I'm being dumb by not participating because I don't feel good.' It's an excuse. Somewhere in there you have to stop living what they've done and live again [Family member, Burns et al., 2006 p120](57)

Through being involved in developing an account of how the life-changing event occurred, and how it has affected them, justice-seekers could potentially be supported to move from a position of overwhelmed/paralysed trauma (as described above) through to feeling that they can re-invest in their lives outside of the redress-reconciliation system, as illustrated by the quotes above.(36)

Details regarding the desire to receive an account of the life-changing events and what this account should consist of are explored in *Subtheme 1.1* : An account, as is the desire to learn from what has happened and prevent it from happening again (Subtheme 2.2: Meaningful outcomes) These subthemes emphasise the practical, action-orientated agenda of organisations seeking to prevent harm reoccurring, but potentially risk overlooking the emotional needs of those who have been harmed.(36) Below we consider how the emotional needs of individuals seeking justice can be supported within the redress-reconciliation pathway through the development of a shared account of what happened and meaningful action.

First, five studies (six papers) noted the need for a safe, appropriate space for meetings with justice-seekers.(52, 56, 68, 74, 76, 77) Here safe means both being physically comfortable and resourced with appropriate amenities,(68, 74, 76, 77) but also emotionally safe where people were protected from unwanted contact with those who had harmed them or the media and where they felt comfortable sharing their story:(52, 56, 68, 76)

I felt very comfortable with the two inspectors. It was a good atmosphere and we felt safe
[Participant – investigation of life-changing event, Wiig et al.,2021 p30](56)

Secondly, fifteen studies (16 papers) highlighted that the people who had been harmed were highly likely to value opportunities to have their say on the life-changing event itself, including factors which may have influenced it and the impact it has had on them and their concerns which have arisen from this:(33, 34, 36, 37, 39, 41, 48, 51, 52, 57, 58, 64, 65, 68, 74, 76)

I was being asked questions that I felt I could only answer no or yes to. I felt I couldn't explain. I mean my daughter had actually been dead for possibly three days before she was found and I was asked when did you last see your daughter or speak to her which had actually been on the Friday evening....You know like, Oh God! I am this bad mother, I hadn't seen my daughter I felt I was being judged as a mother that day. I have to admit I felt far more guilt after the inquest than I did possibly even when she died [Family member – suicide inquest, Biddle et al., 2003 p1037](68)

It's absolutely, fundamentally, about being heard and being able to look the health professionals in their eyes, tell your story, and for them to look you in the eyes, and actually register [Patient, Moore et al., 2017b p791](51)

The above quotes illustrate another component that supports the cathartic movement from trauma to 'closing the chapter. This is that, as well as being able to correct inaccurate recordings of events and have their own views incorporated into the final verdict, supporting justice-seekers to have their

say provides opportunities for professionals to listen. Seventeen studies (18 papers) highlighted how people seeking justice wanted the opportunity to feel listened to and/or feel heard.(26, 30, 32, 35, 38, 40, 45, 48-52, 56-58, 65, 68, 74)

[The patient liaison] was very good at...helping you feel like you were really heard [Patient, Moore et al., 2017a p1598](50)

I don't think any of us ever asked for much, but what we did ask for, we wanted to be heard, we wanted to be taken seriously...[Family member of homicide victim, Englebrecht et al., 2014 p417](58)

Being listened to does not always equate to feeling heard.(51) Three studies highlighted some key requirements to help professionals ensure people felt heard,(35, 38, 51) including the need for active listening,(35) use of open questions and dialogue led by patient priorities,(51) without making assumptions and a need for professionals to receive training on listening skills.(38)

Feeling heard can have a therapeutic value and may help people process their grief.(56) Twenty-two studies (23 papers) contained data which explored other cathartic elements within the redress-reconciliation process.(21, 22, 26, 27, 30, 34, 35, 37, 38, 40-42, 46, 48-52, 56, 58, 68, 74, 76) Four studies highlighted the importance of justice-seekers being able to express their emotions, or 'let off steam' and receive support to process them by professionals.(37, 40, 50, 52) Fifteen studies (16 papers) indicated that those who had been harmed sought some acknowledgment of the hurt they had experienced, both in terms of the initial life-changing event, but also the resulting impact on their lives:(22, 26, 30, 34, 35, 37, 38, 41, 42, 46, 48, 49, 51, 58, 68, 74)

I'm extremely hurt just because I'm still having complications. I'm going to get cut open again. ...Just the fact that he has no idea what I'm going through. And he's just moved on with his life and never called me. That really hurts. It really bothers me [Patient-experiences of disclosure, Duclos et al., 2005 p481](30)

Gutted, let down, disillusioned, conned, angry, bitter. Felt it had all been a waste of time. My daughter suffered tremendously and acknowledgement of this fact alone has not been accepted by anybody yet. Justice has not been done nor seen to have been done [Family of a woman who died in police custody, Shaw et al., 2007 p116](74)

What was really important was being able to tell them about what I had lost because of the injury. ...The treatment injury just destroys everything. My husband is afraid to touch me now in case he hurts me....It's not just the big things, but the little everyday things like cleaning your house.... I got to tell [the hospital staff] about that and they listened to it all and didn't say that

these things were little. It was that, not the compensation, that made me feel healed. It restored my trust in my doctor [Patient, Moore et al., 2017b p791](51)

The quotes above also illustrate two further important points. Firstly, that bereaved family members may seek acknowledgement of the hurt experienced both on their own account, but also on account of the person who died.(30)(Duclos) Secondly, that receiving recognition and validation of the impact the harm can help restore the trust in professionals following harm.(51)

Five additional studies highlighted the importance of receiving validation within the redress-reconciliation process.(21, 27, 34, 56, 76) Such validation encompasses validation of emotions, as illustrated above and also their status as victims.(21, 34, 76) Such acknowledgement and validation are important components of an apology and relevant at multiple stages during the redress-reconciliation process (see *Subtheme 2.2: Meaningful outcomes*).(46, 51)

Eight studies, primarily from the early stages of the redress-reconciliation process, discussed how bereaved family member often felt guilty following the life-changing event:(22, 29, 36, 40, 43, 55, 68, 69)

...when I only had to take care of my daughter and I didn't do that well enough because the end result was she died tragically so it changes your focus professionally [Bereaved parent, Hovey et al., 2014 p269](36)

Before March I blamed the hospital, I blamed myself, I blamed everybody. Like, the guilt was just so raw with me. My own guilt and the guilt that I'd let my son down, and the blame that I needed to pass on to the hospital, and all of that. Since the Open Disclosure I know for a fact that there has been measures put in place so that this doesn't happen again and I've also been in contact with legal since then. The Open Disclosure for me itself actually lifted a great weight off my shoulder. I didn't feel like it was about guilt any more. It was about acceptance. This happened which shouldn't have happened but it did and I have to accept that and move on [Family member – Open Disclosure process, ledema et al., 2007 p115](40)

Three studies indicated that by taking action, either through involvement in the open disclosure process,(40, 55) or suing the hospital,(29) helped alleviate the guilt they experienced. This may be because developing a shared account of what had happened alongside professionals helped reallocate the sense of blame from family members to the professionals involved, through the latter taking responsibility for the harm. Within the context of a mutually empathic relationship, where the professional and/or organisation has expressed remorse (see *Subtheme 2.2: Meaningful outcomes*),

justice-seekers may experience greater validation and thus less anger, potentially helping them reach a point of acceptance.

Alternatively, it may be that by involving justice seekers in purposeful action, for example through the process of developing a narrative and identifying learning points going forwards (see *Subtheme 2.2: Meaningful outcomes*) or pursuing justice for family members through seeking accountability from healthcare organisations,(29) may be therapeutic for those who have experienced harm. This is encapsulated by the concept of 'Therapeutic Action', which we interpret here to mean the acts taken by those who have been harmed to hold those they perceive to be responsible to account,(59, 60) and give meaning to their loss:(37, 74)

[P]robably the most difficult thing I ever did because I felt a tremendous responsibility to my friends, my co-workers, my community, to make sure that my testimony was a part of helping to prosecute those people [Participant, Maderia et al., 2010 p1499](60)

Deriving meaning from the loss could occur through receiving assurance that learning has occurred and the events which have led to the harm will not happen again (see *Subtheme 2.2: Meaningful outcomes*).(37) Two studies (three papers) also highlighted the need for those who had been harmed to witness accountability being taken, and/or justice being done:(57, 59, 60)

I've just been going nuts to see what can be done to move this guy along because I'm apparently the only one that's concerned about it. God, I just feel so helpless, not being able to do anything. Hell, I'm afraid I'm going to die before they execute him. I vowed that I would be here when they...Yet, we've had to go took him to the chamber to do it. It's just been a horrible existence the last ten years [Family member bereaved by homicide, Burns et al., 2006 p82](57)

[Y]ou want to represent your loved one. They can't be there. You want to be there for them [Bereaved family member, Maderia et al., 2010 p1499](60)

This subtheme summarises the emotional impact that having the opportunity to develop a co-produced, comprehensive account of the circumstances leading up to the life-changing event, the event itself and its impact can have on those seeking redress-reconciliation. Developing a shared narrative could provide those who have experienced harm the opportunity to integrate fractured information from multiple sources to construct a thorough understanding of what has happened to them or their loved ones and for this to be reflected in the public account of events. It also allows them to have their say and receive validation of the hurt they have experienced by those they perceive to be responsible for the harm. This validation, alongside being able to express their emotions, and

receive support to process these, can be very cathartic for those seeking justice. As a complement to this, individuals can also appreciate opportunities for involvement in the justice-seeking system, through pursuing accountability from individuals and/or organisations to identifying learning going forwards. This action can help give meaning to the harm they have experienced and provide an end point to the narrative documenting their experiences from prior to the life-changing event, through the justice-seeking process. We propose that it is the combination of a developing a cathartic narrative and opportunities to take therapeutic action which may help some individuals process their trauma and move through to a place of acceptance, and thus feel able to close this chapter of their lives.

Theme summary: Restorative justice

This theme highlights the importance of developing a mutually empathic relationship between those seeking justice and those perceived as being responsible for the harm, where patients and their families feel supported, respected and valued. This can create a space where they can integrate different fractured accounts of what has happened, the impact and how it has been resolved into one coherent narrative. The process of developing this narrative, telling it and it being heard can be cathartic, especially when accompanied by action which gives a meaning to the loss they have experienced. The relationship reduces the distance between the people who have been harmed and those responsible for the harm, reducing opportunities for misunderstandings or inaccuracies to go unresolved and hurt remaining unacknowledged, potentially reducing feelings of isolation, overwhelm and anger and increasing perceptions of fairness of the redress-resolution process and its outcomes.

Appendix A: Search strategies

Bibliographic databases

Database: MEDLINE

Host: Ovid

Issue: 1946 to February 17, 2022

Date Searched: 25/2/2022

Searcher: MR

Hits: 1293

Strategy:

- 1 Malpractice/
- 2 medical errors/
- 3 diagnostic errors/
- 4 missed diagnosis/
- 5 medication errors/
- 6 inappropriate prescribing/
- 7 medication reconciliation/
- 8 near miss, healthcare/
- 9 (medical adj1 (accident* or error* or injur*)).ti,ab.
- 10 (Incident or incidents).ti,ab.
- 11 negligen*.ti,ab.
- 12 adverse event*.ti,ab.
- 13 patient safety.ti,ab.
- 14 ((sudden or unexpected) adj2 (death* or mortalit*)).ti,ab.
- 15 (death* adj5 custody).ti,ab.
- 16 malpractice.ti,ab.
- 17 (homicide* or manslaughter).ti,ab.
- 18 suicide*.ti,ab.
- 19 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18
- 20 Patient Advocacy/
- 21 ((death or mortality) adj1 review*).ti,ab.
- 22 inquest*.ti,ab.
- 23 postmort?m*.ti,ab.
- 24 (medicolegal or medico legal).ti,ab.
- 25 incident investigation*.ti,ab.

26 complaint*.ti,ab.
27 litigation*.ti,ab.
28 (ombudsman or ombudsmen).ti,ab.
29 settlement*.ti,ab.
30 (malpractice adj2 claim).ti,ab.
31 mediation.ti,ab.
32 advocacy.ti,ab.
33 (accountable or accountability).ti,ab.
34 (legitimate or legitimacy).ti,ab.
35 (disclosure adj2 (policy or policies or process*)).ti,ab.
36 "child protection".ti,ab.
37 or/20-36
38 "Compensation and Redress"/
39 resolution.ti,ab.
40 reconciliation.ti,ab.
41 disclosure.ti,ab.
42 justice.ti,ab.
43 (accepting or acceptance or anger or distress* or distrust* or feelings or frustration or grief or
ignored or mistrust* or stress or stressful or traumati* or trust*).ti,ab.
44 bereav*.ti,ab.
45 fairness.ti,ab.
46 responsibility.ti,ab.
47 support.ti,ab.
48 (satisfaction or satisfied or dissatisfaction or dissatisfied).ti,ab.
49 apolog*.ti,ab.
50 closure.ti,ab.
51 or/38-50
52 qualitative research/
53 qualitative*.ti,ab.
54 (experience or experiences or perspective* or phenomenolog*).ti,ab.
55 interview*.ti,ab.
56 (survey* or "focus group*").ti,ab.
57 or/52-56

58 19 and 37 and 51 and 57

Database: HMIC

Host: Ovid

Issue: 1979 to January 2022

Date Searched: 25/2/2022

Searcher: MR

Hits: 103

Strategy:

1 Malpractice/ 277
2 exp professional incompetence/1761
3 medical accidents/ 191
4 adverse events/780
5 medical injury/ 28
6 medical negligence/ 650
7 negligence claims/ 222
8 (medical adj1 (accident* or error* or injur*)).tw. 371
9 (Incident or incidents).tw. 3242
10 negligen*.tw. 657
11 adverse event*.tw. 1212
12 patient safety.tw. 2412
13 ((sudden or unexpected) adj2 (death* or mortalit*)).tw. 356
14 (death* adj5 custody).tw. 12
15 malpractice.tw. 230
16 (homicide* or manslaughter).tw. 282
17 suicide*.tw. 1986
18 or/1-17 10721
19 Patient Advocacy/ 130
20 patient advocates/ 55
21 patient complaints procedures/ 256
22 national patient safety agency/ 113
23 independent complaints & advocacy services/ 11
24 local involvement networks/ 76
25 patient advice & liaison services/ 30
26 ((death or mortality) adj1 review*).tw. 36

27 inquest*.tw. 50
 28 postmort?m*.tw. 37
 29 (medicolegal or medico legal).tw. 198
 30 incident investigation*.tw. 29
 31 complaint*.tw. 2529
 32 litigation*.tw. 650
 33 (ombudsman or ombudsmen).tw. 308
 34 settlement*.tw.325
 35 (malpractice adj2 claim).tw. 5
 36 mediation.tw. 257
 37 advocacy.tw. 1410
 38 (accountable or accountability).tw. 3624
 39 (legitimate or legitimacy).tw. 658
 40 (disclosure adj2 (policy or policies or process*)).tw. 33
 41 "child protection".tw. 1274
 42 or/19-41 11126
 43 compensation/ 418
 44 claims settlements/ 14
 45 reparation/ 2
 46 resolution.ti,ab.818
 47 reconciliation.ti,ab. 115
 48 disclosure.ti,ab.791
 49 justice.ti,ab. 1819
 50 (accepting or acceptance or anger or distress* or distrust* or feelings or frustration or grief or
 ignored or mistrust* or stress or stressful or traumati* or trust*).tw. 29927
 51 bereav*.tw. 755
 52 fairness.ti,ab. 419
 53 responsibility.ti,ab. 5718
 54 support.ti,ab. 31081
 55 (satisfaction or satisfied or dissatisfaction or dissatisfied).tw. 8354
 56 apolog*.ti,ab. 63
 57 closure.ti,ab. 777
 58 or/43-57 70718

59 qualitative research/ 1318
60 qualitative*.ti,ab. 9450
61 (experience or experiences or perspective* or phenomenolog*).ti,ab. 32814
62 interview*.ti,ab. 19119
63 (survey* or "focus group*").tw. 31782
64 or/59-63 71368
65 18 and 42 and 58 and 64 103

Database: CINAHL

Host: EBSCO

Issue: n/a

Date Searched: 25/2/2022

Searcher: MR

Hits: 827

Strategy:

S55 S17 AND S35 AND S48 AND S54

S54 S49 OR S50 OR S51 OR S52 OR S53

S53 TI (survey* or "focus group*") OR AB (survey* or "focus group*")

S52 TI interview* OR AB interview*

S51 TI (experience or experiences or perspective* or phenomenolog*) OR AB (experience or experiences or perspective* or phenomenolog*)

S50 TI qualitative* OR AB qualitative*

S49 (MM "Qualitative Studies+")

S48 S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47

S47 TI closure OR AB closure

S46 TI apolog* OR AB apolog*

S45 TI (satisfaction or satisfied or dissatisfaction or dissatisfied) OR AB (satisfaction or satisfied or dissatisfaction or dissatisfied)

S44 TI support OR AB support

- S43 TI responsibility OR AB responsibility
- S42 TI fairness OR AB fairness
- S41 TI bereav* OR AB bereav*
- S40 TI (accepting or acceptance or anger or distress* or distrust* or feelings or frustration or grief or ignored or mistrust* or stress or stressful or traumati* or trust*) OR AB (accepting or acceptance or anger or distress* or distrust* or feelings or frustration or grief or ignored or mistrust* or stress or stressful or traumati* or trust*)
- S39 TI justice OR AB justice
- S38 TI disclosure OR AB disclosure
- S37 TI reconciliation OR AB reconciliation
- S36 TI resolution OR AB resolution
- S35 S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34
- S34 TI "child protection" OR AB "child protection"
- S33 TI (disclosure N2 (policy or policies or process*)) OR AB (disclosure N2 (policy or policies or process*))
- S32 TI (legitimate or legitimacy) OR AB (legitimate or legitimacy)
- S31 TI (accountable or accountability) OR AB (accountable or accountability)
- S30 TI advocacy OR AB advocacy
- S29 TI mediation OR AB mediation
- S28 TI malpractice N2 claim OR AB malpractice N2 claim
- S27 TI settlement* OR AB settlement*
- S26 TI (ombudsman or ombudsmen) OR AB (ombudsman or ombudsmen)
- S25 TI litigation* OR AB litigation*

S24 TI complaint* OR AB complaint*

S23 TI incident investigation* OR AB incident investigation*

S22 TI (medicolegal or medico legal) OR AB (medicolegal or medico legal)

S21 TI postmort?m* OR AB postmort?m*

S20 TI inquest* OR AB inquest*

S19 TI ((death or mortality) N1 review*) OR AB ((death or mortality) N1 review*)

S18 (MM "Patient Advocacy")

S17 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16

S16 TI suicide OR AB suicide

S15 TI (homicide* or manslaughter) OR AB (homicide* or manslaughter)

S14 TI malpractice OR AB malpractice

S13 TI death* N5 custody OR AB death* N5 custody

S12 TI death* adj5 custody OR AB death* adj5 custody

S11 TI ((sudden or unexpected) N2 (death* or mortalit*)) OR AB ((sudden or unexpected) N2 (death* or mortalit*))

S10 TI patient safety OR AB patient safety

S9 TI adverse event* OR AB adverse event*

S8 TI negligen* OR AB negligen*

S7 TI (incident or incidents) OR AB (incident or incidents)

S6 TI ((medical N1 (accident* or error* or injur*)) OR AB ((medical N1 (accident* or error* or injur*))

S5 (MM "Medication Reconciliation")

S4 (MM "Treatment Errors")

S3 (MH "Diagnostic Errors+")

S2 (MH "Medication Errors+")

S1 (MM "Malpractice")

Database: ASSIA

Host: ProQuest

Issue: n/a

Date Searched: 25/2/2022

Searcher: MR

Hits: 262

Strategy:

((MESH.EXACT(Malpractice)) OR (MESH.EXACT("medical errors")) OR (MESH.EXACT("diagnostic errors")) OR (MESH.EXACT("missed diagnosis")) OR (MESH.EXACT("medication errors")) OR (MESH.EXACT("inappropriate prescribing")) OR (MESH.EXACT("medication reconciliation")) OR (MESH.EXACT("near miss, healthcare")) OR ((TI,AB(medical) NEAR/1 (TI,AB(accident*) OR TI,AB(error*) OR TI,AB(injur*)))) OR ((TI,AB(Incident) OR TI,AB(incidents))) OR (TI,AB(negligen*)) OR (TI,AB(("adverse event" OR "adverse events"))) OR (TI,AB("patient safety")) OR (((TI,AB(sudden) OR TI,AB(unexpected)) NEAR/2 (TI,AB(death*) OR TI,AB(mortalit*)))) OR ((TI,AB(death*) NEAR/5 TI,AB(custody))) OR (TI,AB(malpractice)) OR ((TI,AB(homicide*) OR TI,AB(manslaughter))) OR (TI,AB(suicide*))) AND ((MESH.EXACT("Patient Advocacy")) OR (((TI,AB(death) OR TI,AB(mortality)) NEAR/1 TI,AB(review*))) OR (TI,AB(inquest*)) OR (TI,AB(postmort?m*)) OR ((TI,AB(medicolegal) OR TI,AB("medico legal"))) OR (TI,AB(("incident investigation" OR "incident investigations"))) OR (TI,AB(complaint*)) OR (TI,AB(litigation*)) OR ((TI,AB(ombudsman) OR TI,AB(ombudsmen))) OR (TI,AB(settlement*)) OR ((TI,AB(malpractice) NEAR/2 TI,AB(claim))) OR (TI,AB(mediation)) OR (TI,AB(advocacy)) OR ((TI,AB(accountable) OR TI,AB(accountability))) OR ((TI,AB(legitimate) OR TI,AB(legitimacy))) OR ((TI,AB(disclosure) NEAR/2 (TI,AB(policy) OR TI,AB(policies) OR TI,AB(process*)))) OR (TI,AB("child protection"))) AND ((MESH.EXACT("Compensation and Redress")) OR (TI,AB(resolution)) OR (TI,AB(reconciliation)) OR (TI,AB(disclosure)) OR (TI,AB(justice)) OR ((TI,AB(accepting) OR TI,AB(acceptance) OR TI,AB(anger) OR TI,AB(distress*) OR TI,AB(distrust*) OR TI,AB(feelings) OR TI,AB(frustration) OR TI,AB(grief) OR TI,AB(ignored) OR TI,AB(mistrust*) OR TI,AB(stress) OR TI,AB(stressful) OR TI,AB(traumati*) OR TI,AB(trust*))) OR (TI,AB(bereav*)) OR (TI,AB(fairness)) OR (TI,AB(responsibility)) OR (TI,AB(support)) OR ((TI,AB(satisfaction) OR TI,AB(satisfied) OR TI,AB(dissatisfaction) OR TI,AB(dissatisfied))) OR (TI,AB(apolog*)) OR (TI,AB(closure))) AND ((MESH.EXACT("qualitative research")) OR (TI,AB(qualitative*)) OR ((TI,AB(experience) OR TI,AB(experiences) OR TI,AB(perspective*) OR TI,AB(phenomenolog*))) OR (TI,AB(interview*)) OR ((TI,AB(survey*) OR TI,AB(("focus group" OR "focus groups"))))))

Database: IBSS

Host: ProQuest

Issue: n/a

Date Searched: 25/2/2022

Searcher: MR

Hits: 364

Strategy:

(mainsubject.Exact("patient advocacy") OR TI,AB(inquest* OR postmortem OR "death review" OR "mortality review" OR investigation OR complaint* OR litigation OR ombudsman OR ombudsmen OR settlement* OR (malpractice NEAR/2 claim) OR mediation OR advocacy OR accountability OR accountable OR legitimate OR legitimacy OR (disclosure NEAR/2 polic*) OR "child protection"))

AND

(mainsubject.Exact("medical malpractice")) OR ((TI,AB(medical)) NEAR/1 (TI,AB(incident*)) OR (TI,AB(error*)) OR (TI,AB(injur*)) OR (TI,AB(Incident)) OR (TI,AB(incidents)) OR (TI,AB(negligen*)) OR (TI,AB(("adverse event" OR "adverse events"))) OR (TI,AB("patient safety")) OR (TI,AB(sudden)) OR (TI,AB(unexpected)) NEAR/2 (TI,AB(death*)) OR (TI,AB(mortalit*)) OR (TI,AB(death*)) NEAR/5 (TI,AB(custody)) OR (TI,AB(malpractice)) OR ((TI,AB(homicide*) OR TI,AB(manslaughter)) OR (TI,AB(suicide*)))

AND

(mainsubject.Exact("compensation & redress") OR mainsubject.Exact("settlements & damages") OR TI,AB(resolution OR reconciliation OR disclosure OR justice OR accepting OR acceptance OR anger OR distress* OR distrust* OR feelings OR frustration OR grief OR ignored OR mistrust* OR stress OR stressful OR traumati* OR trust* OR bereav* OR fairness OR responsibility OR support OR satisfaction OR satisfied OR dissatisfaction OR dissatisfied OR apolog* OR closure))

AND

mainsubject.Exact("qualitative research") OR TI,AB(qualitative* OR experience OR experiences OR perspective* OR phenomenolog* OR interview* OR survey* OR "focus group*")

Database: Social Science Citation Index

Host: Web of Science, Clarivate Analytics

Issue: n/a

Date Searched: 25/2/2022

Searcher: MR

Hits: 1531

Strategy:

1. TS=(qualitative* OR experience OR experiences OR perspective* OR phenomenolog* OR interview* OR survey* OR "focus group*")
2. TS=("Compensation and Redress" OR resolution OR reconciliation OR disclosure OR justice OR accepting OR acceptance OR anger OR distress* OR distrust* OR feelings OR frustration OR grief OR ignored OR mistrust* OR stress OR stressful OR traumati* OR trust* OR bereav* OR fairness OR responsibility OR support OR satisfaction OR satisfied OR dissatisfaction OR dissatisfied OR apolog* OR closure)
3. TS=("Patient Advocacy" OR ((death OR mortality) NEAR/1 review*) OR inquest* OR postmortem* OR medicolegal OR "medico legal" OR "incident investigation*" OR complaint* OR litigation* OR ombudsman OR ombudsmen OR settlement* OR (malpractice NEAR/2 claim) OR mediation OR advocacy OR accountable OR accountability OR legitimate OR legitimacy OR (disclosure NEAR/2 (policy OR policies OR process*)) OR "child protection")

4. TS=((Malpractice) OR ("medical errors") OR ("diagnostic errors") OR ("missed diagnosis") OR ("medication errors") OR ("inappropriate prescribing") OR ("medication reconciliation") OR ("near miss, healthcare") OR ((medical NEAR/1 (accident* OR error* OR injur*))) OR ((Incident OR incidents)) OR (negligen*) OR ("adverse event*") OR ("patient safety") OR (((sudden OR unexpected) NEAR/2 (death* OR mortalit*))) OR ((death* NEAR/5 custody)) OR (malpractice) OR ((homicide* OR manslaughter)) OR (suicide*)
5. #1 AND #2 AND #3 AND #4

Table 21: Bibliographic database search results

Database	Number of results
Ovid MEDLINE(R) ALL	1293
ASSIA via ProQuest	262
CINAHL via EBSCOhost	827
HMIC Health Management Information Consortium	103
SSCI	1531
IBSS via ProQuest	334
TOTAL	4350
DUPLICATES	1572
UNIQUE	2278

Follow up bibliographic database searches

Inquests

Database: MEDLINE

Host: Ovid

Date Searched: 27th April

Searcher: SB

Hits: 390

Strategy:

1. (coroner* or coronial or "public inquir*").tw.
2. *"Coroners and Medical Examiners"/
3. 1 or 2
4. qualitative research/
5. qualitative*.tw
6. (experience or experiences).tw.
7. interview*.tw.
8. or/4-7
9. 3 and 8

Notes: Combined with NOT with results of initial bibliographic database searches (above)

Negligence

Database: MEDLINE

Host: Ovid

Date Searched: 27th April

Searcher: SB

Hits: 318

Strategy:

1. (negligen* or malpractice).tw.

2. *malpractice/
3. 1 or 2
4. "Compensation and Redress"/
5. resolution.tw
6. reconciliation.tw
7. disclosure.tw
8. justice.tw
9. bereav*.tw.
10. fairness.tw
11. support.tw
12. (satisfaction or satisfied or dissatisfaction or dissatisfied).tw.
13. apolog*.tw
14. closure.tw.
15. qualitative research/
16. qualitative*.ti,ab.
17. (experience or experiences).ti,ab.
18. interview*.ti,ab.
19. or/4-18
20. qualitative research/
21. qualitative*.tw
22. (experience or experiences).tw.
23. interview*.tw.
24. or/20-23
25. 3 and 19 and 24

Notes: Combined with NOT with results of initial bibliographic database searches (above)

Web searches

Google Scholar

Search engine: Google Scholar

URL: <https://scholar.google.com/>

Date Searched: 24/03/2022

Searcher: LS

Search strategies:

"serious adverse event" (redress OR reconciliation OR justice) qualitative

200 screened
(sorted by
relevance)

Search engine: Google Scholar

URL: <https://scholar.google.com/>

Date Searched: 24-25/03/2022

Searcher: LS

Search strategies:

"medical malpractice" (redress OR reconciliation OR justice) qualitative

700 screened
(sorted by
relevance)

Websites

Website: The Health Foundation

URL: <https://health.org.uk/>

Date Searched: 25/3/2022

Searcher: SB

Search terms:

Adverse events (14 hits)

Litigation (10 hits)

Malpractice (0 hits)

Pages browsed:

Scanned 200 results ordered by relevance in Patient safety section of website (n=387)

<https://health.org.uk/search/topic/156?textsearch=>

Website: Inquest

URL: <https://www.inquest.org.uk/>

Date Searched: 25/3/2022

Searcher: SB

Pages browsed:

Reports and publications: <https://www.inquest.org.uk/Pages/Category/books-and-publications>

Website: Making Families Count

URL: <https://www.makingfamiliescount.org.uk/>

Date Searched:

Searcher: SB

Pages browsed: explored website using menu headings

Website: National Voices

URL: <https://www.nationalvoices.org.uk/>

Date Searched: 25/3/2022

Searcher: SB

<https://www.nationalvoices.org.uk/publications/our-publications>

Search terms:

patient safety (3 hits)

adverse event (0 hits)

malpractice (0 hits)

Pages browsed:

Publications: evidence papers: <https://www.nationalvoices.org.uk/publications/our-publications?combine=&tid=101>

Publications: discussion papers and reports:

<https://www.nationalvoices.org.uk/publications/our-publications?combine=&tid=103>

Website: Patient Safety Movement Foundation
URL: <https://patientsafetymovement.org/>
Date Searched:
Searcher: SB
Pages browsed: explored website using menu headings

Website: Healthcare Safety Investigation Branch
URL: <https://www.hsib.org.uk/>
Date Searched:
Searcher: SB
Pages browsed:

Investigations and reports: <https://www.hsib.org.uk/investigations-and-reports/>

Website: HeinOnline Law Journal Library
URL: <https://home.heinonline.org/content/law-journal-library/>
Date Searched: 27/4/2022
Searcher: SB
<https://www.nationalvoices.org.uk/publications/our-publications>

Search terms:

Article title: bereav* OR fairness OR apolog* OR closure OR disclosure OR redress* OR compensation
OR reconciliation

Subject: restorative justice

Appendix B: Stages of framework synthesis

Key for interpreting tables

Yellow highlighted cell: Additional themes/Changes made in the placement of theme from the previous version

Table 22: Best-fit framework - version 1

V1: Themes Based on Daniels and Sabin	Theme 1: Transparency /Publicity condition	Theme 2: Relevance condition	Theme 3: Legitimacy of process	Theme 4: Opportunity to appeal rationale	Theme 5: Enforcement condition	Theme 6: Other
Subthemes	That an error has occurred: disclosure of relevant information (allow individuals to make choice regarding care/ clinicians/ treatment)	Shared "rules of the game": an agreed process for achieving justices. An agreed goal/outcome to be achieved and consideration of relevant points to all parties	Informed choice of options available	Mechanism for challenge and dispute resolution regarding limit-setting decisions, opportunity for revising decisions in light of further evidence or arguments	Voluntary or public regulation of justice seeking process	First/second order construct data which appears relevant to research question but does not fit in current version of framework
	Information required publicly available	Does outcome/plan match needs of justice seekers?	Ongoing support for justice seekers (health and legal)			
	Consideration of things which could constrain decision making: Government policy, institutional rules	Explicit plan: What is going to happen as a result of outcome	Who is accountable?			
	Of rationales for decisions made during justice seeking process: What decision was reached, how, why?	Use of a reasonable and consistent process to determine justice?				

Table 23: Best-fit framework - version 2

V.2 Addition of descriptive codes. First changes made regarding placement of content within and across themes/ subthemes	Theme 1: Transparency /Publicity condition	Theme 2: Relevance condition	Theme 3: Legitimacy of process	Theme 4: Opportunity to appeal rationale	Theme 5: Enforcement condition	Theme 6: Other
Subthemes	02 Information required publicly available	05 Shared rules of the game- an agreed process for achieving justices. An agreed goal, outcome to be achieved and consideration of relevant points to all parties	08 Use of a reasonable and consistent process to determine justice	12 Mechanism for challenge and dispute resolution regarding limit-setting decisions, opportunity for revising decisions in light of further evidence or arguments	13 Voluntary or public regulation of justice seeking process	First/second order construct data which appears relevant to research question but does not fit in current version of framework
	03 Consideration of things which could constrain decision making - Government policy, institutional rules	06 Does outcome, plan match needs of justice seekers	09 Informed choice of options available			
	04 Of rationales for decisions made during justice seeking process - What decision was reached, how, why	07 Explicit plan - What is going to happen as a result of outcome	10 Ongoing support for justice seekers (health and legal)			
			11 Who is accountable			

Yellow highlight – change to framework since previous version

Table 24: Best-fit framework - version 3

<p>V.3 Further iterative coding of information to descriptive codes. Changes in position and names of subthemes to reflect content. Creation of final theme “Restorative Justice</p>	<p>001 Need for Transparency</p>	<p>002 Relevance of process to justice seeker</p>	<p>003 Trustworthy</p>	<p>004 Restorative Justice</p>
<p>Subthemes</p>	<p>01 An account</p>	<p>05 Shared rules: an agreed process for achieving justices. An agreed goal, outcome to be achieved and consideration of relevant points to all parties</p>	<p>07 Use of a reasonable and consistent process to determine justice</p>	<p>12 Humanising process</p>
	<p>02 Information required publicly available</p>	<p>06 Does outcome match needs of justice seekers</p>	<p>08 Informed choice of options available</p>	<p>13 Closing a chapter (encompasses cathartic narrative and meaningful action)</p>
	<p>03 Consideration of things which could influence justice seeking process</p>		<p>09 Ongoing support for justice seekers (health and legal)</p>	
	<p>04 Of rationales for decisions made during justice seeking process - What decision was reached, how, why</p>		<p>10 Mechanism for challenge and dispute resolution regarding limit-setting decisions, opportunity for revising decisions in light of further evidence or arguments</p>	
			<p>11 Objective input</p>	

Yellow highlight – change to framework since previous version

Appendix C: List of excluded studies

Reference	Reason for exclusion at FT
1 Adams M, Iedema R, Heazell AE, Treadwell M, Booker M, Bevan C, et al. Investigation of the critical factors required to improve the disclosure and discussion of harm with affected women and families: a study protocol for a qualitative, realist study in NHS maternity services (the DISCERN study). <i>Bmj Open</i> 2022;12. https://doi.org/10.1136/bmjopen-2020-048285	Study design
2 Aldrich R. Invisible injuries: patient harms we hear about when we take the time to ask. <i>Medical Journal of Australia</i> 2018;208:293-+. https://doi.org/10.5694/mja17.00822	Study design
3 Amagwula T, Chang PL, Hossain A, Tyner J, Rivers AL, Phelps JY. Preimplantation genetic diagnosis: a systematic review of litigation in the face of new technology. <i>Fertility and sterility</i> 2012;98:1277-82.	Phenomenon of interest
4 Anindito T, Gunarto G, Hafidz J. RECONSTRUCTION OF LEGAL DISPUTES MEDIATION IN HEALTH CARE FOR PATIENTS HOSPITAL BASED ON THE VALUE OF JUSTICE. The 2nd Proceeding "Indonesia Clean of Corruption in 2020" 2020.	Not high income
5 Arnott J, Hesselgreaves H, Nunn AJ, Peak M, Pirmohamed M, Smyth RL, et al. Enhancing Communication about Paediatric Medicines: Lessons from a Qualitative Study of Parents' Experiences of Their Child's Suspected Adverse Drug Reaction. <i>Plos One</i> 2012;7. https://doi.org/10.1371/journal.pone.0046022	Phenomenon of interest
6 Bakhbakhi D, Burden C, Storey C, Heazell AE, Lynch M, Timlin L, et al. PARENTS 2 Study: a qualitative study of the views of healthcare professionals and stakeholders on parental engagement in the perinatal mortality review from "bottom of the pile" to joint learning. <i>Bmj Open</i> 2018;8:9. https://doi.org/10.1136/bmjopen-2018-023792	Population
7 Beardwood BA, French SE. Mediating complaints against nurses: a consumer-oriented educational approach. <i>The Canadian journal of nursing research = Revue canadienne de recherche en sciences infirmieres</i> 2004;36:122-41.	Phenomenon of interest
8 Bekkering HJ, Woodgate RL. The Parental Experience of Unexpectedly Losing a Child in the Pediatric Emergency Department. <i>Omega-Journal of Death and Dying</i> 2021;84:28-50. https://doi.org/10.1177/0030222819876477	Phenomenon of interest
9 Bohn D, Chiasson D, Huyer D. Investigations After Death in Children. <i>Pediatric critical care medicine : a journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies</i> 2018;19:S69-S71.	Study design
10 Bouwman R, Bomhoff M, Robben P, Friele R. Patients' perspectives on the role of their complaints in the regulatory process. <i>Health Expectations</i> 2016;19:483-96. https://doi.org/10.1111/hex.12373	Study design
11 Brown SD, Lehman CD, Truog RD, Browning DM, Gallagher TH. Stepping Out Further from the Shadows: Disclosure of Harmful Radiologic Errors to Patients. <i>Radiology</i> 2012;262:381-6. https://doi.org/10.1148/radiol.11110829	Study design
12 Burden C, Bakhbakhi D, Heazell AE, Lynch M, Timlin L, Bevan C, et al. Parents' Active Role and ENGagement in The review of their Stillbirth/perinatal death 2 (PARENTS 2) study: a mixed-methods study of implementation. <i>BMJ open</i> 2021;11:e044563.	Phenomenon of interest
13 Carr S, Hafford-Letchfield T, Faulkner A, Megele C, Gould D, Khisa C, et al. "Keeping Control": A user-led exploratory study of mental health service user experiences of targeted violence and abuse in the context of adult safeguarding in England. <i>Health & social care in the community</i> 2019;27:e781-e92.	Phenomenon of interest
14 Carter DJ, Brown J, Saunders C. The Patient's Voice: Australian Health Care Quality and Safety Regulation from the Perspective of the Public. <i>Journal of Law and Medicine</i> 2018;25:408-28.	Study design
15 Chervenak JL, Chervenak FA, McCullough LB. A new approach to professional liability reform: placing obligations of stakeholders ahead of their interests. <i>American Journal of Obstetrics and Gynecology</i> 2010;203. https://doi.org/10.1016/j.ajog.2010.03.012	Study design
16 Cline RE, Pepine CJ. Medical malpractice crisis: Florida's recent experience. <i>Circulation</i> 2004;109:2936-8.	Study design

17	Cooper J. Ethical issues and their practical application in a psychological autopsy study of suicide. <i>Journal of clinical nursing</i> 1999;8:467-75.	Phenomenon of interest
18	Dezhi W. On the Law and Trust in Doctor-Patient Disputes: HeinOnline; 2015.	Study design
19	Doherty C, Saunders MNK. Elective surgical patients' narratives of hospitalization: The co-construction of safety. <i>Social Science & Medicine</i> 2013;98:29-36. https://doi.org/10.1016/j.socscimed.2013.08.014	Phenomenon of interest
20	Elder NC, Jacobson CJ, Zink T, Hasse L. How experiencing preventable medical problems changed patients' interactions with primary health care. <i>Annals of Family Medicine</i> 2005;3:537-44. https://doi.org/10.1370/afm.346	Phenomenon of interest
21	Finkel SI, Rosman M. Six elderly suicides in a 1-year period in a rural midwestern community. <i>International psychogeriatrics</i> 1995;7:221-30.	Study design
22	Fisher KA, Mazor KM. Patient and Family Complaints in Cancer Care: What Can We Learn From the Tip of the Iceberg? <i>Joint Commission Journal on Quality and Patient Safety</i> 2017;43:495-7. https://doi.org/10.1016/j.jcjq.2017.07.003	Study design
23	Fleming P, Pease A, Ingram J, Sidebotham P, Cohen MC, Coombs RC, et al. Quality of investigations into unexpected deaths of infants and young children in England after implementation of national child death review procedures in 2008: a retrospective assessment. <i>Archives of disease in childhood</i> 2020;105:270-5.	Study design
24	Garstang J, Griffiths F, Sidebotham P. What do bereaved parents want from professionals after the sudden death of their child: a systematic review of the literature. <i>BMC pediatrics</i> 2014;14:269.	Study design
25	Garstang J, Griffiths F, Sidebotham P. Rigour and Rapport: a qualitative study of parents' and professionals' experiences of joint agency infant death investigation. <i>BMC pediatrics</i> 2017;17:48.	Phenomenon of interest
26	Gaufberg E, Olmsted MW, Bell SK. Third Things as Inspiration and Artifact: A Multi-Stakeholder Qualitative Approach to Understand Patient and Family Emotions after Harmful Events. <i>Journal of Medical Humanities</i> 2019;40:489-504. https://doi.org/10.1007/s10912-019-09563-z	Phenomenon of interest
27	Giardina TD, Haskell H, Menon S, Hallisy J, Southwick FS, Sarkar U, et al. Learning From Patients' Experiences Related To Diagnostic Errors Is Essential For Progress In Patient Safety. <i>Health Affairs</i> 2018;37:1821-7. https://doi.org/10.1377/hlthaff.2018.0698	Phenomenon of interest
28	Greene E. "Can we talk?" Therapeutic jurisprudence, restorative justice, and tort litigation. <i>Conference on Civil Juries and Civil Justice</i> ; May 15-18; Univ Nebraska Lincoln, Lincoln, NE, abstract no. 44, p. 233-56.	Study design
29	Hammervold UE, Norvoll R, Sagvaag H. Post-incident reviews after restraints-Potential and pitfalls. Patients' experiences and considerations. <i>Journal of Psychiatric and Mental Health Nursing</i> ; 10.1111/jpm.12776:12. https://doi.org/10.1111/jpm.12776	Phenomenon of interest
30	Harper S, Smith JR. The Art of Skillful Disclosure. <i>Journal of Perinatal & Neonatal Nursing</i> 2018;32:12-4. https://doi.org/10.1097/jpn.0000000000000313	Study design
31	Harrison M, Darlison L, Gardiner C. Understanding the Experiences of end of Life Care for Patients with Mesothelioma from the Perspective of Bereaved Family Caregivers in the UK: A Qualitative Analysis. <i>Journal of Palliative Care</i> 2022;8258597221079235.	Phenomenon of interest
32	Helmchen LA, Richards MR, McDonald TB. Successful remediation of patient safety incidents: A tale of two medication errors. <i>Health Care Management Review</i> 2011;36:114-23. https://doi.org/10.1097/HMR.0b013e318200f916	Study design
33	Hickson GB, Clayton EW, Githens PB, Sloan FA. FACTORS THAT PROMPTED FAMILIES TO FILE MEDICAL MALPRACTICE CLAIMS FOLLOWING PERINATAL INJURIES. <i>Jama-Journal of the American Medical Association</i> 1992;267:1359-63. https://doi.org/10.1001/jama.267.10.1359	Study design
34	Inquest. Deaths in mental health detention: an investigation framework fit for purpose?: Inquest charitable trust; n.d.	Study design
35	Jayasuriya V. Utility of qualitative methods in a clinical setting: perinatal care in the Western Province. <i>Ceylon Medical Journal</i> 2012;57:10-3.	Population
36	Kachalia AB, Mello MM, Brennan TA, Studdert DM. Beyond negligence: avoidability and medical injury compensation. <i>Social Science & Medicine</i> 2008;66:387-402.	Study design

37	Kennedy M, Gill M. Patient litigation following a homicide-implications for the assessment and management of risk. <i>International Review of Psychiatry</i> 1997;9:179-86.	Study design
38	Koller D, Binder MJ, Alexander S, Darch J. "Everybody Makes Mistakes": Children's Views on Medical Errors and Disclosure. <i>Journal of pediatric nursing</i> 2019;49:1-9. https://doi.org/https://dx.doi.org/10.1016/j.pedn.2019.07.014	Study design
39	Laganá K. The "Right" to a Caring Relationship: The Law and Ethic of Care. <i>The Journal of Perinatal & Neonatal Nursing</i> 2000;14.	Study design
40	Lande KE, Boone G. Medicolegal experiences under the Ohio coroner's system. <i>Journal of the American Medical Association</i> 1953;153:179-82.	Study design
41	Langer T, Martinez W, Bell SK, Lee BS, Varrin P, Browning DM. Patients and families as teachers: a mixed methods assessment of a collaborative learning model for medical error disclosure and prevention. <i>BMJ Quality and Safety</i> 2016;25:615-25.	Phenomenon of interest
42	Langlois NE, Smith K. Follow-up calls to next of kin relating to coronial autopsies. <i>Medicine, science, and the law</i> 2016;56:242-3. https://doi.org/https://dx.doi.org/10.1177/0025802415596360	Study design
43	Liebling HJ, Barrett HR, Artz L. Sexual and gender-based violence and torture experiences of Sudanese refugees in Northern Uganda: health and justice responses. <i>International Journal of Migration, Health & Social Care</i> 2020;16:389-414. https://doi.org/10.1108/IJMHS-10-2019-0081	Not high income
44	Liebman C. Medical Malpractice Mediation: Benefits Gained, Opportunities Lost. <i>Law & Contemp Probs</i> 2011;74.	Study design
45	Mackie R. The Implementation of Coronial Recommendations in Tasmania: Two Case Studies on Child Deaths. <i>Journal of law and medicine</i> 2018;25:503-14.	Study design
46	Mackintosh N, Rance S, Carter W, Sandall J. Working for patient safety: a qualitative study of women's help-seeking during acute perinatal events. <i>Bmc Pregnancy and Childbirth</i> 2017;17. https://doi.org/10.1186/s12884-017-1401-x	Phenomenon of interest
47	Macnab AJ, Northway T, Ryall K, Scott D, Straw G. Death and bereavement in a paediatric intensive care unit: Parental perceptions of staff support. <i>Paediatrics & child health</i> 2003;8:357-62.	Phenomenon of interest
48	Maguire EM, Bokhour BG, Wagner TH, Asch SM, Gifford AL, Gallagher TH, et al. Evaluating the implementation of a national disclosure policy for large-scale adverse events in an integrated health care system: identification of gaps and successes. <i>BMC health services research</i> 2016;16:648.	Phenomenon of interest
49	McLeod LA. Patient transitions from inpatient to outpatient: where are the risks? Can we address them? <i>Journal of Healthcare Risk Management</i> 2013;32:13-9.	Study design
50	Mello MM, Boothman RC, McDonald T, Driver J, Lembitz A, Bouwmeester D, et al. Communication-and-resolution programs: the challenges and lessons learned from six early adopters. <i>Health Aff (Millwood)</i> 2014;33:20-9. https://doi.org/10.1377/hlthaff.2013.0828	Population
51	Moore JS, Mello MM, Bismark M. 'Poking the skunk': Ethical and medico-legal concerns in research about patients' experiences of medical injury. <i>Bioethics</i> 2019;33:948-57. https://doi.org/10.1111/bioe.12599	Study design
52	Murtagh L, Gallagher TH, Andrew P, Mello MM. Disclosure-and-resolution programs that include generous compensation offers may prompt a complex patient response. <i>Health affairs (Project Hope)</i> 2012;31:2681-9. https://doi.org/https://dx.doi.org/10.1377/hlthaff.2012.0185	Study design
53	Navarra MB, Dentzer S, Pinakiewicz D, Sheridan S, Leape L, Lawrence D, et al. NPSF Roundtable: a 360-degree perspective on patient safety. <i>Journal of Patient Safety</i> 2006;2:179-82.	Study design
54	Ock M, Kim HJ, Jo MW, Lee SI. Perceptions of the general public and physicians regarding open disclosure in Korea: a qualitative study. <i>Bmc Medical Ethics</i> 2016;17. https://doi.org/10.1186/s12910-016-0134-0	Population
55	Ozcarar N, Yesiltepe G, Karaman G, Ergonen AT. Domestic violence survivors and their experiences during legal process. <i>Journal of forensic and legal medicine</i> 2016;40:1-7.	Phenomenon of interest

56	Palmer RN. Challenges to the implementation of the new Coroners (Amendment) Rules 2005: experience from a tertiary paediatric pathology centre. <i>Medicine, science, and the law</i> 2008;48:269-70.	Study design
57	Patterson HC. The medical examiner system--experience in Orange county. <i>North Carolina medical journal</i> 1966;27:132-4.	Study design
58	Priyambodo A. LAW ENFORCEMENT IN THE SETTLEMENT OF HEALTH DISPUTES THROUGH MEDIATION EFFORTS. <i>Awang Long Law Review</i> 2021;3.	Not high income
59	Raberus A, Holmstrom IK, Galvin K, Sundler AJ. The nature of patient complaints: a resource for healthcare improvements. <i>International journal for quality in health care : journal of the International Society for Quality in Health Care</i> 2019;31:556-62.	Study design
60	Reed MD, Dabney DA, Tapp SN, Ishoy GA. Tense Relationships between Homicide Co-Victims and Detectives in the Wake of Murder. <i>Deviant Behavior</i> 2020;41:543-61. https://doi.org/10.1080/01639625.2019.1574256	Phenomenon of interest
61	Robbennolt JK. The Effects of Negotiated and Delegated Apologies in Settlement Negotiation. <i>Law and Human Behavior</i> 2013;37:128-35. https://doi.org/10.1037/lhb0000020	Study design
62	Sapoelete R, Muhadar M, Yudianto O, Budiarsih B. The Concept of Penal Mediation for the Crime of Medical Negligence in Realizing Legal Protection for Medical Personnel and Patients or Their Families. <i>International Journal of Multicultural and Multireligious Understanding</i> 2021;8.	Study design
63	Schetky DH, Benedek EP. The sexual abuse victim in the courts. <i>The Psychiatric clinics of North America</i> 1989;12:471-81.	Study design
64	Schulz Moore J, Mello MM, Bismark M. 'Poking the skunk': Ethical and medico-legal concerns in research about patients' experiences of medical injury. <i>Bioethics</i> 2019;33:948-57.	Study design
65	Segest E. Patients' complaint procedures, in a Scandinavian perspective. <i>European journal of health law</i> 1996;3:231-54.	Study design
66	Siegal G, Mello MM, Studdert DM. Adjudicating severe birth injury claims in Florida and Virginia: the experience of a landmark experiment in personal injury compensation. <i>American Journal of Law & Medicine</i> 2008;34:493-537.	Population
67	Simpson AIF, Boldt I, Penney S, Jones R, Kidd S, Nakhost A, et al. Perceptions of procedural justice and coercion among forensic psychiatric patients: a study protocol for a prospective, mixed-methods investigation. <i>BMC psychiatry</i> 2020;20:230.	Population
68	Sladden N, Graydon S. Liability for medical malpractice--recent New Zealand developments. <i>Medicine and law</i> 2009;28:301-15.	Study design
69	Tigard DW. Taking the blame: appropriate responses to medical error. <i>Journal of Medical Ethics</i> 2019;45:101. https://doi.org/10.1136/medethics-2017-104687	Study design
70	TorkmannejadSabzevari M, Eftekhari Yazdi M, Rad M. Lived experiences of women with maternal near miss: a qualitative research. <i>Journal of Maternal-Fetal & Neonatal Medicine</i> 2021:1-8.	Not high income
71	Tumelty ME. Exploring the emotional burdens and impact of medical negligence litigation on the plaintiff and medical practitioner: insights from Ireland. <i>Legal Studies</i> 2021;41:633-56. https://doi.org/10.1017/lst.2021.20	Population
72	Van Niel M, Bismark M, Boothman R, Driver J, Etchegaray J, Fain B, et al. Inclusion of Plaintiff Attorneys in Research into the Effects of Harmful Events. <i>Joint Commission Journal on Quality and Patient Safety</i> 2018;44:757-8. https://doi.org/10.1016/j.jcjq.2018.08.004	Study design
73	Walsh P. The future for Medico-Legal disputes - a patient perspective. <i>The Medico-legal journal</i> 2014;82:18-28.	Study design
74	Wang TH, Lin SF, Tsai KY, Liu YF. Lessons from the MOHW compensation pilot program on birth incidents: First step and looking forward: Elsevier; 2017.	Study design
75	Weisz AN. Reaching African American battered women: increasing the effectiveness of advocacy. <i>Journal of Family Violence</i> 2005;20:91-9. https://doi.org/10.1007/s10896-005-3172-9	Study design

76	Wessel M, Helgesson G, Lynöe N. Experiencing bad treatment: Qualitative study of patient complaints concerning their treatment by public health-care practitioners in the County of Stockholm. <i>Clinical Ethics</i> 2009;4:195-201. https://doi.org/10.1258/ce.2009.009008	Study design
77	Whitney M, Ayvaci ER, Bhatti SM, Duong K, Page LE, Patel TN, et al. A qualitative analysis of satisfaction with justice and desire for revenge in survivors of the September 11, 2001, attacks on New York City's World Trade Center. <i>Peace & Conflict</i> 2019;25:246. dx.doi.org/10.1037/pac0000362	Study design
78	Winship V, Robbennolt JK. Admissions of Guilt in Civil Enforcement. <i>Minnesota Law Review</i> 2018;102:1077-146.	Study design
79	Wong PWC, Chan WSC, Beh PSL, Yau FWS, Yip PSF, Hawton K. Research participation experiences of informants of suicide and control cases: taken from a case-control psychological autopsy study of people who died by suicide. <i>Crisis</i> 2010;31:238-46. dx.doi.org/10.1027/0227-5910/a000025	Study design

Appendix D: List of included studies

Table 25: Summary details for all included studies

Author, Date Country	Focus/Aim	Field of Adverse Event [AE]: Participant relevant AE	Year of data collection Data collection method	Participants [Number]	Phenomenon of Interest
Bakhabki 2017; UK (28)	Bereaved parents' views on involvement in PNMR	Medical: Mid-trimester loss, Termination of pregnancy for congenital abnormality, Stillbirth, Neonatal death	2015 FGD	Parents [11]	AE review
Berliner 1995 USA (75)	Impact of disclosure & intervention on sexually abused children	Sexual abuse: Child sexual abuse	NR Semi-structured interviews, Questionnaires	Child victims and Families [82]	Disclosure
Biddle 2003 UK (68)	Bereaved people's experiences of the suicide inquest	Suicide: Death	NR In-depth interviews	Individuals bereaved by suicide [16]	Coroner's Inquests
Bouwman 2018 Netherlands (21)	Role patients & families have in formal processes after sentinel events	Medical: Sentinel event, Suicide, Suicide attempts	NR Semi-structured interviews	Patients [4], Families [7], Patient counsellor [2], Family counsellor [5], Members of family committee [4], Psychiatrist [4], Medical director [1], Inspector [5], Director [3]	AE review
Burns 2006 USA (57)	Experiences of murdered victims' families with the criminal justice system	Homicide: Death	2005 In-depth interviews	Family members [23]	Litigation process
Butler 2019 Australia (22)	Experiences of police presence in ICU after the death of child	Medical: Death [SIDS, Metabolic disease, Septic shock]	NR Semi-structured interviews	Parents [9]	Coronial investigation
Chapple 2012 UK (69)	People's accounts of their acceptance or resistance to the coroner's verdict	Suicide: Death	2007-2008 Semi-structured interviews	Relatives [38], Friends [2]	Coroner's Inquests

Author, Date Country	Focus/Aim	Field of Adverse Event [AE]: Participant relevant AE	Year of data collection Data collection method	Participants [Number]	Phenomenon of Interest
Chiu 2010 Taiwan (29)	Patients' view of the meaning of filing malpractice lawsuits	Medical: Physician/hospital malpractice, outcomes included death, irreversible complication, vegetative state	2006-2007 Semi-structured interviews	Family members [13]	Litigation process
Dartnall 2019 Australia (71)	Family's: experiences of the coronial process	Missing person	2016-2018 Face-to-face interview	Family members [13], Friends/Family representative [2]	Coroner's Inquests
Davis, 2002 UK (23)	Perspective of family members on the coroner service, particularly the inquest	Varied: Medical accident, Road accident, Suicide	NR Face-to-face and telephone interviews	Family members [16], Coroners [9], Deputy coroners [3], Coroner's officers [13]	Coroner's Inquests
Duclos 2005 USA (30)	Perceptions of patient-provider communication after medical AE	Medical: Perforations, Surgical errors, Suture infections	NR FGD and field notes	Patients [16], Spouses [3]	Disclosure - Communication
Eastwood 1998a (77)	Same as Eastwood 1998b				
Eastwood 1998b Australia (76)	Processes in the criminal justice system which impact upon sexually abused female children	Sexual abuse: Child sexual abuse	NR Semi-structured In-depth Interviews	Female victims [12], Non offending Parents (34), Complainants witnesses [4], Pact workers [6], Legal personnel [3]	Litigation process
Englebrecht 2014 USA (58)	Experiences of homicide survivors within the criminal justice system	Homicide: Death	2011 Focus groups	Family members [18]	Litigation process
Etchegaray 2014 USA (31)	Involving patients & family members going through disclosure in event analysis process	Medical: NR	2010-2011 Semi-structured interviews	Patients [5], Family members [4], Clinicians [6], Hospital administrators [13]	AE review
Fisher 2016 USA (32)	SDMs perspectives on preventable care breakdowns of critically ill patients	Medical: Preventable complication, Inappropriate medication, Delayed, incorrect, missed diagnosis, treatment and nursing care, Premature/ inadequate discharge	2013-2014 In-depth interviews	SDM [70]	Disclosure - Raising concern

Author, Date Country	Focus/Aim	Field of Adverse Event [AE]: Participant relevant AE	Year of data collection Data collection method	Participants [Number]	Phenomenon of Interest
Gallagher 2009; USA (33)	Review of medical error	Medical: Wrong site surgery	NR Interview, Case review	Victim [1], Medical personnel [1]	Post Investigation
Hagensen 2018 Norway (34)	Patients' perspectives of the occurrence of disclosure of, & healthcare orgs' responses to AEs	Medical: Medical: Inadequate surgery; Surgery resulting in nerve damage; Incorrect anaesthesia, medication; Radiation injury; Deficient treatment	2013-2014 Semi-structured interviews	Patients [15]	Disclosure
Hannawa 2017 Switzerland (35)	What features of a disclosure- motivations, knowledge & skills do Swiss patients perceive as competent?	Medical: Medical error	2014 Focus group discussions	Patient and carers [63]	Disclosure
Herman 2005 NR (78)	What justice look like if victims were protagonist, rather than peripheral actors, in the dialectic of criminal law	Sexual Abuse: Sexual abuse (SA), Domestic violence (DV)	NR In-depth interviews	SA victims [12], Relative of DV & SA victims [4], DV victims [5], Primary support person for a wife/sister raped [2]	Post investigation/ post litigation
Hernan 2014 Australia (24)	Experiences of rural general practice & perceptions of safety in health care setting	Medical: Misdiagnosis, Delays in treatment, Not adhering to standard care procedures, Medication errors, Psychological harm	2012 Focus group interviews	Patients and carers [26]	Disclosure - Raising concern
Hovey 2014 Canada (36)	Re-interprets data from patients and families who experienced medical AE	Medical: Medically induced trauma due to healthcare systems failures	NR Unstructured Interviews	Patient/family members [15], Healthcare professionals [6]	Disclosure - Apology
Iedema 2007 Australia (40)	What it is about open disclosure that works, for whom does it work?	Medical: Infection, Missed diagnosis, Drug overdose, Wrong site surgery	2007 Semi-structured In-depth Interviews	Health care professionals [131], Patients [15], Family members [8]	Disclosure

Author, Date Country	Focus/Aim	Field of Adverse Event [AE]: Participant relevant AE	Year of data collection Data collection method	Participants [Number]	Phenomenon of Interest
Iedema 2011 Australia (39)	Patients'/relatives' experiences of AE & incident disclosures	Medical: Death, Failures, Errors or complications of medical & surgical procedures, diagnostic errors, delayed treatment, medication errors & hospital-acquired infections	2009-2010 Semi-structured In-depth Interview	Patients [39], Family members [80]	Disclosure
Iedema 2012a Australia (38)	Understand what patient & family members know of failures in healthcare	Same as Iedema 2011			
Iedema 2012b Australia (37)	Experience of woman whose husband died from AE	Medical: Death from Vasopressin overdose	2010 Semi-structured In-depth Interview	Family member [1]	Disclosure
IPSOS 2016 UK (41)	Journey of parents with a child that experienced birth injury	Medical: Brain injury during birth	2016 Group discussion, Interview	Parents/families [7], Stakeholder [11], Clinicians [4], General public groups [4]	Litigation process
Kamin-Friedman 2021; Israel (25)	Objectives of Israel's Vaccine Injury Compensation Law	Medical: Vaccine-related injuries	NR In-depth interviews	Victims [3], Legal practitioners [4], Physician [2], Jurists [2]; Researchers [2]	Post AE- Other
Kent 2008 Sweden (42)	Reappraisal of current handling of patient complaints in Sweden & elsewhere	Medical: Dental treatment error, others-NR	2006-unknown Semi-structured In-depth Interview, collation of literature & contemporary debate articles	Patients [6], Representatives of patient support orgs & medico-legal specialists (34)	Disclosure - Raising concern
Kim 2021 South Korea (43)	Experiences of patients & their families regarding disclosure after patient safety incidents	Medical: AE - Surgical/procedure related, Diagnosis, Treatment, Death, Permanent disability	2020 In-depth individual interviews	Family members [8], Patients [7]	Disclosure

Author, Date Country	Focus/Aim	Field of Adverse Event [AE]: Participant relevant AE	Year of data collection Data collection method	Participants [Number]	Phenomenon of Interest
Lippel 2007 Canada (62)	How the compensation system & its actors affect the self-reported health of workers	Employment: Back/head injuries, Upper extremity disorders, Fractures, Burns, MSDs, Respiratory disease, Poisoning by neuro-toxic substances, Eye loss, PTSD	2003-2004 Semi-structured interviews	Injured workers [85]	Litigation process
Loren 2021 USA (44)	Experiences of parents & healthcare providers with communication about birth-related AE	Medical: Adverse birth-related newborn outcomes - Brachial plexus injuries, Respiratory problems, Fever/infection, Cardiac problems	2011-2012 Semi-structured In-depth interviews, FGD	Parents [27], Care providers [47]	Disclosure - Communication
Maderia 2008 USA (59)	How do victims' family members & survivors form perceptions of offending criminals & conclusions about the "meaning" of the AE	Homicide: Death	2005-2006 In-depth open-ended interviews	Homicide survivors/ Victims' family members [27], Rescue worker [2]	Litigation process
Maderia 2010 (60)	Understanding of closure	Same as Maderia 2008			
Malone 2007 UK (79)	Emotional & practical needs of people bereaved by homicide	Homicide: Death	NR In-depth interviews, Focus groups	Bereaved people [41]	Post AE- Other
Martin 2021 UK (45)	Offer new insights into the features of orgs' responses to concerns & complaints that give rise to problems	Medical: NR	2018-2019 Interview - narrative approach	Patients and family members [18], Staff [70]	Disclosure - Raising concern
Matthews 2011 Australia (64)	Experiences of surviving families' institutional responses to workplace death	Employment: Workplace death	NR In-depth interviews	Family members [7]	Litigation process

Author, Date Country	Focus/Aim	Field of Adverse Event [AE]: Participant relevant AE	Year of data collection Data collection method	Participants [Number]	Phenomenon of Interest
Matthews 2017 Australia (63)	Health and financial consequences of work AE for surviving families. Adequacy of institutional responses in meeting families needs	Employment: Work-related death	NR In-depth interviews	Family members [55]	Litigation process
Mazor 2010 USA (26)	Events parents perceived as error and response by providers	Medical: Incorrect medication, Postoperative severe infection, Missed fracture diagnosis, Incorrect diagnosis	2007-2008 In-depth qualitative interviews	Parents [35]	Disclosure - Communication
Mazor 2012 USA (47)	Patients' perceptions of preventable, harmful event & interactions with clinicians after events	Same as Mazor 2013			Disclosure - Communication
Mazor 2013 USA (46)	Patients' perspectives on problematic events & on clinicians' responses to these events	Medical: Perceived delays in diagnosis and/or treatment, Infections delaying recovery, Delayed response to surgical complications/chemotherapy side effects	NR In-depth telephone interviews	Patients [78]	Disclosure - Communication
McQueen 2021 UK (48)	Explore what 'good' patient/family involvement in AE reviews may involve	Medical: Adult death/palliative care, Fall, Delayed diagnosis, Medication error, Mental health, Addiction, Suicide, Neonatal death, Surgical complications	2021 Semi-structured telephone interviews	Patients [4], Family members [15]	AE review
Melville 2012 UK (49)	Investigate how claimants experience their lawyer's efforts	Medical: Minor injuries, Moderate injuries, Serious injuries, Death	NR In-depth interviews	Patient [19], Family Member [11]	Litigation process
Moore 2017a USA (50)	Experiences of patients and family members with medical injuries and CRPs	Medical: Death, Permanent physical harm, Temporary physical harm	2016 Semi structured telephone and face to face interviews	Patients [27], Family members [3], Staff [10]	Litigation process

Author, Date Country	Focus/Aim	Field of Adverse Event [AE]: Participant relevant AE	Year of data collection Data collection method	Participants [Number]	Phenomenon of Interest
Moore 2017b New Zealand (51)	Factors that facilitate/impede reconciliation following patient safety incidents	Medical: Sentinel Injury; Serious injury; Major injury; Minor injury	2015 Semi-structured interviews	Patients [6], Family members [56], Lawyers specialising in ACC claims [5], Administrators of public hospitals [12], ACC staff [3]	Litigation process
Myren 2021 Netherlands (52)	Explore how patient participation at M&MM can be practiced and learning points to achieve change	Medical: Injury, Blood loss, Infection leading to prolonged hospital stay or readmission	NR Semi-structured interview	Patients [8], Professionals [17]	AE review
Ngo 2020 Australia (66)	Nature of information sought by family member following work AE	Employment: Workplace death	2014-2015 Semi-structured interviews	Family members [40]	Disclosure
Ngo 2021 Australia (65)	What are the reasons why family members may want/not want inquest to be held after work AE?	Employment: Workplace death	2014-2015 Semi-structured interviews	Family members [40]	Coroner's Inquests
Ocloo 2010 UK (27)	Looks at the occurrence of medical harm	Medical: Medical harm [Misdiagnosis, wrong prescription, others - NR]	2003-2006 Observation, Analysis of websites of network members and legal documents, Interviews	Adults with experience of medical harm [10], Other participants [14 groups], Individuals questionnaires [18]	Litigation process
Outland 2020 USA (72)	Impact of police killings on the lives of the family and community of youth victims	Death in custody: Police killing	NR In-depth interviews	Relative [3], Legal practitioner [2], Reporters [2], Clergy [3], Friends, neighbours & residents in deceased community and the location where homicide by police occurred [25]	Disclosure
Piper 2014 Australia (53)	Analyse rural patients'/ families' experiences of open disclosure	Medical: Delayed treatment, Ongoing suffering, Death	2009-2011 Semi structured In-depth interviews	Rural patients [13]	Disclosure

Author, Date Country	Focus/Aim	Field of Adverse Event [AE]: Participant relevant AE	Year of data collection Data collection method	Participants [Number]	Phenomenon of Interest
Pyo 2019 Korea (54)	Life experience of victims of medical accidents after accidents and litigations	Medical: Physical disability	NR In-depth interview, news footage & reports	Medical accident victim [1]	Litigation process
Saco 2018 USA (80)	What injustices do homicide survivors experience? How does the system perpetuate these injustices?	Homicide: Death	NR Face-to-face or Telephone Semi-structured interviews	Survivors of homicide violence among experts [12]; Other experts [24]	Post litigation/Post Justice seeking
Sandler 2008 UK (73)	Issues in relation to the deaths of women in prison	Death in custody	NR Case studies, Discussion, Interviews, Evidence review	Families, Prison officials (34)	Inquests
Shaw 2007 UK (74)	Procedures that surround investigation of deaths in prison & police custody	Death in custody	NR Casework, Surveys, Questionnaires, Meetings and Consultations	Caseworkers (34), Legal practitioners [23], NGOs (34), Families of persons who died in custody [158]	Coroner's Inquests
Snell 2011 UK (67)	Discusses victimization & exclusion of victims of corporate crime from treatment as real victims of real crime	Employment: Workplace death	NR Semi-structured interviews	Bereaved families [6]	AE review/ Coroner's Inquests
Sorensen 2010 Australia (55)	Patients & health professionals experience of Open Disclosure	Medical: NR	NR Semi-structured open-ended interviews	Nursing [20], medical [49], Family members [8], Clinical / administrative managerial [59], Policy coordinators [3], Patients [15]	Disclosure
Spillane 2019; USA (70)	Bereaved family members experience of the inquest process	Suicide: Death	2014-2016 Semi-structured interviews	Family member [18]	Coroner's Inquests

Author, Date Country	Focus/Aim	Field of Adverse Event [AE]: Participant relevant AE	Year of data collection Data collection method	Participants [Number]	Phenomenon of Interest
Umbreit 2000; USA (61)	Victim-offender mediation between surviving family member and death row inmate	Homicide: Death	1998 Interviews	Offenders [2], Family members of the persons they murdered [3]	Litigation process - Mediation- dialogue
Wellman 2018 USA (81)	How do cold case homicide survivors navigate their open- ended journey through grief?	Homicide: Death	NR Face to face/ telephone semi-structured in-depth interviews	Family members [24]	Post litigation/ Post Justice seeking
Wiig 2021 Norway (56)	Next of kin's perspective of involvement in new regulatory investigation process of AE	Medical: Death	2017-2018 Face-to-face meeting	Next of kin [29], Regulatory inspectors (34)	AE review

ACC = Accident Compensation Corporation; AE = Adverse Event; CRP = Communication-and-Resolution Programs; FGD – Focus Group Discussion; ICU – Intensive Care Unit; M&MM = Morbidity & Mortality Meeting; NR – Not Reported; PNMR = Perinatal mortality review process; PTSD - Post Traumatic Stress Disorder; SDM – Surrogate Decision Maker

Appendix E: Prioritisation matrix

Table 26: Matrix for prioritising medical studies

Field of Adverse Event (n = 61)	Phenomenon of Interest				
	Raising concerns, In process of disclosure, Investigation, Communication, Disclosure, Apology (n= 23)	Adverse event review/ Coroner's inquest (n=15)	Experience of Litigation process (n=16)	Post complaints/ investigation, Post Litigation/justice-seeking (n=5)	Post adverse event - Other (n = 2)
Medical (n = 35)	Butler 2019 (22), Duclos 2005 (30), Fisher 2016 (32), Hagensen 2018 (34), Hannawa 2017 (35), Hernan 2014 (24), Hovey 2014 (36), Iedema 2007 (40), 2011 (39), 2012a (38), 2012b (37), Kent 2008 (42), Kim 2021 (43), Loren 2021 (44), Martin 2021 (45), Mazor 2010 (26), Mazor 2012 (47), Mazor 2013 (46), Piper 2014 (53), Sorensen 2010 (55)	Bakbakhi 2017 (28), Bouwman 2018 (21), Etchegaray 2014 (31), McQueen 2021 (48), Myren 2021 (52), Wiig 2021 (56)	IPSOS 2016* (41), Moore 2017b (51), Melville 2012 (49), Moore 2017a (50), Ocloo 2010 (27), Pyo 2019 (54)	Chiu 2010 (29), Gallagher 2009* (33)	Kamin-Friedman 2021 (25)
Death in custody/ Police killing (n = 3)	Outland 2020 (72)	Sandler 2008, (73), Shaw 2007* (74)	x	x	x
Employment/work-related incident (n = 6)	Ngo 2020 (66)	Ngo 2021 (65), Snell 2011* (67)	Lippel 2007 (62), Matthews 2012* (64), Matthews 2017** (63)	x	x
Suicide (n = 3)	x	Biddle 2003, Chapple 2012****, Spillane 2019	x	x	x
Missing person (n=1)	x	Dartnall 2019(71)	x	x	x
Homicide (n = 6)	x	Davis 2002 (23)	Burns 2006 (57), Englebrecht 2014 (58), Maderia 2008 (59), Maderia 2010 (60), Umbreit 2000 (61)	x	x

Field of Adverse Event (n = 61)	Phenomenon of Interest				
	Raising concerns, In process of disclosure, Investigation, Communication, Disclosure, Apology (n= 23)	Adverse event review/ Coroner's inquest (n=15)	Experience of Litigation process (n=16)	Post complaints/ investigation, Post Litigation/justice-seeking (n=5)	Post adverse event - Other (n = 2)
Sexual Abuse (n = 7)	Berliner 1995*** (75)	x	Eastwood 1998a, (77) Eastwood 1998b* (76)	Herman 2005* (78) Saco 2018(80) Wellmann 2018 (81)	Malone 2007 (79)

Green text = High amount relevant data, Orange text = Medium amount of relevant data, Red text = Low amount relevant data; * = Relevant to Disclosure; ** = Relevant to Adverse event review/Coroner's Inquest; *** = Also relevant to Litigation process; **** = Relevant to outcomes

Table 27: Matrix for prioritising non-medical studies

Author/Year Field of AE	Stage of justice seeking	Existing themes/descriptive codes	Useful extra detail	Novel themes/ideas	Addresses/Adds depth to weak subthemes (Include - Yes/No)
Berliner 1995 (75) Sexual abuse	Disclosure and Litigation process	Need for Reassurance after being heard, Person-centred professional, Info on what happens next? Discomfort/trauma in the justice process, Respectful treatment	Discomfort/trauma in the justice process, Information, communication, (Children wondered why their case wasn't taken to court but indicated parents may have made the choice to protect them)	NA	No
Biddle 2003 (68) Suicide	Coroner's inquest	Preparation and information provided, To speak and be heard, Difference in what victims expect and receive, Time delay, Balance judicial process with human needs, Tick boxes to record events that doesn't reflect actual experience	Justice process exacerbating grief/traumatic, court setting like a criminal, interferes with grief work, Provide options of choices available	Some details on justice doesn't always bring closure (Re- Justice isn't always possible), media intrusion	Yes - Justice isn't always possible
Burns 2006 (57) Homicide	Litigation process	Offender-oriented not victim-oriented, Long waiting time, Poor information and communication, Need to cater for victims need	Traumatic process, forgive but still pay for crime, closure may never occur	Disliking/agreeing with the term "victims", Noninterest in restorative justice which may be attributed to event and justice process	Yes - Not interested in restorative justice
Chapple 2012 Suicide (69)	Coroner's inquest	Content with suicide verdict	Mechanisms to challenge suicide verdict	NA	Yes - Mechanism to challenge verdict
Dartnall 2019 (71) Missing person	Coroner's inquest	Being heard as therapeutic and cathartic, information and communication, Be human with me, timely investigation, Distress through findings from investigations	Variable perception of the formal environment (court setting), Need for support services, media useful/intrusive	NA	No

Author/Year Field of AE	Stage of justice seeking	Existing themes/descriptive codes	Useful extra detail	Novel themes/ideas	Addresses/Adds depth to weak subthemes (Include - Yes/No)
Davis 2002 (23) Varied	Coroner's inquest	Waiting time, Communication problem, Empathetic approach, Limited involvement, Setting	Difference in what victims expect and receive	Ability to recall events affected by long wait times	No
Eastwood 1998a (77)	Same as Eastwood 1998b				Yes - Sibling paper of 1998b
Eastwood 1998b Sexual abuse (76)	Investigation and Litigation process	Lack of compassion and empathy, Lengthy waiting times, Information and communication challenges, "calling for it"	Traumatic process, Prosecutor changed plea from sexual assault to common assault without informing family (Re- Of what decision was made and why?)	NA	Yes - Of what decision was made and why?
Englebrecht 2014 (58) Homicide	Litigation process	Lack of compassion and empathy, Little involvement in process, Not allowed to address offender, offender-oriented, Inconsistencies in sentencing, Exacerbate grief, Need to be heard, Reassurance	Prosecutor received negotiated plea against the wishes of the family (Of what decision was made and why?), Usurping of victimhood by the state, Need for advocates/support	NA	Yes - Of what decision was made and why?
Herman 2005 (78) Sexual abuse	Post investigation/ Post Litigation	Offender-oriented not victim- oriented, Need for sensitivity and compassion, Adversial legal system, Acknowledgement of harm by perpetrator, Apology, Manipulated system	Vindication and need for solidarity from the family members, community	Moving on without holding on to anger and indignation, Apology as a manipulation tool, Forgiveness as an injustice imposed on victims	No
Lippel 2007 (62) Employment	Litigation process	Painting injured workers as fraud, power imbalance, lack of person- centred response,	Traumatic process impacting health, Support by union, Feeling of being punished for filing a claim, Social support and validation help with vindication	NA	No

Author/Year Field of AE	Stage of justice seeking	Existing themes/descriptive codes	Useful extra detail	Novel themes/ideas	Addresses/Adds depth to weak subthemes (Include - Yes/No)
Maderia 2008 Homicide (59)	Litigation process	Lack of remorse by offender, Involvement/attendance in legal proceedings	Moving on after execution	NA	Yes- Attainable closure
Maderia 2010 (60) Homicide	Litigation process	Involvement/attendance in legal proceedings	Closure may not exist but can learn to cope (Re-Justice isn't always possible)	Public pressure can yield desired results in court system	Yes - Justice isn't always possible
Malone 2007 (79) Homicide	Post-adverse event other	Financial cost, Delayed process, Poor information and communication, Criminal proceedings exacerbate trauma, Difference in outcome expectation	Need for support, Need for contact with offender to speak	NA	No
Matthews 2011 (64) Employment	Disclosure and Litigation process	Route to disclosure, Timeliness, communication, obtaining info, trauma/acknowledgement, consistent support person, what happened, financial compensation, punishment/retribution, responsibility, recognition of needs, need for information re: support for process, info re: next steps/choice, need for formal process	Need for regular updates, Follow-up. Responsibility, Unrecognised blame. Struggle to get financial compensation, Financial compensation not enough	Viewing body, intrusive media during legal proceedings. Speaks to mechanism to appeal. Lack of recognition of families	Yes - Mechanism to challenge verdict
Matthews 2017 (63) Employment	Litigation process	Timely and accurate information, Participation in processes, Who is accountable, Actions taken to prevent similar incidents occurring, Access to support	NA	A thorough investigation	No

Author/Year Field of AE	Stage of justice seeking	Existing themes/descriptive codes	Useful extra detail	Novel themes/ideas	Addresses/Adds depth to weak subthemes (Include - Yes/No)
Ngo 2020 (66) Employment	Disclosure	What happened, accountability, difficulty obtaining info, accuracy of info, coherence of messages received, defensiveness, involvement, being heard, accuracy of information, accountability	If pain and suffering, what caused death/incident, difficulty obtaining info - next of kin status, privacy - censored reports	Rigour of investigation	No
Ngo 2021 (65) Employment	Coroner's inquest	What happened, Accountability, Trauma, Difficulty understanding info, Technicalities, Access to info, Accuracy of info/trust, Involvement of key stakeholders, Timeliness, Involvement, Answers, Dialogue, Have their say, Being heard	Accuracy of info: if info doesn't match own understanding, justice not obtained. Independent scrutiny - role of coroner in scrutinising history of organisation. Want to know historical antecedents/wider picture of why incident occurred	Mechanism of challenge: inquest provides a route to do this, rigour of investigation	Yes - Mechanism to challenge verdict
Outland 2020 (72) Police killings	Disclosure	Route to disclosure, Accountability, need for external eye and support	NA	Police intimidation, Intrusive media	No
Saco 2018 (80) Homicide	Post justice seeking	NA	Person-centred theme i.e. justice isn't possible	NA	Yes - Justice isn't always possible
Sandler 2008 (73) Death in custody/police killing	Adverse event review/Coroner's inquests	Defensive system, Need for financial support, Desire for proactiveness, Apology, Empathy, Need for info & support, Funding, Family involvement in investigation	Battle to achieve funding - a dehumanising process, Need for time between receiving report and inquest date	Signposting to support post trial, peer support	No

Author/Year Field of AE	Stage of justice seeking	Existing themes/descriptive codes	Useful extra detail	Novel themes/ideas	Addresses/Adds depth to weak subthemes (Include - Yes/No)
Shaw 2007 (74) Death in custody/police killing	Disclosure and Coroner's Inquests	Lots! Routes to disclosure, privacy, empathy, compassion, need for info, accuracy of info, how info disclosed, need for written info, consistent contact person, timeliness, follow-up, trauma, need for independent bodies, preparation, legal support, involvement in investigation /inquest, perceived bias, etc	Need for support post disclosure, not being left alone, need for ongoing, info re: justice procedure/coroner, info under 'account' re: people doing jobs properly, link between involvement and humanisation of process, impact of human process on fair process, family role in investigation process, privacy, a safe space, etc.	Speaks to Mechanisms to challenge/resolve dispute, Signpost to further support, peer support, support as carers, access to body, post-mortem info, need for regular updates/follow up	Y- Mechanisms to challenge verdict
Snell 2011 (67) Employment	Disclosure and Coroner's Inquests	Need for ongoing support, need for competent support, shared goals, empathy, desire for people to take initiative, what happened, prevent happening again, adversarial process, lack of consideration of needs, accuracy of information, trauma, funding/legal aid, financial impact, space to acknowledge emotions	Another aspect bureaucracy of process: 'not in public interest', cost of pursuing	Self-blame re: how treated during investigation. Mechanism to challenge? (re: asking police to continue investigation), rigorousness of investigation, lack of control	No
Spillane 2019 (70) Suicide	Coroner's inquest	Preparation, Need for info, Trauma, Privacy, What Happened, Adversarial, Timeliness, Taking into account emotions alongside formal processes, Choice of time, What happened, Alleviate guilt	Trauma: re watching other cases, privacy re: disclosure of sensitive info, what happened - unexpected info, refutational: what happened, what happened- degree of suffering, refutational-answers	Presence of media	No

Author/Year Field of AE	Stage of justice seeking	Existing themes/descriptive codes	Useful extra detail	Novel themes/ideas	Addresses/Adds depth to weak subthemes (Include - Yes/No)
Umbreit 2000 (61) Homicide	Mediation- dialogue/ Litigation process	Trauma, What happened, Route to disclosure, Be heard, accountability, preparation, need for support/advocate (via mediator), two way dialogue, need for equivalence, emotional support, formal documentation, have their say, sincerity, assurance won't happen again?? Answers, revenge, informed about process	What happened: Reasons why	Desire for connection with offender. Forgiveness. Life revolving around case. Humanising process/ involvement of key stakeholder, wider family communication. Outcomes: Healing/ renewal. Humanising process - for perpetrator	No
Wellman 2018 (81) Homicide	Post litigation/ Post Justice seeking	NA	Offers insight/an alternative angle looking into inverse of restorative justice, Trial process/outcomes not meeting expectations	NA	No

Green highlight: prioritised for synthesis, Amber highlight: not prioritised for synthesis

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