

**National Ethics Advisory Committee**

**16 March 2023**

**9:00am – 4.00pm**

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## Attendees

**NEAC members:** Professor John McMillan (Chair), Dr Penny Haworth, Associate Professor Vanessa Jordan, Shannon Hanrahan (Deputy Chair), Dr Cindy Towns, Dr Lindsey MacDonald, Dr Hansa Patel, Rochelle Style, Maree Candish, Nora Parore.

**Apologies:** Edmond Carrucan, Seini Taufa.

**Welcome and whakawhanaungatanga**

1. The meeting began with a Karakia and Whakawhanaungatanga to welcome new members and those supporting NEAC’s work from Manatū Hauora. The Chair farewelled Dr Cindy Towns and Dr Penny Haworth and acknowledged their mahi and contributions to NEAC over the last three years.
2. A discussion was had about NEAC’s terms of reference, noting that these are updated through approval by the Minister. The possibility and importance of co-opting members and broadening the range of expertise was also discussed.

## Declaration of Interests

1. Members declared amendments to be made to the declaration of interests.

*Actions*

* Secretariat to update members’ recorded declarations of interests.
* Secretariat to circulate a recent article about ethics and transparency.

## Approval of minutes from NEAC’s 24 November 2023 meeting

1. Members made minor changes and approved the minutes from NEAC’s meeting on 24 November 2023.

*Action*

* Secretariat to make amendments and upload 24 November minutes to NEAC’s webpage.

## Actions Arising

1. The actions arising were noted, and the Chair thanked members and the secretariat for assisting with the high workload and correspondence between meetings. In particular, NEAC’s response to two public consultations were noted and the Chair asked that these be added to the actions arising worksheet.
2. Members discussed a possible response to the Health and Disability Commissioner (HDC) regarding the Commission’s work in undertaking a full review of the Health and Disability Services Consumers' Rights (the Code). The review of the Code was discussed in further detail later in the meeting under the item *HDC and Right 7(4)*. Members also discussed the need for NEAC to have close working relationships with HDC in the interests of consistency and sharing expertise. The Secretariat noted also the importance of developing a robust internal policy to support co-opting expertise and fees.
3. Members approved the agenda.

*Actions*

* Secretariat to update the actions arising.
* Secretariat to upload the 16 March agenda to NEAC’s webpage.
* Secretariat to circulate a final copy of the response to the Law Commission’s consultation on capacity and decision making to all members.

## Secretariat’s update

*Ethics team staffing update*

1. The Manager, Ethics updated NEAC on staffing changes in the Ethics team at Manatū Hauora.

*Appointments update*

1. The Manager, Ethics updated NEAC on the status of committee appointments and vacant positions, noting that the advertisement of three positions on NEAC went live on Friday 17 March. The advertised positions are for an expert in ethics, epidemiology and consumer or community perspective. NEAC members were asked to circulate the advertisement widely.

*Long-term Insights Briefing on Precision Health – NEAC submission*

1. Experts from the Long-Term Insights team attended online to talk members through their work programme and discuss NEAC’s submission on the long-term insights briefing on precision health. The Long-Term Insights team took members through key points in the work and noted opportunities for ongoing discussions with NEAC.
2. It was noted that the primary aim of the briefing is a think piece to inform future strategic policy and legislative change. The briefing will be a long-term horizon piece discussing the opportunities and challenges so that it can stimulate discussion of how to use precision health technologies appropriately and efficiently in health. .
3. NEAC discussed the need to consider the types of investment, privacy issues with respect to the use of health data and the role of the briefing to reflect the variety in perspectives and ethical tensions within ‘precision health’. It was noted that the briefing should have an exploratory framing and acknowledged the limitations of precision health to achieve desired health outcomes. It was also noted that there are ethical challenges due to limited data from minority groups which the technologies mentioned in the briefing rely on. The broader issue of equity and resource allocation within the health system was then discussed and that, although attractive, new technologies are not a panacea for the challenges the health system faces.
4. The team thanked NEAC for their written response to the consultation response to the long-term insights briefing and answered further questions from members. NEAC expressed interest in this work and if they would like further input from NEAC to contact the Secretariat.

## Chair’s update

1. The Secretariat updated NEAC on the 14th Global Summit of National Bioethics Committees in March 2024 as the Chair has been invited to be on the International Steering Group. All slides and talks from the 13th Global Summit of National Bioethics Committees will be shared on [the conference website](https://globalsummitlisbon.com/global-summit/).
2. The committee discussed the importance of wrapping up longstanding projects and having the Secretariat support to enable this.
3. The committee also picked up their conversation from the November meeting regarding the relationship between NEAC and the Health and Disability Ethics Committees (HDECs), noting that section 92 of the Pae Ora (Healthy Futures) Act, under which NEAC is established, states that “the committee must determine nationally consistent ethical standards across the health sector and provide **scrutiny** for national health research and services.”
4. It was suggested that a template for HDEC’s to use in reporting issues to NEAC might be helpful.

## Ministry operations and New Minister of Health update

1. The Manager, Ethics updated NEAC on the Cabinet reshuffle and it was confirmed that Minister Ayesha Verall is responsible for ethics with Minister Peeni Henare retaining the appointments function. NEAC was also briefed about the ways of working with the new Minister and how the Ministry and NEAC work together and operate, in terms of notifying Ministers of work, decisions and updates.

*Briefing to the Incoming Minister*

1. NEAC considered a draft of the Briefing to the Incoming Minister (BIM) which aims to introduce the Minister to NEAC functions, composition and work programme. NEAC agreed to invite the Minister to attend a meeting in the briefing to discuss the work programme and work on the horizon.
2. Members discussed the draft BIM and suggested amendments.

 *Action*

* Secretariat to work with the Chair and Deputy Chair to finalise the BIM.

## NEAC work programme

1. The Secretariat took members through the current work programme priorities and it was agreed that completing the review of the National Ethical Standards for Health and Disability Research and Quality Improvement (the Standards) is the highest priority work.

## Standards Review Update

1. The Chair introduced this item and noted that this review is an important item on NEAC’s work programme. NEAC publicly consulted on the Standards in early 2021 and sought feedback about how stakeholders thought the Standards were working. There was a discussion about resourcing for this project and a member noted that the context of the review period has been at a time where the pandemic and health reforms are changing the landscape of the health system.
2. The Secretariat updated members on the status of this work. Individuals and external reviewers have been asked to comment on specific sections (e.g. research and Pacific peoples, research with stem cells and reprogrammed cells) which have resulted in minor amendments.  Most of the chapters have now been reviewed, with the remaining ones requiring external input, these include the genomics section and the data chapter.
3. The Secretariat has also conducted some additional analysis to understand how the Standards are used by the HDECs, reviewing which Standards are most commonly cited in provisional approvals and declines over the last two years. Following the initial data collection, the Secretariat is reviewing what the data means for the operation of the Standards and will be analysing the data with reference to the HDEC decisions.
4. The intention was that the Standards are reviewed and updated where necessary to ensure that they stay fit for purpose. There was concern among members that the Standards claim to be a living document when reviewing the Standards is a significant piece of work and they are a document that researchers rely on so need to be stable. It was suggested that part of the review could be to amend the Standards, so that a full review was conducted every five years or so.
5. Members discussed relevant work that ties into the review of the Standards, specifically the HDCs work programme and possible changes to the Code, the establishment of the Therapeutic Products Bill and the implications for the research landscape and Standards.
6. It was agreed that the Secretariat will work with members to update the remaining sections and bring a draft of the revised Standards to the May NEAC meeting for review and approval. The updated Standards will then be consulted on before the new version is finalised and implemented. It is anticipated that this will be the end of 2023.

*Action*

* Secretariat to set up working group meetings with interested members to progress and develop revised chapters between meetings.
* Secretariat to prepare updated sections and cover papers outlining changes and rationale for changes, for consideration by the committee in May.

## Ethical Guidance for a Pandemic (EGAP) update

1. The Secretariat updated NEAC on the completed analysis report from the EGAP consultation.
2. The Secretariat talked through the findings noting the characteristics and key points from the consultation and members discussed how it would inform the next iteration of the EGAP document.
3. Members thanked the Secretariat for the amount of work and resource to complete this report and had a discussion about the findings. Specifically, the committee discussed demographics of responses, noting that there appeared to have been better engagement with Māori and that the focus group held with Asian Public Health was useful for the consultation.
4. It was noted that we know a lot more now about the impacts of the different pandemic measures e.g. impacts on children for missed schooling and impacts on elderly and the committee could reflect on this in developing the final version. It was also suggested that including the case examples would be helpful and that case examples from a previous iteration of the document would be a good place to start.
5. There was a discussion about the recent flooding and emergencies in Aotearoa New Zealand focusing on the practicality and tika of undertaking disaster research during emergency situations.
6. It was noted that there remains a gap for ethical guidance for ICUs during a pandemic and that this is partly because they have their own protocols. A member stressed the importance of national level ICU guidance and not piecemeal advice. NEAC agreed to consider this separately to the EGAP document.
7. The current iteration was then discussed and how NEAC would like to incorporate the input received from the consultation. It was suggested that the next iteration could be structured to have different points and ways of accessing it similar to the approach of the Nuffield Council on Bioethics (UK). A few members agreed to join a small working group to finalise the EGAP document.
8. The working group would look at incorporating such elements as introducing case examples and whether parts of the report could be tailored to different audiences.

*Actions*

* Secretariat to publish the EGAP consultation report on NEAC’s webpage.
* Secretariat and working group to finalise the EGAP document and a final draft will be brought to a future NEAC meeting.

## NEAC response to ACART’s consultation on Human Reproductive Research

1. The Advisory Committee on Assisted Reproductive Technology (ACART) is undertaking a two-stage consultation on amending the guidelines for human reproductive research. A small working group assisted the Secretariat to draft a response to ACART’s consultation which was then considered by the full committee at the meeting.
2. The committee noted the ethical issues in the document are well thought out and that research on embryos can be a divisive issue. NEAC discussed the proposed changes and any further protections or considerations that are relevant to comment on, including whether the distinction between viable and non-viable is ethically distinguishable in the context of research given that they will never be used in a pregnancy.
3. Members also discussed the key ethical question of using embryos in research that are surplus as opposed to creating embryos for research and the different research possibilities these options create. There was also a brief discussion about stem cell lines and some uncertainty about whether research on cell lines derived from embryos would be considered by ECART or HDEC or both.
4. Data and Cell line ownership was discussed noting historical cases of exporting and ownership of cell lines and the need for ethical and legal protections. ACART notes that this is a matter of particular interest to many Māori, in part due to the importance of whakapapa. A Māori cell line has a whakapapa to whānau, hapū, iwi and ancestors and there are many implications for the whakapapa, including for the mana and tapu of the whakapapa. ACART state that in Te Ao Māori, the cell line is treated in the same way as an embryo. NEAC support the implications for tikanga Māori and acknowledged ACART’s work particularly in chapter 7 of the consultation. NEAC also discussed equity of access to treatment and research and eligibility for public funding as a Te Tiriti right.
5. Members noted previous approaches to sending letters and how they would like to approach this letter, either sending on behalf of NEAC or as endorsed by all members and asked for the final draft to be circulated so that all members have the chance to contribute before submitting a response to ACART.
6. A member of NEAC (who is also a member of ACART) was present for this agenda item and provided clarification of a few points but did not contribute to the discussion or decisions about NEAC’s response.

*Action*

Secretariat to make amendments and circulate the draft response to all members.

Modernisation of Ethics programme

1. The Manager, Ethics took members through planned proposed changes to modernise and strengthen the ethics system. Suggestions for improvement included looking at embedding ethics into health reforms, for example adequate and culturally appropriate engagement with Māori in health research and looking into how HDEC’s can have oversight about consultation and outcomes once a study is approved.
2. Other changes included improving the structure of committees and a mandate outlining the need for updating the ethics landscape, exploring the possibility of co-opting experts for review, fee structure, member satisfaction and retention of reviewers to strengthen the support that is provided to the committees.
3. Members were advised that the Modernisation of Ethics programme is moving into the engagement phase, which will include surveys seeking feedback from the sector about how best to improve the experiences of both researchers and committee members. NEAC will be kept up to date on the progress of the Modernisation of Ethics programme and asked for input as appropriate.

*Action*

1. Secretariat to update NEAC on the progress of the Modernisation of Ethics programme at the May meeting and contact NEAC members for input in between meetings if required.

## Clinical ethics

1. The committee noted that the letter they had requested be sent to the Minister about moral distress in the health workforce and clinical ethics had been sent.
2. NEAC discussed clinical ethics and that this was something that could be added to their work programme. It was agreed that this would be added to the items to be discussed with the Minister when the NEAC work programme is approved.

## Research with Adult Participants who are Unable to Provide Informed Consent

1. The Manager, Ethics provided an update on the letter to the HDC regarding ‘Research with Adult Participants who are Unable to Provide Informed Consent’. The background to this work was provided for the benefit of new members and the committee discussed this work in the context of the HDC’s revision of the Code.
2. As well as the ongoing discussions about adults who are not able to consent, it was suggested that the Code does not work well for research because it was not designed with research in mind.
3. A meeting between the HDC, NEAC and the Ethics team is scheduled for late March and members were asked for their views on the Code to bring to the meeting.

*Action*

* Secretariat to write up discussion points from this meeting and include in the May NEAC papers.

## Work between meetings

1. NEAC discussed upcoming work between meetings. Working groups for the Standards and EGAP document will progress these and bring them back to a future meeting. Members also agreed to approve via email the final response to ACART’s consultation.