

# Health and Disability Ethics Committee

## Terms of Reference

**Scope** These Terms of Reference apply to all Health and Disability Ethics Committees (HDECs) established by the Minister of Health, including:

- Northern A Health and Disability Ethics Committee
- Northern B Health and Disability Ethics Committee
- Central Health and Disability Ethics Committee
- Southern Health and Disability Ethics Committee.

For the purposes of these Terms of Reference, the four HDECs are collectively referred to as the Health and Disability Ethics Committees (HDECs).

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**Establishment** The HDECs are Ministerial committees established pursuant to section 87 of the Pae Ora Act (2022).

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**Purpose and approach – Te Kaupapa** The function of the HDECs is to secure the benefits of health and disability research by checking that it meets or exceeds established ethical standards. These standards are contained in:

*The National Ethical Standards for Health and Disability Research and Quality Improvement (NEAC, 2019).*

In doing so, the HDECs must act in accordance with the procedural rules contained in the Standard Operating Procedures for Health and Disability Ethics Committees and with the requirements of New Zealand law.

To support this the HDECs are expected to provide independent ethical review that:

- recognises the special relationship between the Crown and Māori under Te Tiriti o Waitangi, with a view to improve the health and wellbeing of Māori
- prioritises equity-based approaches, particularly for Māori
- is informed by and reflects the perspectives of Māori and Pacific peoples and the wider community.

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**Authority** Jointly with any other health and disability ethics committee(s), the HDECs shall have responsibility for reviewing health and disability research occurring anywhere in New Zealand.

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**Membership**

Each HDEC commonly comprises eight to 11 members.

At least three members of each HDEC must be laypersons. A layperson is a person who:

- is not a registered health practitioner, and has not been a registered health practitioner at any time during the five years preceding the date of their appointment
- is not involved in conducting health or disability research, or employed by an organisation whose primary purpose relates to health and disability research<sup>1</sup>
- would not otherwise be construed by virtue of employment, profession, relationship or otherwise to have a potential conflict or bias.

Each HDEC's lay membership should collectively have experience and expertise in:

- law (preferably medico-legal expertise)
- ethical and moral reasoning
- the perspectives of consumers of health and disability services, and the community.

Each HDEC's non-lay membership should also include persons with experience and expertise in:

- the design and conduct of observational studies
- the provision of health and disability services
- and must include at least two persons with experience and expertise in the design and conduct of interventions studies.

Either lay or non-lay membership must include at least one member who is confident in mātauranga Māori.

At least two members should have confidence in mātauranga Māori.

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**Terms of appointment**

The Minister of Health may appoint members of the HDECs for terms of office of up to five years.

Any member of the HDECs may resign at any time by giving written notice of this to the Minister of Health.

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<sup>1</sup> For example, a lay member who fills a medico-legal or ethicist role may work at an institution that does conduct health research, but either they are not primarily involved, or it is not the primary purpose of the institution e.g., a university.

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Any member of the HDECs may be removed from office by the Minister of Health, at any time and entirely at the Minister's discretion, by written notice to the member.

Any member who is absent without reasonable excuse from three consecutive Committee meetings they are assigned to shall be considered to have vacated their office. It is expected that all members will strive to attend all meetings they are assigned to, sending apologies to the Secretariat a fortnight in advance for required absences.

Every member of the HDECs shall continue in office until their successor comes into office unless they resign, vacate, are removed from office, or are informed by the Minister that their services are no longer required.

Members may be assigned to meetings of another HDEC where required.

No person may be appointed to be a member of more than one HDEC at the same time, other than when members are co-opted across committees in accordance with the Standard Operating Procedures.

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**Training and education**

Newly appointed members must receive induction materials upon appointment, and training and support on an ongoing basis.

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**Duties of members**

All persons appointed as members of the HDECs must:

- review full, expedited, and post-approval applications as assigned by the Secretariat
  - be committed to securing the benefits of health and disability research by checking that research meets or exceeds established ethical standards
  - perform their functions impartially and with good faith, honesty, and integrity, identifying and actively managing any real or perceived conflicts of interest.
  - treat other members, researchers and the secretariat courteously and with respect at all times
  - comply with any Code of Conduct or similar expectations issued by the Ministry for the purpose of supporting the effective operation of the HDEC system
  - possess an attitude that is accepting of the values of other professions and community perspectives
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- make all reasonable efforts to participate fully in the Committee's business
  - meet reasonable expectations set by the Secretariat (including in the Standard Operating Procedures)
  - act responsibly with regard to the effective and efficient use of public funds
  - treat commercially sensitive information as confidential
  - ensure that any written or oral communication undertaken as a member is professional and appropriate
  - keep the Chair and Secretariat informed of any potential conflicts of interest that may arise in a meeting, well before the meeting.

Collectively all members of the HDEC are expected to demonstrate the following expertise and attributes:

- knowledge of and expertise in the obligations of the Crown under Te Tiriti o Waitangi, National Ethical Standards for Health and Disability Research, and Pae Ora (healthy futures) Act
  - knowledge of and expertise in the role of the health and disability research sector in achieving equity and improving health outcomes for Māori, Pacific peoples and other populations experiencing inequity.
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### **Disclosures**

In their relationship to the Minister and Ministry of Health, Committee members should be guided by a "no surprises" principle. As a general rule, members should inform the Ministry of Health promptly about matters of significance outside their involvement in the Committee, particularly where these matters may make their membership controversial or if the member may become the subject of public debate.

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### **Chairperson**

The Minister shall appoint a lay member of each HDEC to be its Chairperson. The Chairperson shall preside at every meeting at which they are present.

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### **Deputy Chairperson**

The Minister shall appoint a member of each HDEC to be the Deputy Chairperson.

The Deputy Chairperson may act in place of the Chairperson where the Chairperson is unavailable or has a conflict of interest.

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|                                       | Where required, another HDEC member may act in place of the Chairperson or Deputy Chairperson.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| <b>Consultation</b>                   | The HDECs may consult with experts in performing their functions.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Reporting</b>                      | <p>The HDECs must provide a single annual report on their activities to the Minister of Health. This report must include:</p> <ul style="list-style-type: none"> <li>• a report from the Chairpersons on the operation and performance of the HDEC system during the year</li> <li>• information on the operation and performance of the HDEC system</li> <li>• information on compliance with review timelines, including the number and proportion of applications reviewed within required timeframes</li> <li>• a list of complaints received about decisions made by the HDECs</li> <li>• any other information requested by the Minister of Health.</li> </ul> |
| <b>Fees and allowances</b>            | <p>Members of the HDEC shall be paid fees in accordance with the Public Service Commission's framework for fees for statutory bodies. The HDEC is a Group 4 Level 3 body for the purposes of this framework.</p> <p>Information on current fee rates, allowances, and reimbursement arrangements will be maintained and made available by the Ministry of Health.</p> <p>Actual and reasonable expenses (including travel) may be reimbursed with prior-approval from the Secretariat in line with the Ministry's policies and procedures.</p>                                                                                                                       |
| <b>Role of the Ministry of Health</b> | <p>The Ministry of Health supports the effective operation of the Health and Disability Ethics Committees (HDECs) on behalf of the Minister of Health by providing Secretariat services and administering the HDEC system.</p> <p>The Ministry is responsible for ensuring that HDECs are able to perform their functions efficiently, consistently, and in accordance with these Terms of Reference, the Standard Operating Procedures, and all relevant legislation.</p> <p>In carrying out these responsibilities, the Ministry must maintain and support the independence of HDECs in their ethical review and decision-making functions.</p>                    |