



National Ethics Advisory Committee

Kāhui Matatika o te Motu

National Ethics  
Advisory Committee  
Kāhui Matatika o te Motu  
**Annual Report 2018**

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Seventeenth Annual Report  
to the Minister of Health

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## Foreword

**E ngā iwi, e ngā mana, e ngā reo. E ngā karangatanga maha, tēnei te mihi.**

**Tēnei te mihi i runga i ā tātou mate kua whetūrangitia. Rātou kua piki ake ki Paerau ki te huihuinga o te Kahurangi, moe mai rā.**

**Hoki mai ki ā tātou te hunga ora e pīkau nei ngā mahi mo ā tātou whānau. Tēnā tātou katoa.**

This annual report sets out the activities of the National Ethics Advisory Committee – Kāhui Matatika o te Motu (NEAC) and summarises its advice on matters referred to it under section 16 of the New Zealand Public Health and Disability Act 2000.

NEAC is an independent advisor to the Minister of Health and operates independently of the Ministry of Health and its work. NEAC's statutory functions are broad and strategic. They include advising the Minister of Health on ethical issues of national significance in respect of health and disability matters and determining nationally consistent ethical standards across the health system. NEAC's view of ethics involves identifying what matters, explaining how the sector can act and encouraging ethical decision-making.

NEAC's main focus during 2018 has been the review of our 2012 ethical guidelines (or standards) for researchers. NEAC members and the standards working group have been updating the main chapters in those guidelines and, in particular, developing new chapters not previously covered. We released a draft version of the revised standards for public consultation in July 2018, and the public feedback followed the 80/20 rule of being 80 percent positive. Some feedback suggested particular areas to strengthen and include, which became the main focus between September and December.

We would like to thank the many organisations and individuals who contributed to our work and public consultations this year. Your input helps us to ensure that our work is useful and addresses the issues that you consider important.

In October this year, we farewelled Julian Crane, a health researcher and member who made a significant contribution to NEAC governance over many years.

We have continued to be exceptionally well supported by the Secretariat at the Ministry of Health over a period of significant change during 2017 and 2018.

On behalf of NEAC, I am pleased to present this annual report for 2018.



Neil Pickering  
**Acting chair**  
**National Ethics Advisory Committee**  
**Kāhui Matatika o te Motu**

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# Introduction to the National Ethics Advisory Committee

## Functions of the National Ethics Advisory Committee

The National Ethics Advisory Committee – Kāhui Matatika o te Motu (NEAC) is an independent advisor to the Minister of Health. Its statutory functions, under section 16 of the New Zealand Public Health and Disability Act 2000 (the Act), are to:

- advise the Minister on ethical issues of national significance in respect of health and disability matters (including research and health services)
- determine nationally consistent ethical standards across the health sector
- provide scrutiny for national health research and health services.

NEAC works within the context of the Act and key health and disability policy statements. Section 16(6) of the Act states that NEAC must, 'at least once a year, deliver to the Minister a report setting out its activities and summarising its advice on the matters referred to it under this section'.

## Membership of the National Ethics Advisory Committee

The Minister appoints the members of NEAC, who come from a range of professions and backgrounds and bring expertise in ethics, clinical leadership, health service provision, health and disability research, epidemiology, law, Māori health and consumer advocacy.

Julian Crane left the Committee in 2018.

Short biographies of all committee members appear on pages 6 to 8.

# Work in 2018

## Research Ethics Work In 2018

NEAC's work involves identifying what matters and how best to act on it, and encouraging ethical decision-making. NEAC produces work that is both principled and practical and not identifiable with any particular sector interest or group. NEAC agrees its work programme with the Minister.

## Representation on the Working Group

NEAC reconvened in May 2018 following a year's hiatus while the Ministry of Health restructured its functions. During that time, a Ministry-convened working group was developed to rapidly progress revision of the 2012 *Ethical Guidelines for Observational Studies* and *Ethical Guidelines for Intervention Studies* (that is, to develop revised standards). Wayne Miles and Neil Pickering represented NEAC on the working group.

The working group prepared an early draft of the revised standards, and in April 2018 the Ministry sought NEAC's endorsement and support to take them forward. As part of their development, the revised standards underwent significant review for relevant sections by Pacific policy teams and academics, stem cell academics, the Ministry's legal team, Māori policy and research groups internally, and an external Māori 'weaving' session undertaken by Māui Hudson and Barry Smith in conjunction with the Secretariat. The revised standards were checked for consistency with the draft Therapeutic Products and Medicines Bill.

## Public Consultation and Analysis

In June, the committee agreed that, subject to minor changes, the revised standards were ready to be released for public consultation. It was agreed that consultation would run for six weeks. Meetings were held with interested parties, and the Secretariat provided a summary of submissions for the committee. The consultation document was published on NEAC's website, and the Ministry of Health's website and Twitter account, in July.

Public consultation on the revised standards was conducted through an online portal called Citizen Space, which gave the Secretariat the ability to revise the submissions in depth. The public consultation had a low level of lay engagement; most submitters were interested groups.

Public feedback generally stressed the importance of clarity, and agreed that it was helpful to researchers to replace the two 2012 guidelines with one cohesive document.

The main themes from the public consultation were:

- inclusion, representation and the fairness of the advancement of knowledge
- safeguards, the wider ethics landscape and the impact of the standards on research
- accessibility, complexity and functionality
- balancing protections with facilitating knowledge advancement
- gaps in ethical guidance.



Taking into account the responses from the public consultation, NEAC created four new streams of work to strengthen the final standards. These were:

- structural changes to existing content and scope of review
- acceptance of uncontroversial changes
- new content generation
- high-level feedback beyond the scope of the standards to report back to the Ministry of Health about the wider research environment.

The Secretariat's main focus between August and November 2018 was compilation of responses from the public consultation into one comprehensive submissions analysis document for NEAC to review.

### **Key Sections Strengthened in the Standards**

There was a strong theme in submissions that the disability section of the guidelines needed strengthening. In response, NEAC directed the Secretariat to obtain some more specific information on disability from strategic and representative groups.

NEAC agreed that a section on innovative practice should also be included. The resulting section was based on the cross-sectoral ethics work NEAC undertook in 2014.

In developing the revised standards, NEAC frequently discussed the tension between ethics and the law. NEAC noted relevant feedback from submitters and reiterated the view that the revised standards were to be ethical standards, not legal standards. NEAC directed the Secretariat to develop a section on ethics and the law, following the format of the Australian National Statement on Ethical Conduct in Human Research, in which the tension between ethics and the law was set out clearly, alongside a substantive list of regulation, legislation and law for researchers to be aware of. This decision was based on the view that the law is not written for research, and that there have certainly been cases in New Zealand where something has been ethical but unclear in terms of legality.

After seeing the online functionality of a similar set of Ministry of Health guidelines, NEAC agreed that the revised standards should be turned into a HTML web page to facilitate future updating. The aim was that the revised standards would be an interactive and living document that facilitated richer engagement with researchers.

Following the completion of this long-term work, The Ministry of Health's Ethics Team proposed a roadshow aimed at familiarising researchers with the revised standards.

### **Working Groups to Finalise the Revised Standards**

NEAC directed the Secretariat to develop a project plan for the revised standards, and establish small working groups of experts to provide peer review or content advice. NEAC considered whether it wanted to lead any projects, and ultimately decided that it would commission the work and review it as necessary, and then review the full draft at an in-person meeting in May 2018. The Secretariat advised NEAC of working group members for the projects it established, as well as deadlines and the project directives. NEAC members had the opportunity to participate in the work as they desired.

## Other Work in 2018

NEAC members and Secretariat staff attended a range of events in 2018, including the New Zealand Association of Clinical Research conference in August.

### **Modernisation of the Ethics IT System**

The Ministry of Health advised NEAC that a full change of the ethics IT system had been added to the work programme, aiming to establish an online system that was more responsive to the volume and complexity of the work of researchers, Health and Disability Ethics Committee (HDEC) members and ethics staff.

The Ministry planned to review NEAC's terms of reference, and those of all other ethics committees, in tandem with this process.

### **Quality Improvement and the Health Quality & Safety Commission**

The Secretariat met with the Health Quality & Safety Commission (HQSC) in 2018 to discuss the ethics of quality improvement. NEAC worked with the HQSC on ethical advice for the sector on quality improvement and similar knowledge-generating activities as part of a section of the revised standards.

### **The World Health Organization Regional Summit 2019**

In April 2018, NEAC received an invitation from the World Health Organization (WHO) to host the 2019 WHO regional summit for the Asia-Pacific Regional Meeting for National Bioethics/Ethics Committees (AP-NEC) in New Zealand. The AP-NEC aims to provide a platform for participants to exchange ideas, build support and foster collaboration in strengthening national capacities and drive sustainable action on health ethics, including public health ethics, clinical care ethics and research ethics, with a focus on regional priority issues in the context of the United Nations' Sustainable Development Goals.

The Ministry supported the summit, and provided Secretariat support and funding. The WHO provided the bulk of funding. Once NEAC had indicated its support for the summit being held in New Zealand, the Secretariat put a steering group in place, chaired by Neil Pickering.

In 2018, NEAC agreed that the summit would be held in October 2019 at Te Papa in Wellington, and discussed possible topics for the summit, including global warming, antimicrobial resistance and organ donation.

The Secretariat contacted Tourism New Zealand to enquire about funding for AP-NEC which was secured for 2019.

## **Monitoring Health and Disability Ethics Committees**

### **Background**

HDECs are ministerial committees (established under section 11 of the New Zealand Public Health and Disability Act) whose function is to secure the benefits of health and disability research by checking that it meets or exceeds established ethical standards. There are four HDECs nationally.

A number of changes have been made to the HDECs' review process since 1 July 2012. These include: introducing new standard operating procedures and an online application system, reducing the seven previous HDECs to four and reducing committee membership from 12 to 8.

To mitigate concerns about the potential impact of these changes, the Minister of Health asked the Ministry to work with NEAC on monitoring and reviewing the changes.

### **Progress in 2018**

Several members of the HDECs were involved in the working group set up to review the 2012 guidelines and consider the gaps in those documents.

### **Health Research Council Ethics Committee and Health Research Council**

The NEAC Secretariat facilitates conversations between the Ministry of Health and the Health Research Council (HRC) of New Zealand. The Secretariat met with the HRC Ethics Committee and the HRC in October 2018 in Auckland to discuss the HDEC annual reports and a range of nationally significant ethical challenges, such as using the Integrated Data Infrastructure (IDI) (a large research database administered by Stats NZ) and de-identified data. The HRC re-approved the HDECs, following their annual report submission.

The Secretariat also facilitated a stronger working relationship between NEAC and the HRC. NEAC confirmed its interest in a regular high-level sector meeting on national ethics. An MOU was discussed, in order, to share relevant information and to maintain the provision of strong and consistent advice to ministers.

## National Ethics Advisory Committee Members

### **Neil Pickering – Deputy Chair, Health Research Council of New Zealand Nominee**

Neil is an Associate Professor in the Bioethics Centre at the University of Otago. He has published on a range of ethical issues, and has been a member of a number of research projects both in New Zealand and in his previous job in the United Kingdom. His primary area of research is philosophy of mental health.

He was a member of the University of Otago Human Research Ethics Committee from 1999 to 2005. He was also on the HRC Ethics Committee from 2005 to 2010, and was acting chair from 2007 to 2008. He is currently a member of the editorial board of the *Journal of Bioethical Inquiry* and a member of the committee of the Australasian Association of Bioethics and Health Law.

Neil was appointed to NEAC in April 2013 and reappointed in July 2016. He was appointed deputy chair in September 2016, and has been acting chair since October 2016.

### **Maureen Holdaway – Health Researcher**

Maureen is the deputy director for the Research Centre for Māori Health and Development, Massey University, and a registered nurse with extensive experience in primary health care.

Maureen has worked in the health and education sectors for many years. Her key areas of research expertise are Māori and indigenous health development, primary health care and health workforce development.

Maureen has collaborated on national and international studies focusing on indigenous health and development. She is a named investigator on two core programme grants for the Research Centre for Māori Health and Development, a number of individual HRC grants and other research involving significant collaborations within Massey University and with other universities and health service providers, both nationally and internationally.

Maureen was reappointed to NEAC in October 2018.

### **Kahu McClintock – Representing the Interests of Māori**

Kahu McClintock (Waikato/Maniapoto, Ngāti Mutunga and Ngāti Porou) is the manager research at Te Rau Matatini/Te Rau Ora. Kahu has worked in the health and disability sector for over 20 years, with a special focus on Māori health research and child and adolescent mental health.

Kahu was a member of the Māori Health Committee within the HRC from 2008 to 2014, and chair of Ngā Kanohi Kitea Community Research Committee within the HRC during that term. She is the lead for Te Rā o Te Waka Hourua.

Kahu was reappointed to NEAC in 2018.

## **Wayne Miles – Health Professional**

Wayne is the director of Awhina Research and Knowledge, Waitemata District Health Board and a clinical associate professor at the Department of Psychological Medicine, the University of Auckland. He has had extensive experience as a psychiatrist, a clinical leader and a clinical researcher.

Wayne has been an HDEC member for seven years, and is a member of the HRC College of Experts. His past roles have included president of the Royal Australian and New Zealand College of Psychiatrists and chair of the Council of Medical Colleges in New Zealand.

Wayne was reappointed to NEAC in 2016.

## **Liz Richards – Community/Consumer**

Liz is an independent director and trustee for the Tasman Bays Heritage Trust. Her previous roles include chair of the Top of the South Health Alliance, chair of the Upper South A Health and Disability Ethics Committee and deputy chair of the Canterbury Community Trust and the Nelson Marlborough District Health Board. Liz has also been active in governance roles for a number of community organisations in the Nelson region.

Liz has worked in health promotion and public sector housing management, and lectured in housing studies at Salford University.

Liz was appointed to NEAC in October 2015.

## **Hope Tupara – Health Professional**

Hope Tupara works from home, mostly in private contract research and as a practising midwife. She has published papers in the *New Zealand College of Midwives Journal*, the *Cambridge Quarterly of Health Care Ethics* and the *American Journal of Bioethics*.

Hope has a special interest in iwi development, the Māori Women's Welfare League and Whānau Ora.

Hope was appointed to NEAC in October 2015.

## **Dana Wensley – Lawyer**

Dana has a Ph.D. in medical law and ethics from King's College, London and her research transcends the traditional boundaries between law, medicine and ethics. She has held posts as research fellow at the Human Genome Research Centre (University of Otago) and assistant editor of the *Bulletin of Medical Ethics* (London). Dana has served as community representative on the Hospital Advisory Committee of the Nelson Marlborough District Health Board and is interested in health equity and allocation of resources at a local and national level. In 2016 she was elected to the Tasman District Council and has served as Chair of the Accessibility for All Forum (Nelson/Tasman). Dana currently chairs the Regulatory Committee of Tasman District Council.

Dana was appointed to NEAC in October 2015.

## Julian Crane – Health Researcher

Julian Crane is a general physician by training. He is the director of the Wellington Asthma Research Group and a co-director of the HRC’s Housing and Health Research Programme at the University of Otago, Wellington.

Julian’s main research interests are asthma and allergic disease, the effects of housing on respiratory health and, more recently, smoking cessation. Julian has also been involved in the International Study of Asthma and Allergies in Childhood (ISAAC) research collaboration.

Julian’s term on NEAC ended in October 2018 when his membership expired.

## Adriana Gunder (QSM) – Community/Consumer

Adriana was involved in biological and medical research for many years, mainly in Italy and the United Kingdom.

Adriana had polio when she was an infant; as a consequence, she feels strongly about disability and accessibility issues and is involved with disability organisations. Adriana has served on the Board of the New Zealand Red Cross (2012–2014), the New Zealand Health Practitioners Disciplinary Tribunal (2010–2015) and the Ethics Committee on Assisted Reproductive Technology (2010–2016).

Adriana is involved with community and charity organisations and is a Justice of the Peace. She is a current member of the Medical Sciences Council.

Adriana was awarded the Queen’s Service Medal for service to the community in June 2012.

Adriana was appointed to NEAC in October 2011.

## Member Attendance at NEAC Meetings in 2018

Meeting Attendance in 2019	1 May 2018	6 June 2018	2 July 2018	22 November 2018	23 November 2018
Neil Pickering (acting chair)	✓	✓	✓	✓	✓
Liz Richards	✓	✓	✓	✓	✓
Wayne Miles	✓	✓	✓	✓	✓
Maureen Holdaway	✓	✓	✓	✓	✓
Kahu McClintock	✓	✓	✓	Apol	Apol
Hope Tupara	Apol	✓	Apol	Apol	✓
Dana Wensley	✓	✓	✓	Apol	Apol
Adriana Gunder	✓	✓	✓	✓	✓
Julian Crane	Apol	✓	✓	N/A	N/A
<b>Total members present</b>	<b>7</b>	<b>9</b>	<b>8</b>	<b>5</b>	<b>6</b>

✓ = Present Apol = Apologies Note: Julian Crane left the committee in October 2018.

# National Ethics Advisory Committee Secretariat

## Role of the National Ethics Advisory Committee Secretariat

The NEAC Secretariat provides dedicated analytical policy and administrative support to NEAC. It is located in the Ministry of Health.

## Membership of the National Ethics Advisory Committee Secretariat

The NEAC Secretariat in 2018 comprised:

- Rob Mchawk, Acting Manager Ethics
- Philippa Bascand, Manager Ethics
- Nic Aagaard, Principal Advisor
- Fox Swindells, Acting Senior Advisor
- Hayley Robertson, Senior Advisor
- Moana Tupaea, Group Administrator.

## Contact Details for the National Ethics Advisory Committee

Contact details for NEAC are as follows:

<b>Email</b>	neac@health.govt.nz
<b>Postal Address</b>	PO Box 5013, Wellington 6145
<b>Website</b>	<a href="http://www.neac.health.govt.nz">www.neac.health.govt.nz</a>



# Appendix: Terms of reference for the National Ethics Advisory Committee

These terms of reference came into effect in December 2013.

1. The National Advisory Committee on Health and Disability Support Services Ethics (the National Ethics Advisory Committee) is a ministerial advisory committee established under section 16 of the New Zealand Public Health and Disability Act 2000 (the Act). The National Ethics Advisory Committee is established by and accountable to the Minister of Health.

## Functions of the Committee

2. The National Ethics Advisory Committee's statutory functions are to:
  - provide advice to the Minister of Health on ethical issues of national significance in respect of any health and disability matters (including research and health services)
  - determine nationally consistent ethical standards across the health and disability sector and provide scrutiny for national health research and health services.
3. As part of its functions the Committee is also required to:
  - consult with any members of the public, persons involved in the funding or provision of services, and other persons that the committee considers appropriate before providing advice on an issue (section 16(4) of the Act refers)
  - at least annually, deliver to the Minister of Health a report setting out its activities and summarising its advice on the matters referred to it under section 16 of the Act by the Minister of Health.
4. In undertaking its functions, the Committee is expected to:
  - provide advice on priority issues of national significance as requested by the Minister of Health
  - provide advice to the Minister of Health regarding ethical issues concerning emerging areas of health research and innovative practice. The advice is to include the Committee's rationale for its advice and any relevant evidence and/or documentation
  - provide advice to the Minister of Health regarding aspects of ethical review in New Zealand, including the setting of principles and guidelines in relation to each of the different types of health research and innovative practice. The advice is to include the Committee's rationale for its advice and any relevant evidence and/or documentation
  - develop and promote national ethical guidelines for health research and health and disability support services. The guidelines should address how to conduct different types of health research (including ethical issues relating to Māori health research) and innovative practice in an ethical manner and should establish parameters for, and provide guidance on, the ethical review of such types of health research and health and disability support services

- monitor and review the operation of the health and disability ethics committees for the purposes of providing direction, guidance and leadership to ensure the ongoing quality and consistency of ethical review in the health and disability sector
- undertake its tasks in a manner consistent with the principles of the Treaty of Waitangi
- develop guidelines on conducting observational studies in an ethical manner and establish parameters for the ethical review of observational studies (including guidance on weighing up the harms and benefits of this type of research).

## **Composition of the Committee**

5. The National Ethics Advisory Committee will have a maximum of 12 members appointed by the Minister of Health.
6. The Committee's membership must include:
  - two health professionals (one of whom must be a registered medical practitioner)
  - three community/consumer representatives (must not be health professionals, health researchers, or professional members)
  - one member nominated by the Health Research Council of New Zealand
  - two or more Māori members (one of whom must have a background in Māori research and/or ethics).
7. The membership must also have expertise in the following areas:
  - ethics
  - research (qualitative and quantitative)
  - epidemiology
  - law.

## **Terms and Conditions of Appointment**

8. Members of the National Ethics Advisory Committee are appointed by the Minister of Health for a term of up to three years. The terms of members of the Committee will be staggered to ensure continuity of membership. No member may be appointed for more than six consecutive years unless an additional period of up to 12 months is confirmed to allow for continuity of projects.
9. Unless a person sooner vacates their office, every appointed member of the Committee will continue in office until their successor comes into office.
10. Any member of the Committee may at any time resign as a member by advising the Minister of Health in writing.
11. Any member of the Committee may at any time be removed from office by the Minister of Health for inability to perform the functions of office, bankruptcy, neglect of duty, or misconduct, proved to the satisfaction of the Minister.

12. The Minister may from time to time alter or reconstitute the Committee, or discharge any member of the Committee or appoint new members to the Committee for the purpose of decreasing or increasing the membership or filling any vacancies.

## **Chairperson and Deputy Chairperson**

13. The Minister will from time to time appoint a member of the National Ethics Advisory Committee to be its Chairperson. The Chairperson will preside at every meeting of the Committee at which they are present. The Chairperson may appoint a member as Deputy Chairperson, in consultation with the Minister. The Deputy Chairperson may exercise the powers of the Chairperson in situations where the Chairperson is not present or is unable to act (eg, if the Chairperson has a conflict of interest).

## **Duties and Responsibilities of a Member**

14. This section sets out the Minister of Health's expectations on the duties and responsibilities of a person appointed as a member of the National Ethics Advisory Committee. This is intended to aid members by providing them with a common set of principles for appropriate conduct and behaviour and serves to protect the Committee and its members.
15. As an independent statutory body, the Committee conducts its activities in an open and ethical manner, and operates in an effective and efficient way within the parameters of its functions as set out in its Terms of Reference.
16. Committee members should have a commitment to work in the best interests of the Committee.
17. Members are expected to make every effort to attend all the Committee meetings and devote sufficient time to become familiar with the affairs of the Committee and the wider environment within which it operates.
18. Members are expected to act responsibly with regard to the effective and efficient administration of the Committee and the use of Committee funds.
19. Members will:
  - be diligent, prepared and participate
  - be respectful, loyal and supportive
  - not denigrate or harm the image of the Committee.
20. The Committee as a whole will:
  - ensure that the independent views of members are given due weight and consideration
  - ensure fair and full participation of members
  - regularly review its own performance
  - act in accordance with the principles of the Treaty of Waitangi.

## **Conflicts of Interest**

21. Members must perform their functions in good faith, honestly and impartially, and avoid situations that might compromise their integrity or otherwise lead to conflicts of interest. They must also be, and be seen to be, independent of the Minister of Health and the Ministry of Health. Proper observation of these principles will protect the National Ethics Advisory Committee and its members and will ensure it retains public confidence.
22. Members attend meetings and undertake Committee activities as independent persons responsible to the Committee as a whole. Members are not appointed as representatives of professional organisations and groups. The Committee should not, therefore, assume that a particular group's interests have been taken into account because a member is associated with a particular group.
23. Members are required to declare any actual or perceived interests to the full Committee. The Committee will then determine whether or not the interest represents a conflict, and if so, what action will be taken.
24. The Chairperson will ask members to declare any actual or perceived interests at the start of each meeting.

## **Confidentiality**

### **General**

25. The public has a right to be informed about the issues being considered by the National Ethics Advisory Committee. The Committee should have procedures in place for the release of information and processing requests for information.
26. Individual members must observe the following duties in relation to Committee information. These provisions ensure that the Committee as a whole maintains control over the appropriate release of information concerning issues before it.

### **General Meeting Discussions**

27. Key discussion points in meetings are recorded in the meeting minutes. Upon request, a member's dissenting views may be recorded in the meeting minutes.
28. Members must ensure that the confidentiality of Committee business is maintained. Members must be clear about what Committee matters are permitted to be discussed with people that are not Committee members and, in doing so, should be familiar with the information that is publically available about the Committee's work.
29. Meetings of the Committee, including agenda material and draft minutes, are confidential. Committee members must ensure that Committee documents are kept secure to ensure that the confidentiality of Committee work is maintained. Committee correspondence or papers can only be released with the approval of the Committee.
30. Members are free to express their own views within the context of Committee meetings, or as part of the general business of the Committee.

31. Members may communicate general meeting discussions with other Committee members that were not present during at the meeting.
32. At no time should members individually divulge details of Committee matters or decisions of the Committee to persons who are not Committee members. Disclosure of Committee business to anyone outside the Committee must be on the decision of the Committee, or between meetings, at the discretion of the Chairperson. In choosing to release or withhold information, the Committee must comply with the provisions of the Official Information Act 1982 and the Privacy Act 1993.

### **'In Committee' Discussions**

33. At no time will a Committee member discuss the conduct or performance of another member who is not present at the 'in committee' session.
34. The meeting minutes will note that an 'in committee' session took place. A record of 'in committee' discussions will be kept in the Chairperson's notes.
35. 'In committee' discussions can be communicated with other Committee members who were not present during the 'in committee' session. This can either be done formally by the Chairperson or informally by another Committee member.

### **Media Policy**

36. Only the Chairperson is authorised to comment publicly on the affairs and policies of the Committee, and where appropriate, the Chairperson will advise the Minister of Health in advance. The Chairperson may delegate comment to other Committee members.
37. Where the Chairperson has delegated comment to another Committee member, the member must publicly support a course of action decided by the Committee. If unable to do so, members must not publicly comment on decisions.
38. The Chairperson, members and Secretariat will not support any action or public statement that is derogatory or in any way damaging to the Committee.
39. Members have the right to comment to the media on any matter in their professional capacity, as long as they do not attribute the comment to the Committee or imply that they are speaking on behalf of the Committee. If a member is forewarned of being asked to comment to the media, they should advise the Committee accordingly. If a Committee member is not forewarned, they should advise the Chairperson immediately after making comment to the media.

### **Working Arrangements**

40. The National Ethics Advisory Committee will agree a work programme with the Minister of Health.
41. In carrying out its Terms of Reference, the Committee must:
  - provide the Minister of Health with advance notice of any media statements or reports to be published

- ensure its advice is published and widely available
- ensure that, in developing any advice and guidelines, an appropriate balance exists between protecting the rights and wellbeing of patients and research participants, and facilitating health research and innovative practice
- ensure that, where appropriate, any advice or guidelines contain clear guidance on the application of ethical principles that is appropriate to the type of health research or innovative practice being considered (due regard should be given to the different nature of qualitative and quantitative approaches to research)
- ensure that any advice and guidelines comply with the laws of New Zealand
- ensure appropriate consultation has occurred in accordance with the requirements set out below.

## **Consultation**

42. In meeting its obligations to consult before providing advice to the Minister, the National Ethics Advisory Committee will, where appropriate, make reasonable attempts to consult with:

- health and disability ethics committees
- the Advisory Committee on Assisted Reproductive Technology
- the Health Research Council Ethics Committee
- any other Ethics Committee established by the Minister of Health
- organisations that represent affected patients or other groups of the community
- relevant whānau, hapū and iwi
- a reasonably representative sample of affected patients or members of the public or, if the Committee thinks it more appropriate, a reasonably representative sample of people who would be entitled to consent on behalf of the affected patients or members of the public
- a reasonably representative sample of affected health researchers and/or affected health professionals
- relevant government bodies.

43. The Committee will ensure that stakeholders are provided with feedback following consultation, in line with good consultation practice.

## **Performance Measures**

44. The National Ethics Advisory Committee will be effectively meeting its tasks when it provides relevant and timely advice to the Minister of Health based on research, analysis and consultation with appropriate groups and organisations.

45. The Committee must:

- agree in advance to a work programme with the Minister of Health
- achieve its agreed work programme
- stay within its allocated budget.

## Meetings of the Committee

46. Meetings will be held at such times and places as the National Ethics Advisory Committee or the Chairperson of the Committee decides.
47. At any meeting, a quorum will consist of six members. A quorum must include either the Chairperson or Deputy Chairperson. An effort will be made to ensure reasonable representation of community/consumer members and members with specialist knowledge and experience.
48. Every question before any meeting will generally be determined by consensus decision-making. Where a consensus cannot be reached a majority vote will apply. Where a decision cannot be reached through consensus and a majority vote is made, the Chairperson will have the casting vote.
49. Subject to the provisions set out above, the Committee may regulate its own procedures.

## Reporting

50. The National Ethics Advisory Committee will:
  - keep minutes of all Committee meetings which outline the issues discussed and include a clear record of any decisions or recommendations made
  - prepare an annual report to the Minister of Health setting out its activities and comparing its performance to its agreed work programme and summarising any advice that it has given to the Minister of Health (as per section 16(6) of the Act). The report is to include the Committee's rationale for its advice and any relevant evidence and/or documentation. This report will be tabled by the Minister of Health in the House of Representatives pursuant to section 16(7) of the Act.

## Secretariat

51. The Ministry of Health will provide dedicated analytical policy and administrative support to the National Ethics Advisory Committee through Secretariat staff, consistent with the Memorandum of Understanding between the Committee and the Ministry of Health. Secretariat staff are Ministry employees and are funded through the Committee's allocated budget.

## Fees and Allowances

52. Members of the National Ethics Advisory Committee are entitled to be paid fees for attendance at meetings. The level of attendance fees are set in accordance with Cabinet Office Circular CO (12) 6, *Fees framework for members appointed to bodies in which the Crown has an interest*.
53. The Chairperson will receive \$430 per day (plus half a day's preparation fee) and an allowance of two extra days per month to cover additional work undertaken by the Chairperson.
54. The attendance fee for members is set at \$320 per day (plus half a day's preparation fee).

55. The Ministry of Health pays for actual and reasonable travel and accommodation expenses of the Committee members.



