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|  | **Terms of Reference**  **Central Health and Disability Ethics Committee** |

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

**Function** 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.

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

**Membership** The HDEC should usually 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
* 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 must include at least one lawyer, preferably with medico-legal expertise.

The HDEC’s lay membership should include persons with experience and expertise in:

* ethical and moral reasoning
* the perspectives of consumers of health and disability services, and the community.

The HDEC’s non-lay membership must include at least two persons with experience and expertise in the design and conduct of intervention~~s~~ studies. It should also include persons with experience and expertise in:

* the design and conduct of observational studies
* the provision of health and disability services.

At least one member should have a recognised awareness of te reo Māori and understanding of tikanga Māori.

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

Unless they sooner resign, vacate or are removed from their office, every member of the HDEC shall continue in office until their successor comes into office.

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.

**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
* 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.

**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.

**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 $365 per day for meetings, preparation, and business conducted between meetings, to a maximum of nine days work per month.

Other members shall receive a fee of $270 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 travel and accommodation expenses incurred by members and associated with the work of the HDEC shall be reimbursed.