



LITERATURE REVIEW

Review of the National Mortality Review Function

January 2022

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Introduction

The purpose of this literature review is to inform the review of the National Mortality Review Programme (NMRP) being undertaken by Francis Health. Capturing relevant findings from international literature will ensure that any recommendations made to the NMRP are evidence based and grounded by best practice methodologies.

The scope of the literature review includes:

- International models and best practice of mortality reviews
- Indigenous models of mortality reviews and data sovereignty
- Effectiveness of (recommendations from) mortality review findings to achieve tangible system wide changes

It is acknowledged that a previous literature review was conducted by Martin Jenkins in 2013 which covered some aspects of the scope outlined above. The present literature review aims to build on the findings of the previous review by a rapid scan of recent literature (2012 onwards) and focusing on emerging topics relevant to the NMRP given the establishment of the suicide mortality review committee in 2017 in addition to a priority on giving effect to Te Tiriti o Waitangi and Māori data sovereignty.



Methodology

Search topics

The review utilised the databases of the University of Auckland Library and google scholar to access a variety of health, social and indigenous studies research. In addition, the review utilised grey literature from government agencies and professional bodies from Australia, Canada, the United Kingdom (UK) and the United States of America (USA). Literature was also provided by the HQSC secretariat.

The key search topics for this literature review include:

- International mortality review models and frameworks
- Mortality review approaches for indigenous populations
- Data sovereignty and equity reporting for indigenous populations
- Te Ao Māori and approach to mortality
- Best practices for implementing recommendations from mortality reviews

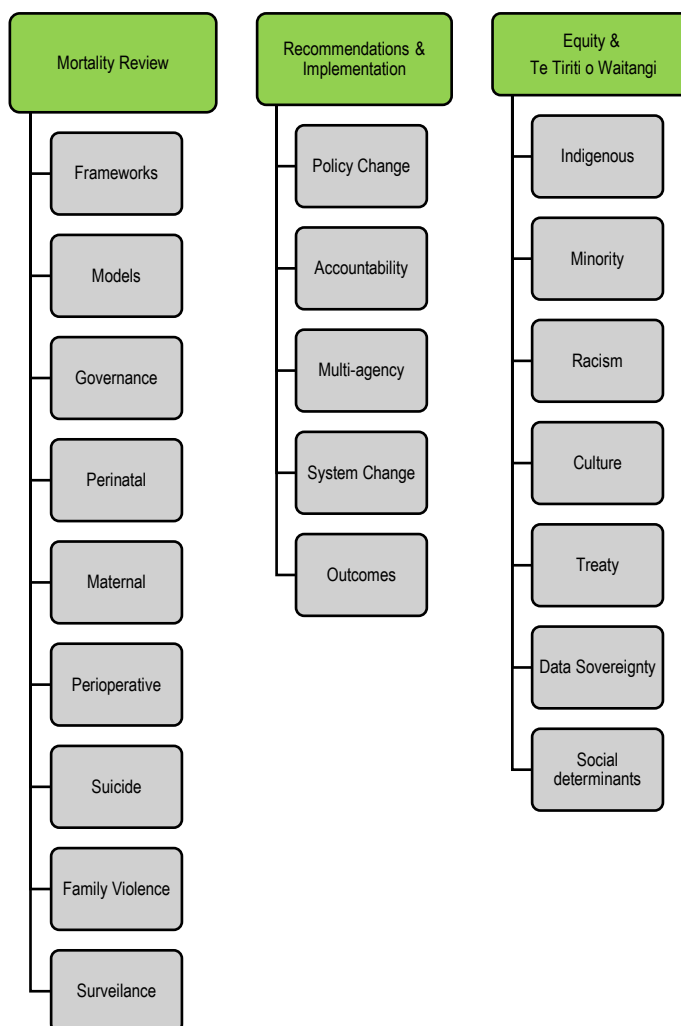


FIGURE 1 DIAGRAM OF KEY SEARCH TERMS USED



Search strategy

Searches were carried out utilising the following search terms in both published literature databases and internet search engines:

TABLE 1 SEARCH TERMS

Search Terms
Fatality review team, morality review team, death review team, fatality review committee, death review committee, mortality review committee, fatality review board, death review board, mortality review board, fatality review program, death review program, mortality review program, fatality review process, death review process, mortality review process, family violence review, domestic violence review, infant mortality review, suicide mortality review, suicide death review
Indigenous mortality review, indigenous death review, data sovereignty, indigenous data, sovereignty, Māori data sovereignty
Mortality review, morbidity review, mortality review recommendations, mortality review implementation, mortality review methodologies, mortality review cross sector, mortality review framework, mortality review intervention logic

Sources were screened by date, title, abstract and a brief scan to determine relevance. The final report includes a total of 53 sources:

- 26 journal articles
- 18 reports
- 8 books / book excerpts
- 1 dataset



Literature Review

The following report covers a number of domains regarding mortality reviews, both overseas and in New Zealand. First, approaches to different modes of mortality are compiled by country (Australia, USA, UK and NZ). This is followed by a review of indigenous mortality review methodologies with the consideration of data sovereignty- this is complemented by examples from several jurisdictions. A summary of papers that provide suggestions on translating mortality review recommendations into tangible changes is then discussed. Finally, the report explores the processes of all-cause mortality monitoring bodies in Europe.

Approaches to Mortality Reviews Overseas

Internationally, a wide range of approaches have been adopted to carry out mortality reviews. Hospitals and other clinical settings are the focus of the majority of mortality reviews from other jurisdictions. This approach differs from the methodology applied in New Zealand- one that considers wider determinants of health and ensures inputs from cross-sectoral agencies. Therefore, there is limited available literature with a comparative focus with which to consider alongside the broader approach taken in New Zealand. Furthermore, the structure of New Zealand's mortality review programme is unique in that it is a centralised system operating on a national scale. Internationally, mortality review procedures are organised by locality and as such are relatively more fragmented.

Domestic and Family Violence Deaths

Australia

(Bugeja, Butler et al. 2013), (Domestic Violence Review Team, 2018)

In 2011, the Australian Domestic and Family Violence Death Review Network was established as a unique collaboration between domestic family violence death review mechanisms throughout Australia. Network members have expert knowledge of domestic violence issues and access to extensive information on domestic violence deaths. The objective is to provide a more complete, holistic understanding of the circumstances and context of mortality associated with domestic and family violence by aggregating several local review teams.

Central to this network is extensive data sharing between organisations. A range of data sources informs the review committees including the coronial files, evidence briefs, police reports of death, media reporting, sentencing remarks and agency records.

The network has also established a robust inclusion criterion to determine which cases should fall under its jurisdiction. These include 1. the case type; 2. the role of human purpose in the event resulting in a death (intent); 3. the relationship between the parties (i.e., the deceased-offender relationship); and 4. the domestic



and family violence context (i.e., whether or not the homicide occurred in a context of domestic and family violence).

While individual processes may vary across local teams, the criteria are intended to establish national standards for the storage, ownership and dissemination of data so that it may be shared across jurisdictions. Ultimately, contributing to the development of a national database on domestic and family violence related deaths; with the purpose of preventing future deaths.

UK

Since the implementation of Section 9 of the Domestic Violence, Crime and Victims Act (2004) in 2011, Domestic Homicide Reviews (DHRs) have been a statutory requirement (Sharp-Jeffs and Kelly 2016). A DHR is a multi-agency review of the circumstances surrounding the death of a person aged 16 or over. The scope of deaths reviewed by DHR includes deaths that appear to have resulted from violence, abuse or neglect by a person to whom they were related to, had been in an intimate relationship with or a member of a shared household (UK Home Office, 2016). The multi-agency DHRs have commonly involved health, police, social, school, housing and prison services. A review of DHRs identified a number of issues relating to collaboration between agencies with a shared interest in the same case. The issues identified encompass information sharing, differing risk assessments between organisations, and inconsistencies in organisational policy on domestic abuse (UK Home Office, 2016).

When a domestic homicide occurs, the relevant local Community Safety Partnership (CSP) are informed by the police. Overall responsibility for establishing a review rests with the CSP. CSPs were set up under Sections 5-7 of the Crime and Disorder Act 1998 and consist of representatives from the 'responsible authorities', including police, local authorities, fire and rescue authorities, probation service and health. Following a DHR, recommendations are made to ensure that relevant authorities have learned from every case. An analysis of recommendations found that the majority of recommendations were directed towards services in CSPs (UK Home Office, 2016).

USA

(Websdale 2020), (Storer, Lindhorst et al. 2013)

Across the United States Domestic and Family Violence Review Teams (DFVRTs) vary between participating jurisdictions, as do legal-political mandates. Uniform reporting systems require legal and ethical ways for teams to communicate with each other to report and share data to a central repository. A lack of which has created confusion amongst DFVRT members about what information can be publicly dispensed to interested parties. Actors in DFVRTs are largely multi-agency, including medical professionals, community partners, law enforcement, and domestic violence advocates. The most common form of outputs are community, organisational and system-level recommendations to prevent further family violence deaths. DFVRTs strive for a "no blame" philosophy to inspire cross-sectoral collaboration and develop collective prioritisation of goals and objectives.



The literature indicates that no uniform outputs are released regarding DFVRT findings, however, examples of DFVRT recommendations influencing policy are provided- such as the formulation of a new felony law following a DFVRT investigation. Furthermore, anecdotal evidence regarding outcomes of fatality reviews is published at ndfvri.org. This evidence provides a suggestive, rather than a causal link of the implementation of DFVRT recommendations leading to improved outcomes.

Child Death Reviews

Australia

(Fraser, Sidebotham et al. 2014)

Currently, in Australia, there is no national legislation or guidance regarding child death review (CDR). Every state contains different legislative, operational frameworks, and reporting laws. Given the lack of a national system, there is no standardised process in terms of review panel teams. As of 2015, CDR teams have been established in all 8 states. Victoria is the only state in which the family of the deceased are involved in the review. The outputs of reviews are reported at the state level, but there is no national collation of data.

The scope of deaths reviewed varies between states but typically cases involve child abuse only with some jurisdictions including serious injury.

Those involved in retrospective mortality reviews are largely multiagency and multisectoral.

The data sources include documentation, case record reviews and interviews with key informants in some states.

UK

(Fraser, Sidebotham et al. 2014)

In the UK, a child death 'overview' is undertaken for all unexpected deaths in the United Kingdom. The child death review is a joint-agency process involving health, social care, and police. The reviews are primarily carried out by standardised child death review panels that cover local government authority areas (typical population of 500,000 people).

Child death review panels aim to analyse information about each death and identify any case giving rise to serious case review, any matter of concern for the welfare of children in the area of the authority and any wider public health and safety concern from a particular death or pattern of deaths.

The scope of the review includes all deaths of children aged 0-18 years from all causes. Participants of the review are multi-agency with a fixed core membership with co-opted specialists included as needed. Data sources include submitted proformas from all professionals with knowledge of the child and family and data taken from case records.



In reviewing cause of death, an ecological framework analysis is applied, which consists of an assessment of contribution of different factors. Though the family is engaged in CDR processes, no direct family is present at the panel review.

The key outputs of CDRs include recommendations to local safeguarding children boards and constituent agencies; an annual report; scarce collation and analysis of data at the national level.

USA

(Fraser, Sidebotham et al. 2014)

There is a strong emphasis on CDRs in the US, with 43 states mandating CDRs through legislation. In the case of child abuse deaths, federal law also encourages a review.

There is variation in the scope of CDRs: all states review deaths up to age 18 years, with most covering SUIDs, accidents, murders, suicides, and preventable natural deaths; one state reviews only child abuse deaths.

The review panels are multi-agency and are comprised of health professionals, social services, law enforcement, social services, education and mental health workers. All participating agencies are encouraged to provide any relevant data for a given case.

A public health and injury prevention approach under an ecological model is used as the analytical framework to review deaths.

Currently, family is not involved in the CDR process. However, some jurisdictions are developing a framework to include family using a similar model to the UK.

The outputs of CDRs in the US include recommendations to governors, state legislators, state and local agencies, and the public for policy and practice improvements. Forty-two states issue annual reports to contribute to a national internet-based data collation.

High level Child Death Review Findings

In England and New Zealand, child death reviews are governed by national legislation, whereas child death reviews in the USA are governed by state law. Statutory frameworks offer the advantage of standardising all aspects of review processes. As an example, in England, a prospective rapid-response investigation of all unexpected deaths ensures that the scene of death examination, tests, and final review take place systematically, thereby enhancing a coroner's understanding of the cause of death. The USA, England, Australia, and New Zealand have multi-agency mortality overview panels whose remit is broadly similar: to undertake a comprehensive systematic review to make recommendations to prevent future deaths.



Maternal Death Reviews

Australia

In Australia, there is no established national framework to report maternal and perinatal deaths. Instead, these frameworks operate at the state level and are run by the health systems of each jurisdiction under the State and Territory Maternal Mortality Committees. In 2013 a centralised system to report maternal mortality, the National Maternal Mortality Data Collection (NMMDC) was established. The NMMDC receives maternal death data from various jurisdictions within Australia.

Maternal death is defined as the death of a woman while pregnant or within 42 days of the end of pregnancy, regardless of the duration or outcome of the pregnancy. Maternal deaths are divided into two categories, direct and indirect. Direct maternal deaths are those resulting from obstetric complications of pregnancy or its management. Indirect maternal deaths are those resulting from diseases or conditions that were not due to a direct obstetric cause but were aggravated by the physiologic effects of pregnancy (Australian Institute of Health and Welfare, 2020).

Maternal death data collection is highly variable between jurisdictions. For example, Queensland Health conducts dedicated searches of hospital administrative data sets intended for the sole purpose of identifying maternal deaths whereas in Western Australia the Maternal Mortality Committee appoints an investigator when it is notified of such a death (Australian Institute of Health and Welfare, 2018).

The National Maternity Plan has indicated the need to develop national databases to support the implementation of performance benchmarks, ensure that data definitions enable appropriate and valid data collection, ensure definitions are consistent across jurisdictions and services and provide national data on primary maternity care (Australian Health Ministers' Advisory Council, 2014).

These changes are likely to provide a clearer picture of maternal deaths in Australia. Currently, the literature indicates that a significant portion of late maternal deaths are potentially related to suicide; however, without a clear review of the cases by multidisciplinary committees, the relationship between pregnancy and suicide more than 42 days after the end of pregnancy remains speculative (Humphrey, 2016)

UK

In the UK, Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK (MMBRACE) is the national organisation with the responsibility for collating and reviewing maternal deaths. Maternal deaths are reported to MBRRACE-UK, NIMACH or to MDE Ireland by the staff caring for the women concerned, or through other sources including coroners, procurators fiscal and media reports. The contents of MMBRACE reporting are largely centred around deaths in clinical settings. The process of review for maternal deaths is called the Confidential Enquiry into Maternal Deaths and is regarded as the gold standard for detailed investigation and process improvement regarding maternal mortality (Knight, Nair et al. 2016).

Following the notification of a death occurring during or up to one year after the end of pregnancy, staff at the hospital where the death occurred are asked to provide basic surveillance data, including the woman's socio-



demographic and pregnancy details and cause of death. They also send a full copy of the women's medical records, including an autopsy report where a post-mortem examination has been undertaken. The anonymised records are then uploaded onto a secure electronic viewing portal for confidential review. Multidisciplinary assessors are recruited through their relevant professional associations, and trained in the MBRRACE-UK confidential enquiry processes (Knight, Nair et al. 2016).

A multi-disciplinary chapter-writing meeting is then held, at which all confidential reviews are considered and the main messages for future care are identified to develop the recommendations which then form the basis of the confidential enquiry report (Knight and Tuffnell 2018).

USA

Only two-thirds of U.S. states have multidisciplinary maternal mortality review committees (MMRCs) recognised by the CDC that review each maternal death, some of which appear to be highly functional in addressing local issues (Aspen Health Strategy Group, 2021). However, there is concern that state-specific reviews may facilitate a focus on the identification of individual physician errors or of one-time systems errors unique to a specific hospital (Clark and Belfort 2017). There is acknowledgement that a large burden of maternal deaths are the result of environmental factors such as social and cultural issues. State specific mortality reviews provide limited input on these areas. Some maternal mortality review committees (MMRCs) have sought legislative approval to conduct interviews with family and community members to better identify gaps and problematic themes in service provision (Clark and Belfort 2017).

The CDC has developed a standardised data collection system for state MMRCs called the Maternal Mortality Review Information Application (Collier and Molina 2019).

New Zealand

(Helps et al., 2021) (World Health Organisation, 2016)

In a recent paper comparing perinatal mortality audits across four different countries, key strengths of the Perinatal & Maternal Mortality Review Committee are identified. One distinguishing feature of the PMMRC is that it was the only body to engage relevant stakeholders in the development of recommendations. The authors note that this function of the PMMRC is significant and in accordance with World Health Organisation's best practice guidelines for reducing perinatal deaths at a national level.

Furthermore, reports published by the PMMRC include information on the progress of recommendations from previous reports, including any national initiatives planned or commenced. Providing these updates gives a clear overview of which recommendations are being implemented and which require further attention.



Perioperative Mortality Reviews

UK

(HQIP, 2018 & Findley, 2011)

In the United Kingdom, the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) audits and monitors perioperative deaths. This is a mandatory process in which hospitals and other healthcare organisations are required to participate. Hospitals provide the NCEPOD with all cases over a specified time period, from which around 500 cases are semi-randomly selected for review. The NCEPOD notes that an operational strength lies in having a local NCEPOD reporter in every UK hospital as this ensures continuity, quality and compliance with NCEPOD processes.

For each new study done by the NCEPOD, around 30 case reviewers are recruited, most of which are from a clinical background, though NCEPOD reviews also include patients in the Study Advisory Groups. During case reviews, clinical and organisational questionnaires for hospitals with cases are also considered, in addition to patient data. NCEPOD maintains a strong emphasis on developing recommendations to improve future practice, an iterative process issued to develop recommendations that are targeted. The report is published and made available free of charge along with a self-assessment checklist for hospitals, including an audit tool to measure change. NCEPOD also provide audit toolkits which are accessible on the website.

Following regular reports produced by NCEPOD, impact assessments are conducted every six months and stakeholder reviews every two years. This enables NCEPOD to monitor the uptake of recommendations and follow through with impact assessments.

USA

(Whitlock, 2015)

In the US, there is no federal mandate to review perioperative deaths, this more commonly occurs at the state and individual hospital level. However, the infrastructure to collect nationwide data on perioperative outcomes does exist in the form of the National Anaesthesia Clinical Outcomes Registry. Using this data, retrospective cohort studies are often conducted. Independent researchers have published around the limitations of this registry, describing how the available data is limited and single dimensional, and lacks the remit to influence changes.

Australia

(Jenkins, 2021)

There is no national system to record anaesthesia related mortality in Australia. However, there are state-based committees across most of Australia, which gives the ability to collect near-total data for the whole of the country. At the state-level, a wide variety of bodies, procedures and methodologies exist to review perioperative deaths.



In Victoria, the Victorian Perioperative Consultative Council (VPCC) is the body that audits perioperative deaths. Two of the major causes of perioperative death in this state are a fractured neck of femur or acute abdominal pathology. These conditions also cause significant morbidity and loss of function among patients who survive their surgery and anaesthesia. The VPCC will encourage health services to participate in the Australia and New Zealand Hip Fracture Registry and Emergency Laparotomy audit. These quality improvement registries address the process of delivery and patient-related outcomes of care, with key performance indicators.

In Tasmania, the Tasmanian Audit of Surgical Mortality has developed key goals to improve clinical safety. These include collaborating with the cross-jurisdictional/national project, to develop best practice standards and guidelines for surgical practice and promoting the use of independent audits among surgeons.

Suicide Mortality Reviews

USA

The US Centre for Fatality Review and Prevention (2020) offers best practice guidelines for conducting suicide mortality reviews.

Data sources	Avenues of investigation for agencies involved	Death scene investigation protocols
Medical records, including primary care and emergency treatment Mental health records Substance use treatment records Family and peer interviews Child welfare records School records Law enforcement records Job/occupational records Social connections, including social media records, email records, texts, and other personal correspondence	Identity, including sexual orientation and gender identity Medical history, including mental health history and treatment, substance use history and treatment, history of impulsive behaviours, history of trauma, medication history and current prescriptions Family and social relationships; including relationship(s) with a significant other Living environment, including members of the household and those present at the time of the suicide School experience, academic history, peer and teacher relationships, and challenges Job or occupational history Warning signs or behaviour changes within the 30 days prior to the death	Any communication from the decedent about suicidal ideation or evidence of suicidal behaviours including a suicide note, social media posts, or text messages Evidence of substance use leading up to the suicide, including alcohol and marijuana Detailed notes about how the body was found Location(s) of other individuals in the area where the body was found Description of how the decedent died as well as any information about the decedent accessed them Following suicide mortality reviews, a recommended framework is provided to act upon



Following suicide mortality reviews, a recommended framework is provided to ensure actionable plans are produced and is outlined below. (Centre for Fatality Review and Prevention, 2020).

- **Describe the problem and its context:** Use data and other sources to understand how suicide affects the community and to describe the problem and its context. Fatality review data should be used to help understand the problem.
- **Choose long-term goals:** Identify a small set of realistic and achievable long-term goals (e.g., reduce the suicide rate).
- **Identify key risk and protective factors:** Prioritise the key risk and protective factors on which to focus prevention efforts.
- **Select or develop interventions:** Begin planning the approach by deciding which activity or combination of activities best address the key risks and protective factors.
- **Plan the evaluation:** Develop an evaluation plan to track progress towards long term goals, show the value of prevention efforts, and provide the information needed to refine, expand, or determine other next steps.
- **Implement and evaluate activities:** Use the evaluation data to monitor implementation, solve problems, and enhance prevention.

UK

In the UK, the National Confidential Inquiry into Suicide and Safety in Mental Health (University of Manchester, 2021) collects in-depth information on all suicides in the UK since 1996. NCISH recommendations have improved patient safety in mental health settings and have also reduced patient suicide rates, contributing to an overall reduction in suicide in the UK (Appleby, Kapur et al. 2021).

Alternative approaches to monitoring suicide

The literature base on suicide mortality review functions and frameworks is limited. However, alternative approaches to preventing suicide at a national level include national suicide prevention programmes. A recent study evaluated the effectiveness of national suicide prevention programmes by comparing suicide rates between control countries, and countries in which a prevention programmes had been implemented (Lewitzka et al., 2019). It was found that the implementation of a national suicide prevention programme is effective, with a major reduction in suicide rates, especially in males over 25 years.

A recent narrative analysis conducted by Zalsman et al. (2016) investigated the effectiveness of different suicide prevention strategies. There is sufficient evidence to support the strategies below as effective potential interventions using new social media, mobile technologies, and continuous monitoring of large datasets seem to be the next field to explore.

- Standards for evaluating suicide prevention initiatives are hard to come by. As a gold standard, randomised trials are the best approach whenever possible.



- Suicide prevention plans should be integrated with evaluative research, including access to adequate funding to encourage and allow such studies to take place. As suicide is a leading cause of death and disability, health-care providers and policy makers need to implement proven, evidence-based, and cost-effective plans to reduce it.
- This knowledge can be used to develop new suicide prevention strategies and action plans (both in health and other sectors), and to help agencies and services in the redesign of their policies, procedures and services.

In the US, a few states have utilised data from the National Violent Death Reporting System (NVDRS) to support local suicide prevention activities (Powell et al., 2006). These data describe victim characteristics and link them with suicide event characteristics, so the NVDRS can assist localities in clarifying their suicide issues. New suicide prevention partnerships have been formed based on NVDRS data findings.

Best Practices for Effective Mortality Reviews

Despite variance in mortality review methodologies outlined above, a literature review of 31 articles provides further considerations to support effective mortality reviews (Joseph et al., 2018). Though the review focuses on clinical contexts, the following recommendations are applicable to all mortality review functions.

- **Timing:** the literature widely acknowledged that timeframes of mortality reviews are important, but the evidence is unclear on the optimal time to conduct mortality reviews. This varies between jurisdictions and within the literature; options such as within 24 hours, within a week, weekly, monthly and bi-monthly are employed.
- **Terms of reference:** in incident reports and occurrence reports, only factual information should be provided, and any statements of blame, speculation, opinion or commentary about what led to the event must be restrained. It is crucial for mortality reviews to serve as a supportive, safe, and blame-free forum for improvement and accountability.
- **Governance and follow-up:** risk or quality teams are usually involved in the follow-up after MMRs because findings may be the result of issues with system processes. Leadership can be involved in the findings of MMRs but there is varied evidence of positions for follow-ups within the organisation. To assist with process improvement based on the MMR findings, improvement interventions determined by the MMRs should be communicated to frontline staff through governance and management positions. Leadership can monitor the progress, gain feedback, inform policy development, and improve the quality of care in the future.

Indigenous data sovereignty and equity

Indigenous data across colonising settler nation states largely resembles what Walter (2016) identifies as 5D data. This refers to the tendency of mainstream indigenous statistics to primarily focus on items relating to Indigenous differences, disparities, disadvantages, dysfunctions, and deprivations (Walter and Suina 2019). Additionally, 5D data is derived from a set of research practices that tend to the aggregate, thereby



decontextualising data which often leads to the unfavourable portrayal of indigenous peoples (Walter & Andersen, 2013).

While Indigenous peoples and geographies require different kinds of data, there is a broad consensus that data meets Indigenous needs and aspirations. (Rainie, Rodriguez-Lonebear et al. 2017, Walter and Suina 2019). These include, but are not limited to:

- Data that disrupt deficit narratives
- Data that are disaggregated
- Data that reflect the embodied social, political, historical, and cultural realities of Indigenous people's lives, as Indigenous peoples
- Data that address Indigenous nation re-building agendas.

Pertinent to disparities in indigenous mortality rates, Freemantle et al. (2015) highlight the inaccuracies in the identification of Indigenous status and collection of and access to data as a key barrier to the implementation of evidence-based public health initiatives and policies to reduce avoidable deaths. The inaccuracies through partial or erroneous data collection of indigenous population groups have historically been common within the settler nations (Australia, New Zealand, USA and Canada) through undercounting and exclusions of Indigenous groups from population health datasets which has affected the quality of Indigenous mortality rates.

According to the United Nations (2006), the preferred approach is to enable Indigenous persons to self-identify in censuses and other data collections, rather than be defined or have this imposed upon them by institutions. There have been advancements in the inclusion of Indigenous people in key data collections, but challenges remain with hesitancy to self-identify in fear of systemic racism (Coleman et al., 2016). It is important that definitions and methods of self-identification are agreed upon with Indigenous peoples enabled by data ownership, indigenous data collectors and community engagement strategies. Freemantle et al. (2015) assert that creating a partnership between indigenous organisations and institutional data agencies is essential to not only improve accuracy and reduce gaps in mortality rates, but also to enable transparency in the use and access to data for Indigenous health care planners and practitioners to inform policy change and initiatives.

The following is a comparison of progress in enabling indigenous data sovereignty across settler nations and examines frameworks and governance models that have been developed, as well as examples of data sovereignty applied in different indigenous contexts.

Canada

As a response to the problem of alienating indigenous groups from their own data, the OCAP (Ownership, Control, Access and Possession) framework was developed in Canada (Bruhn 2014).



- Ownership refers to the relationship of a First Nations community to its cultural knowledge, data, and information. The principle states that a community or group owns information collectively in the same way that an individual owns his or her personal information.
- Control asserts that First Nation communities and representative bodies are within their rights to control research and information management processes which affect them, including all stages of research projects, research policies, resources, processes, frameworks, data management, etc.
- Access refers to the right of First Nations people to access information and data about themselves and their communities regardless of where these are held, and to make decisions regarding access to their collective information.
- Possession refers to the actual custody and holding of the data. It is distinguished from ownership for being more literal in its understanding.

New Zealand

Ensuring Equity in Mortality Reviews

In 2019, Ngā Pou Arawhenua, the Māori caucus for the MRCs published Te Pou—the Māori Responsive Rubric (Wilson et al., 2020). Te Pou was developed to provide good practice expectations for the interpretation and reporting of Māori mortality, including disparities. A particular focus of Te Pou was to facilitate the generation of robust recommendations by the MRCs to advance equity in service delivery and prevention efforts by government agencies.

Te Pou outlines the four pou:

- Tika (Getting the story and the interpretation right)
- Manaakitanga (Being culturally and socially responsible)
- Mana (Advancing equity, self-determination, and social justice)
- Mahi tahi (Establishing relationships for positive change).

While the rubric was well received by the MRCs, the review found that there was a wide range of understanding within these committees pertaining to Māori health, equity and Te Tiriti o Waitangi. This poses a significant barrier to ensuring that MRCs would be able to effectively incorporate an equity lens in mortality reviews. Wilson et al suggest that more work needs to be done in this area. Furthermore, it was found that the rubric was not intertwined throughout the MRC process as intended.

In order to fully uphold the four pou, indigenous data protocols should be more formally integrated into the collection, analysis, and interpretation of data, such as in accordance with the principles of Māori data sovereignty developed by Te Mana Raraunga.

Implicit in Māori data sovereignty is the desire for data to be used in ways that support and enhance the collective well-being and self-determination of Indigenous people. (Hudson et al., 2016). In practice, Indigenous data sovereignty means that Indigenous peoples need to be the decision-makers around how data about them are used or deployed.



Māori Data Sovereignty (MDS) (Lovett et al., 2019)

Advocates for MDS in New Zealand are developing culturally appropriate data solutions which are tikanga-based. The following principles for MDS have been developed:

- Models of Māori/Iwi data governance for the Integrated Data Infrastructure and wider government data collection processes
- Cultural license as the social license alternative for community acceptability of data use
- Assessments of organisational capability to incorporate MDS through a Māori Data Audit Tool

Traditional data ecosystems are underpinned by Eurocentric legal concepts that emphasise the individual and give priority to characteristics such as privacy and ownership. This framework is not entirely coherent with the large-scale open data environments which are beginning to emerge. Approaches to data rights need to be reconceptualised, ensuring that communities from which data is drawn are the beneficiaries of data, rather than those who collect and produce the data. IDS and MDS demands clear lines of accountability and benefit-sharing; at the heart of these demands is a call for power-sharing. Seen this way, the potential benefits of embedding MDS principles across government data ecosystems extend beyond Māori to include the wider public

Australia

The Mayi Kuwayu: That National Study of Aboriginal and Torres Strait Islander Wellbeing (Lovett et al., 2019)

Mayi Kuwayu is a national Aboriginal and Torres Strait Islander longitudinal study. The study has been funded to develop understanding of the intersection between culture, health and wellbeing. The study was designed to adhere to IDS and IDG. The data development considerations in the Mayi Kuwayu Study include:

- Ensuring that data indicators are relevant and meaningful to indigenous peoples. This was achieved through the development of new data items that represent cultural expression and practice
- The Australian Code for the Responsible Conduct of Research that requires research data ownership and storage to be described
- Adherence to research ethics and intellectual property. Acknowledgement is given to sources of information and also to those who have contributed to the research. In cases where Indigenous knowledge contributes to intellectual property, it is important to recognise the contribution, where appropriate, by transferring or sharing intellectual property and any benefits that result from the research
- An Indigenous Data Governance group that develops data access and release protocols based on IDS principles.

In order to address the data processes above, the Mayi Kuwayu Study has developed a number of mechanisms. These include the involvement of Aboriginal and Torres Strait Islander communities within the leadership and management of the study from the outset, through the majority leadership of the study by



Aboriginal Chief Investigators and research staff. The research team conducted 24 focus groups with a wide range of Aboriginal and Torres Strait Islander groups across Australia to develop cultural data items; feedback was incorporated into measurement priorities while also seeking suggestions to ensure the methodology was culturally appropriate. The research institute and participants are co-owners of the data set in this study, as per institutional policy. Data storage, access, analysis, and dissemination protocols are being developed by the research team and the study governance group.

USA

Building a data revolution in Indian Country (Rodriguez-Lonebear, 2016)

Indigenous peoples in the United States are still catching up to the levels of indigenous data governance occurring in Australia, Canada and New Zealand. Historically, similar to other settler nations, the focus of Native Americans is at census levels where previously data has not been accurately or completely collected. Indigenous policymakers operate without reliable data that can be disaggregated to inform policy. The US also has no statistical data standard to manage and report tribal population data across agencies.

Unlike NZ, the US has no consistent criteria to delimit tribal populations in tribal country, state or federal datasets. Two-hundred and ninety-five sources of Indian country data were reviewed. It was found that less than 2% are from a tribal source, the remainder were from census or administrative agencies that each with their own methodology and definitions and administrative datasets. In addition, the dominant conventional demographic approaches, and methods do not support tribal development, and fail to illuminate the complex social structures, reality and aspirations of tribal nations.

Rodriguez-Lonebear (2016) highlights the need for more comprehensive tribal data systems to facilitate the relationship between federal and tribal priorities. In qualitative interviews conducted with 15 tribal leaders, all view that the futures of their tribes need to be built on data that are controlled by tribes. Tribes are often best positioned to capture the realities of their tribal situations but lack the capabilities to capture and analyse data.

Indigenous Mortality Monitoring and Reporting: Best Practices

The International Group for Indigenous Health Measurement (IGIHM) provides guidance around the best practice processes pertaining to the monitoring and reporting of indigenous mortality. The guidance consists of recommendations developed in workshops over the course of two years and covers identification, community engagement, and data usage (Coleman et al., 2016).

- Indigenous identifiers should be used in key data inputs such as the census, birth, and death certificates, with consistent phraseology employed between these inputs
 - New Zealand satisfies this recommendation through consistent identification across population statistics and the national health index number.
- Indigenous people should have the right to self-identify



- It is essential to involve indigenous communities at all stages of collection, analysis, and dissemination of data, as well as establish and maintain indigenous community ownership and reporting for all data processes.
 - In NZ, there are a few specific Māori led organisations which provide oversight. Te Kete Hauora is one such example and provided guidance for the Kaitiake Groups for Breast and Bowel Cancer Screening until 2016.
- The creation of partnerships between Indigenous peoples and statistical agencies is essential for national and regional data collection.
 - The Data Iwi Leaders Group of the National Iwi Chairs Forum is currently involved in the co-design of a Māori Data Governance model with Stats NZ to develop approaches to data governance which reflect Māori interests
- The triangulation of data is needed in situations where vital statistical records are incompletely identified or registered.
 - Multiple administrative databases are available in New Zealand that can be utilised to support Māori identification in cancer registries, and it has been shown that when multiple Māori identity databases are linked, Māori identification can be more accurate (and health disparities can be documented more accurately).
- Establishing practices to ensure data effective linkage occurs should be implemented in all collection events to adjust for under-identification.
- In order to avoid circularity, backcasting estimates of health trends should be based on sound underpinning assumptions about mortality trends.
 - Backcasting is a method of estimating what the population would have been in the years before the census to determine the current population count. A mortality estimate is required in this method. It becomes circular, then, if this is applied to mortality trends. It is therefore necessary to have some external, validated measure for the mortality assumption.
- While indirect methods are permitted in the calculation of life tables, assumptions in the methods need to be carefully considered.
 - The UN recommends using indirect methods when existing data is not clear. However, these practices are becoming less common in all nations.
- Mortality estimates are never 100% correct and this uncertainty needs to be explicitly acknowledged in official statistics.
 - In Australia, data pertaining to life expectancy are reported to one decimal point when uncertainty in the numerator and denominator are +/- 1.3 years.



Indigenous Mortality Monitoring and Reporting: Family Violence Reviews

(Wilson, 2017)

Worldwide, indigenous populations are overrepresented in deaths caused by family violence. When discussing domestic violence deaths in indigenous contexts, the literature suggests the term 'family violence' be used rather than 'domestic violence'. This acknowledges traditional indigenous family structures which include extended families, differing from the notion of the nuclear family. It also acknowledges that family violence within indigenous contexts is more pervasive than intimate partner violence.

Historical, social, and emotional landscapes should guide family violence death reviews as they help consider the intergenerational impact of colonisation on Māori, including education, assimilation, and urbanisation. These landscapes consider changes in cultural values, beliefs, practices and whānau functioning that have allowed violence to persist in some whānau and communities. It is within this context that the New Zealand Family Violence Death Review Committee (FVDRC) recognised the relationship of whānau violence with the persistent effects of colonisation, which extends beyond commonly understood coercive control and entrapment strategies associated with family violence. To prevent and eradicate whānau violence, individualised and culturally based interventions are needed.

Given the disproportionate impact of family violence, indigenous representation on death review committees is fundamental for culturally responsive interpretations of death reviews and recommendations arising from them. Wilson (2017) provides four key domains which can ensure improved future outcomes:

- **Being culturally responsive**
 - Reporting indigenous identities strengthens analysis and aids understanding. Enabling relevant and culturally appropriate recommendations.
- **Team composition**
 - Culturally responsive death reviews require the involvement of those with indigenous expertise, such as elders with a sound understanding of family violence and the aspects of the local context that may contribute to family violence.
- **Analysis of Information**
 - Taking a life-course approach that is inclusive of earlier generations, historical trauma, adverse childhood experiences and the broader effects of poverty.
 - Understanding local historical factors, such as colonisation and historical trauma, and contemporary factors, such as racism and marginalisation relevant to the indigenous community where a homicide occurred.
- **Recommendations**
 - Re-establishing and strengthening indigenous identity and cultural connections are important. While this is beyond the scope of death review committees, consideration should



be given to this when shaping recommendations for interventions and prevention initiatives. This means death review committees must also share their reports with relevant indigenous and community organisations.

Translating mortality review findings into policy recommendations

Suicide Reviews

A systematic review by Ramsey, Galway & Davidson (2021) looked to identify how recommendations from Serious Adverse Incident (SAI) reviews can be effectively implemented to contribute to reducing deaths by suicide within mental health services. The function of mortality review teams is to document learnings to prevent future deaths, therefore it is important to identify the most effective methods for implementing these recommendations.

The review identified 4 key implications for translating recommendations into policy:

Communication

- Investigative processes should ensure that each review following a patient suicide produces both recommendations for frontline services and recommendations that relate to wider systemic or strategic policies and procedures. Both types of recommendations should be presented in a way that will support or indicate the proposed methods of implementation. Additionally, recommendations should be communicated in a timely way to ensure they are translated into practice
- Evidence suggests that practical, sensible, and achievable recommendations are more likely to be implemented (Vrklevski et al., 2018)

Organisation of systems

- Thematic findings on implementation and evaluation support the development of standardised processes for implementation of recommendations from patient deaths by suicide
- Processes should include clear timescales for implementation and evaluation of the implementation
- Organisations committed to a robust culture of safety and learning (including implementation of recommendations and evaluation) can offer key direction for policy and practice and the potential to reduce patient suicides.

Culture and leadership in the implementation of recommendations

- A shift towards strong leadership and organisational culture to encourage a move away from the rhetoric of inevitability and blame
- To support organisations to change their cultural view towards suicide deaths, organisational leaders with experience in reducing the number of patient deaths by suicide, could work to support leaders in other organisations to reduce suicide deaths among the people that they serve (Battaglia et al., 2013).



Further investment in improved methodologies for evaluation of the implementation

- There is a lack of robust, causal evidence that implementation of recommendations results in safer patient care
- Further research to explore the effectiveness of change is vital to discover whether the implementation of recommendations has been effective in reducing patient suicide rates
- Ideally the data used to assess the effectiveness of implementation should be independent of the data generating the recommendations to be implemented

Scottish National Framework for Serious Adverse Events

(Healthcare Improvement Scotland, 2013)

After analysis of the adverse event and agreement on the contributory causes, the review team should make recommendations to improve future care delivery. The recommendations are actions that the review team want the lead director/senior manager and the involved services to consider. A recommendation must make clear what it aims to improve or how it will minimise risk. The review team should consider how the recommendations will support changes in practice and quality improvement. For example, recommendations for interventions that design out as far as possible the human component in the process achieve more than recommendations that rely on changing the behaviour of people. High reliability is rarely achievable with interventions that rely on people behaving consistently. The recommendations should indicate the timescale for making a decision about whether the recommendations will be accepted and for developing the improvement plan, but it is not the responsibility of the review team to produce the improvement plan.

Lessons from Maternal Mortality Review Committees

(Anderson & Sokol, 2020)

- Creating actionable recommendations
 - All recommendations should be clear, concise, and actionable. Each recommendation should be themed and given a priority score. Recommendations that are similar in nature should be bundled and refined to identify overarching commonalities. It is recommended that standardised processes are implemented to facilitate dissemination and ensure follow up.
- Advocate for financial and policy support
 - Anderson notes that coordination between organisations with similar interests regarding policy actions facilitated the translation of recommendations into policy actions. For example, stakeholders from maternal and infant care mortality review groups have collaborated to gain the attention of policy makers. This has allowed for cross-sectoral collaboration and the development of highly integrated interventions.

A separate mortality review committee offers further insights into the implementation of mortality review recommendations (Shellhaas et al., 2019).



- It is acknowledged that though the maternal mortality review committees produce recommendations, they might not be the best placed organisation to implement these recommendations.
- In the context of maternity mortality, state perinatal quality collaborative, perinatal centres, medical associations or advocacy organisations need to be engaged to ensure effective implementation.
- Underpinning this is the need to identify relevant stakeholders with a joint interest in the implementation of recommendations to establish the support required to enact change.

Lessons from a Child Death Review Committee

- Mazzola and colleagues (2013) found that child death review committees experience major difficulties in implementing recommendations.
- Addressing these challenges requires:
 - Improved information sharing processes between relevant stakeholders.
 - Timely publications of reports that highlight specific and measurable recommendations.
 - Integrating findings from child mortality reports with strategic needs assessments.

Recommendations of Domestic and Family Violence Death Reviews in Australia

(Australian Human Rights Commission, 2016)

Across different states in Australia, domestic and family violence death review teams have differing approaches to formulating recommendations and monitoring progress and uptake of the recommendations. In Victoria, Queensland and South Australia, recommendations are delivered via coronial findings. In New South Wales, recommendations are set out in the state's DFVDRT annual reports. While in Western Australia, the Ombudsman makes recommendations to public authorities.

In particular, the recommendations proposed by Queensland DFVDRT contain specific recommendations made to the Minister as to legislation, policies practices, services, and communications for implementation by government and non-government agencies.

In New South Wales recommendations are tabled in Parliament. They identify specific agencies to lead implementation and mandate agencies and government to co-ordinate a whole-of-government response (whether support, support in principle, or not support) for each recommendation within six months of the report being published. Subsequently, monitoring reports are published annually to highlight progress made on the recommendations which require responses from agencies and governments on progress and activity on implementation. These reports are made public to foster accountability.

Although effort has been made on ensuring agencies are held accountable to the recommendations made by the DFVDRT, a survey by the Australian Human Rights Commission to the Coroners indicated that improvement would be made by establishing a national reporting monitoring system.



All-cause mortality monitoring

(Statens Serum Institut, n.d.) (Cox et al., 2010)

Timely and robust epidemiological monitoring of disease is a key component of public health preparedness and can be used to inform prevention or control strategies, as well as be of value to policy makers and the public. The emergence of COVID-19 has highlighted the utility of bodies with this monitoring function. In Europe, 24 countries contribute to EuroMOMO, a mortality monitoring activity that aims to detect and measure excess deaths related to seasonal influenza, pandemics and other public health threats.

The most recent overhaul of EuroMOMO intends to deliver weekly updates regarding the following indicators:

1. Observed number of deaths
2. Expected Number of Deaths (Expected Baseline)
3. Deviation from the baseline (difference between observed and expected number of deaths)
4. Number of Deaths corrected for delay in data transmission

Using these indicators and various statistical tools, EuroMOMO has the capability to rapidly analyse fluctuations in mortality data. EuroMOMO cites its utility in the 2009 H1N1 pandemic where it was able to identify an absence of an increase in excess mortality despite an increase in reported cases. Such outputs are particularly useful in the context of an emerging pandemic caused by a new infectious agent, where the true mortality burden is difficult to ascertain and compare between countries. These outputs facilitate more effective decision making for government, health officials and other relevant authorities.

Beyond its use in pandemics, monitoring of all-cause deaths through bodies like Be-MOMO (Belgium) or EuroMOMO provides a major source of timely data on the progression and impact of health threats, crucial to guide health service response and public health decision-making. The need for high-quality early warning has been accentuated by several public health issues: 1) the expected increase in extreme weather events due to climate change 2) the possibility of infectious and non-infectious diseases emerging 3) concern over deliberate releases of dangerous substances.

Conclusion

This review was able to compare international mortality review practices and identify some emerging initiatives to improve the monitoring of mortality at a national level. Due to the paucity of work in this area, these practices have been drawn from a collection of case studies, policy documents and discussion papers rather than best-practice literature.

Although the examined countries for the most part lack a single national entity responsible for mortality reviews, many have processes in place which function well at the local and state level. Ideas for developing recommendations that are relevant and applicable to the New Zealand context. Including engaging with the wider sector and incorporating a focus on holding government and other agencies accountable for progress



and uptake of recommendations.

Given that the SuMRC committee was not established at the time of the previous literature review, it is worth noting that scant literature was found specific to a distinct entity like that of SuMRC. Rather, the 'physiology' of a suicide review function manifested itself through suicide prevention programmes which monitored deaths and promoted preventative initiatives, and within the scope of other existing mortality review functions such as domestic and family violence review teams.

Throughout the literature, there was a recurring emphasis on the importance of mortality reviews being "blame-free" as this enables collective prioritisation of goals and fosters cross-sector collaboration. Another emerging finding relates to the involvement of whānau in mortality reviews. A practice which is becoming increasingly common in child death reviews, though there is inconclusive evidence around the impact of whānau inclusion. There is consistent messaging from a growing number of studies as to the efficacy of mortality review entities in the reduction of preventable mortality.

Literature on approaches to mortality reviews for indigenous populations was rather limited internationally. However, it was identified that New Zealand's mortality review programme is at the vanguard of producing literature and studies in this domain. Likewise, many frameworks and discussion papers were found on indigenous data sovereignty, but international literature (white and grey) point to New Zealand as being at the forefront of improving indigenous data sovereignty and promoting control over access, collection and outputs of data. As a light touch literature review, there is a possibility that the review did not locate all relevant studies. It is also possible that relevant indigenous approach descriptions have been misclassified.

While this review intended to capture practices that enable the translation of mortality review recommendations into tangible system wide changes, the literature base was limited and acknowledges that implementing recommendations is a challenge faced by mortality review committees in all jurisdictions.

Broadly, the literature suggests the following to improve the implementation of recommendations into practice:

- Recommendations should be actionable
- Recommendations should be made to a wide range of stakeholders at the community, service delivery and policy level
- It is important to identify and engage the most relevant stakeholders within the context of the recommendations
- Information sharing between key stakeholders can facilitate the implementation of recommendations
 - Quarterly/annual publications that are standardised support this
- Aligning recommendations with needs assessments of key stakeholders
- Recommendations should be underpinned by robust evaluation frameworks

Despite these limitations, the review can be used to compare approaches from international models of practice and inform consideration of any adoptions into New Zealand mortality review functions.



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