First Principles Review of the National Mortality Review Function

Terms of Reference

July 2021

Te Kāwanatanga o Aotearoa

Health Quality & Safety Commission New Zealand
Kupu Taurangi Hauora o Aotearoa

Purpose

1. These terms of reference set out the purpose of a first principles review (the review) of the national mortality review function, as well as its scope, approach, process, outputs and timeline. The terms of reference also include the governance and stakeholder input.
2. The review intends to reflect on whether we can enhance the value and contribution that mortality review makes to system improvement in health and across government. It will provide a blueprint for a refreshed national mortality review function, identifying what is the most appropriate and effective way to undertake mortality review, and deliver the most useful information for impact, in Aotearoa New Zealand. It will be underpinned by Te Tiriti o Waitangi (Te Tiriti) partnership in its design and delivery, while cognisant of future health system changes relating to Health New Zealand, the Māori Health Authority and the Ministry of Health.
3. The intention of the review is to ensure that any future blueprint of the national mortality review function:
    a. fully embeds and enacts Te Tiriti and supports mana motuhake to ensure we meet our responsibilities, obligations and commitments
    b. articulates a clear intention for a national mortality review function, and is supported and understood by key stakeholders
    c. operates with impact, effectiveness and efficiency
    d. produces actionable recommendations that seek to inform sustainable system improvement at both local and national levels.

Background

4. The Health Quality & Safety Commission (the Commission) was established in 2010. Included among its statutory duties, the Commission inherited a mortality review function involving four mortality review committees (MRCs). The four MRCs all seek to reduce preventable mortality within their scope. MRCs were previously ministerial committees that reported to the Minister of Health and became 'statutory advisors' to the Commission board in 2010 legislation amendment.[1] The MRCs include the following:
    a. Child and Youth Mortality Review Committee (CYMRC), established in 2002, which reviews deaths of children and young people aged 28 days to 24 years.
    b. Perinatal and Maternal Mortality Review Committee (PMMRC), established in 2005, which advises how to reduce the number of deaths of babies and mothers in New Zealand. The Committee are also supported by a Neonatal Encephalopathy Working Group (NEWG) and Maternal Mortality Review Working Group (MMRWG).
    c. Family Violence Death Review Committee (FVDRC), established in 2008, which reviews all deaths related to family violence in Aotearoa New Zealand.
    d. Perioperative Mortality Review Committee (POMRC), established in 2010, which reviews all deaths related to surgery.
5. In 2017 a fifth MRC, the Suicide Mortality Review Committee (SuMRC), was established by the Commission to review and advise on how to reduce the number of deaths by suicide in Aotearoa New Zealand. Additional funding was provided from the Ministry of Health, within an annual contracting arrangement, to support the SuMRC.
6. The current national mortality review programme (NMRP) costs approximately $3.2 million per annum across four MRCs, with the SuMRC funded in addition to this.
7. The NMRP has greatly contributed to the knowledge and surveillance of key issues within the five scope areas of the MRCs. The MRCs have provided valuable focus, advice and recommendations aimed at driving improvement and the MRCs are well known within their areas of expertise. The analysis and epidemiology applied through mortality review to date has been fundamental to achieving this.
8. Twenty years on from the legislation that founded the current mortality review system, it is appropriate to reflect on whether we can enhance the value and contribution that mortality review makes to system improvement in health and across government. Mortality review in Aotearoa New Zealand needs to give true effect to

[1] Under Section 59E of the New Zealand Public Health and Disability Act – see https://www.hqsc.govt.nz/our-programmes/mrc/about-us/legislation.

our responsibilities to Te Tiriti, supporting mana motuhake; place equity at the centre of quality; drive and facilitate significant system- and service-level improvement; and more strongly centre on consumers and whānau.

9. In March 2021, the Commission received its Letter of Expectations (LoE) from the Minister of Health, Hon Andrew Little, asking it to:

> 'consider whether the current mortality review committee structures are fit for purpose and delivering the most useful information in the most effective manner. Once the impact of the Health and Disability System Review on the wider sector are known, HQSC could also give some consideration to whether changes to the role and functions of the committees would be appropriate and provide me with some advice accordingly.'

Scope

10. In response to the Minister of Health's LoE, the Commission's board agreed, at their meeting on 26 March 2021, to undertake a 'first principles' review of the national mortality review function in Aotearoa New Zealand, with a vision to redesigning 'a quality, Te Tiriti-based, mortality review system to last a generation'.
11. The review will provide the board with a vision and intention for the national mortality review function in Aotearoa New Zealand. It will also identify the fundamentals of mortality review required to achieve the vision and intention. The review will not assume that the current committee structure will continue.
12. The review will identify a blueprint for a national mortality review function. The scope of the review is limited to:
    a. exploration of the purpose and relevance of national mortality review and whether it is still a required system-level improvement function
    b. a review of the data and methodologies, including privacy and legal considerations, that provide the current foundation for national mortality review in Aotearoa New Zealand
    c. an assessment of what has been achieved across the MRCs since their inception
    d. design of a national mortality review blueprint, including function and structure, which aligns with the *Principles of Māori Data Sovereignty*[2] and *Te Pou – Māori responsive rubric and guidelines*[3]
    e. a review of the legislative provisions [in the Act] and whether these need to be changed to support the revised national mortality review function identified through the review.

[2] Te Mana Raraunga Māori Data Sovereignty Network. 2018. *Principles of Māori Data Sovereignty*. URL: https://static1.squarespace.com/static/58e9b10f9de4bb8d1fb5ebbc/t/5bda208b4ae237cd89ee16e9/1541021836126/TMR+Ma%CC%84ori+Data+Sovereignty+Principles+Oct+2018.pdf.
[3] Health Quality & Safety Commission. 2019. *Te Pou – Māori responsive rubric and guidelines*. URL: www.hqsc.govt.nz/publications-and-resources/publication/3903.

Approach

13. The review will do the following:

a. *Map the current state*

i. Complete a review and critical analysis of the current NMRP – a history or whakapapa of the NMRP, what has worked, what has effected change, what improved outcomes can be attributed to the NMRP, what have been the barriers to transformational change and the extent to which it meets its objectives, and the limitations of the current scope. The review should give particular regard to:

- a comprehensive assessment of the review methodologies used across the current NMRP, including a review and analysis of the data ecosystem that is its current foundation and its enactment of Te Tiriti, and alignment with the *Principles of Māori Data Sovereignty* and *Te Pou – Māori responsive rubric and guidelines*
- an assessment and analysis of the privacy and legal considerations and the interface with other death review functions (ie, Office of the Chief Coroner) that currently exist across mortality review and its data ecosystem, identifying any issues or constraints that might exist in enabling a changed future state.

b. *Articulate a future state*

i. Provide a comprehensive assessment of the purpose and intention of mortality review, its relevance in 2021 and how it can contribute to service- and system-level improvement. What should an agile, responsive national mortality review function look like in 2021? Should morbidity or near-misses,[4] and the relationship to the reporting and review of adverse events, be reviewed alongside mortality? Preventable death versus non-preventable death? What should the review of Māori mortality look like? Where does a surveillance function fit? How is Te Tiriti operationalised in the review of mortality? The assessment should give regard to:

- recognising the kaitiaki role that the national mortality review function holds in reviewing particular deaths and harm, in order to learn about how to best reduce preventable deaths in the future for families and whānau
- acknowledging the place of tapu and noa in mortality review and explore how the review of deaths can traverse these concepts to enable system-level improvements

[4] Across the current MRC scopes there are various terminology used to describe near death or morbidity.

- learning from best practice, international and Indigenous knowledge within mortality review
- what would be the most effective way of using the knowledge and data held by the NMRP to help reduce preventable deaths
- considering the Commission's role and responsibilities in relation to local and regional review.

c. *Future design recommendation*

   i. Design a mortality review blueprint informed by the current state review and the articulated future state, underpinned by Te Tiriti. The design should give particular regard to:
      - alignment of the *Principles of Māori Data Sovereignty* and *Te Pou – Māori responsive rubric and guidelines* in the design of the national mortality review function
      - consider the context and impact of the larger health and disability system transformation and the role of the Commission in the monitoring and support of quality care, and how mortality review contributes to this.

   ii. Develop costings for the revised national mortality review function.

Process

14. The review will be undertaken in the following phased methodology.

Phase 1 – planning

15. Further planning will be undertaken once the review team has been established. The review plan will provide the detail of the review against the terms of reference. This will include more specific information on the outputs, timeframes and associated milestones, stakeholder engagement and communications, external working group and confirmation of the governance and advisory arrangements.

Phase 2 – information-gathering

16. The information-gathering phase includes two key aspects, a literature review and stakeholder engagement. The scope and methodology for the literature review will be established during the planning phase.

    a. *Literature review*
        i. The purpose of the literature review is to learn from local and international best practice and lessons learnt. The review will be a synthesis that incorporates quantitative and qualitative information and commentary.
        ii. The literature review will consider: differences between what is done in Aotearoa New Zealand and what is done elsewhere, and the relative benefits of differing approaches; any information on Indigenous models or experiences; and emerging issues of relevance.
        iii. Searches will be conducted on research databases and government agency sites.

    b. *Stakeholder engagement*
        i. The purpose of the engagement is to understand the needs of the current and future system from a broad range of stakeholder groups, previously and currently engaged across all aspects of national and local mortality review, including Māori health, social and justice sector expertise, consumer advocacy groups and government agencies.
        ii. The purpose of this phase is three-fold:
            - Ensuring existing knowledge and expertise is captured and utilised.
            - Ensuring the sector is able to have meaningful input to the review and that they are heard, and their contributions are valued.
            - Gathering a broad range of views about what a future national mortality review function would look like and why.

Phase 3 – critical review of the current NMRP

17. Specific activities during this phase will include: mapping of current processes and their alignment with the *Principles of Māori Data Sovereignty* and *Te Pou – Māori responsive rubric and guidelines*; review of governance structures and processes; review of secretariat support; review of legislative requirements; and stocktake of recommendations and translation into quality improvement/system-level improvements. Is the programme delivering what it was designed to deliver?
18. This will require specific stakeholder engagement and a review of the NMRP to date. The work undertaken by MartinJenkins in 2012 could provide useful intelligence into this phase of the review.

Phase 4 – future state mapping, final analysis and reporting

19. This phase will bring together all the information gathered through the course of the review to reimagine a blueprint for mortality review in Aotearoa New Zealand. A final report will provide:
    a. a summary of the literature review
    b. a summary of stakeholder feedback regarding what a future national mortality review function should include, including structure governance
    c. an overview of the current programme's strengths and weaknesses, including an assessment of the current data ecosystem and its alignment with the *Principles of Māori Data Sovereignty* and *Te Pou – Māori responsive rubric and guidelines*
    d. a summary of legislative requirements, issues and barriers to change
    e. a blueprint for a refreshed national mortality review function, underpinned by Te Tiriti, with clear, actionable recommendations to direct the future of the NMRP and costings
    f. advice to manage the process for implementing any recommended changes (eg, key steps in the development of a realistic change programme, issues to consider and timing).
20. The Commission requires two face-to-face presentations to its board. The first is to provide and seek initial feedback on a draft report on the review; and finally, to present the final report.

Outputs and timeline

To be confirmed during the planning phase.

Governance and advisory arrangements

21. The final review report is being produced for the consideration by the Commission's board. The review recommendations will be considered by the board at the conclusion of the review.

Board oversight group

22. The board has nominated a sub-group of the board to oversee the review, comprising Professor Peter Crampton, Dr Tristram Ingram, Dr Collin Tukuitonga, Ria Earp and Rowena Lewis.
23. The board oversight group will meet as required in accordance with the milestones set out in the planning phase.

Expert advisory group

24. The review process will be overseen by an expert advisory group (EAG). The EAG will be established during the planning phase to provide ongoing guidance to the review team, in accordance with the terms of reference, for the duration of the review. A representative from the review team will meet with the EAG [frequency to be confirmed] to provide updates on the progress of the review.
25. The EAG will comprise mortality review expertise, Māori health and social sector expertise, and consumer/lived experience representatives.

Stakeholders

26. The review will be informed by a broad range of stakeholders. A stakeholder engagement plan will be more fully developed during the planning phase of the review and as such will be overseen by the EAG.
27. Key stakeholders and stakeholder groups include (but are not limited to): NMRP governance (committee chairs, committee members, Ngā Pou Arawhenua), Commission governance, NMRP secretariat (Commission-based), NMRP agents (including working groups, CYMRC local coordinators and groups, PMMRC local coordinators, the New Zealand Mortality Review Data Group), Māori and iwi leaders, key health and disability stakeholders and consumers [to be expanded], expertise in the epidemiology of mortality review, Māori health/public health experts, non-health stakeholders – wider systems, including social and justice sector stakeholders, public and consumer representatives, Office of the Chief Coroner, consumer advisory network and Office of the Children's Commissioner.