# **Appendix D - Central Health and Disability Ethics Committee Terms of Reference**

## Terms of Reference

**Establishment** TheCentral Health and Disability Ethics Committee (HDEC) is a Ministerial committee established pursuant to section 87 of the Pae Ora Act (2022).

**Purpose and approach – Te Kaupapa**

The function of the HDEC 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 HDEC 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 HDEC is 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.

**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.

**Membership**  The HDEC may commonly comprise eight members.

At least three members of the 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[[1]](#footnote-1)
* would not otherwise be construed by virtue of employment, profession, relationship or otherwise to have a potential conflict or bias.

The 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.

The 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.

**Terms of appointment** The Minister of Health may appoint members of the HDEC for terms of office of up to five years.

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

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 shall be considered to have vacated their office. It is expected that all members will strive to attend all meetings, sending apologies to the Secretariat a fortnight in advance for required absences.

Every member of the HDEC 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.

No person may be appointed to be a member of more than one health and disability ethics committee at the same time, other than when members are co-opted across committees in accordance with Chapter 5 of the SOPs.

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

**Duties of members** All persons appointed as members of the HDEC must:

* 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
* possess an attitude that is accepting of the values of other professions and community perspectives
* make all reasonable efforts to participate fully in the Committee's business
* 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.

**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.

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

**Deputy Chairperson** The Minister shall appoint a non-lay member of an HDEC to be the relevant Deputy Chairperson. The Deputy Chair will support the Chair in expedited review, and post-approval submissions

The Deputy Chairperson or alternative HDEC Chair may preside at single meetings where the Chair is absent or has a conflict of interest. For longer-term absences another HDEC Chair should preside.

**Consultation**  The HDEC may consult with experts in performing its functions.

**Reporting** The HDEC must provide an annual report on its activities to the Minister of Health. This report must include:

* a report from the Chairperson on the Committee’s work during the year
* a list of members, including brief biographical details
* details of meetings held during the year, including attendance by members
* a brief summary of the applications reviewed during the year, including for each application the title, the name of the Principal Investigator, the final decision reached, and the time taken to reach that decision
* a list of instances of non-respect for review timelines, giving brief reasons
* a list of complaints received about decisions made by the HDEC.

**Fees and allowances** 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 level 4(4) body for the purposes of this framework.

The Chairperson shall receive a fee of $498 per day for meetings, preparation, and business conducted between meetings, to a maximum of nine days work per month.

The Deputy Chairperson shall receive a fee of $369 per day for meetings, meeting preparation and business conducted between meetings, to a maximum of nine days work per month.

Other members shall receive a fee of $369 per day in respect of meetings, meeting preparation and business conducted between meetings, to a maximum of four days' work per month.

Actual and reasonable training expenses (including travel) may be incurred by members and may be reimbursed with prior-approval from the Secretariat.

1. 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. [↑](#footnote-ref-1)