



**National Council of
Women of New Zealand**

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Wahine O Aotearoa

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**Submission to the Ministry of Health on the Terms of Reference for
Multi-Centre and Regional Ethics Committees**

The National Council of Women of New Zealand (NCWNZ) is an umbrella organisation representing 41 nationally organised societies. It has 33 branches throughout the country attended by representatives of those societies and some 150 other societies. The Council's function is to serve women, the family and the community at local, national and international levels through research, study, discussion and action. NCWNZ has a longstanding history of encouraging the promotion of social and health issues, particularly as they affect women.

There have been several resolutions passed by NCWNZ regarding ethics committees. In 1988 the resolution passed was to, "urge the appropriate Ministers to ensure that all professional ethical committees and all committees established to approve medical research have appropriate lay persons included in their representation."

In 1992 another resolution was passed to "urge the establishment of a national ethics committee to set standards for all biotechnical research and that these standards be open to public scrutiny."

Again, in 1994, part of a resolution passed asked, "the Minister of Health to ensure that all ethics committees in the area defined by the Health and Disability Act 1992 have as their focus the interests of consumers."

In 2003 NCWNZ was pleased to be able to make submissions regarding, "System of Ethical Review of Health and Disability Research in New Zealand" and "Ethical Review of Observational Research, Audit and Related Activities", which we feel positions us well to make this submission.

It is gratifying to see that the resolutions and submissions mentioned above are being reflected in this current discussion document.

Members of the Health Standing Committee, and other interested parties were asked for their input into this document. The following is a summary of their comments.

GENERAL COMMENT

NCWNZ supports the National Ethics Advisory Committee (NEAC) recommendations to form a Multi-Centre Ethics Committee (MEC) to review national health and disability research. This structure would concentrate expert resources, improve efficiency, provide consistent standards and give greater accountability nationally.

Reducing the number of Regional Ethics Committees (RECs) may however, reduce the local input. Concern was expressed that there appears to be no provision for input from District Health Boards (DHBs), although it is recognised that members of committees actually represent no particular organisation, but are there because of their own expertise.





Concern was expressed at how the disestablishment of the current RECs and the establishment of the six new RECs will be carried out, particularly in terms of current personnel. It is always of concern when people have to, in effect, reapply for their jobs, even though in modified form. It would seem a transition period would be best as then all expertise would not be lost at the same time.

Respondents feel that the working relationship/accountability between NEAC and MEC needs to be very clearly established especially as the MEC's primary role is "to provide independent ethical review...."

Some respondents expressed concern regarding the close proximity of the Ministry of Health to these committees, as they would not want political intervention to compromise their independent functions.

NCWNZ would like to see a clear statement included regarding the interfaces between MEC, RECs, HRC, University and other Ethics Committees.

Members felt that MEC should not be confined to Wellington and that meetings should from time to time be held in other main centres. This might in some cases mean that costs of travel would be evened out.

SPECIFIC COMMENT

Statutory Approvals

Giving statutory rights to these committees is appropriate.

Composition and Membership

NCWNZ agrees that there needs to be a good balance of lay and expert members on the committees.

This section appears to be dealt with reasonably well. While allowing that the most suitable persons be appointed, one respondent was concerned about the under-representation of women on these councils and that there should be provision for at least three of the members to be women. The rationale for including at least three is that should only one woman sit on the committee she could have trouble at times having a woman's viewpoint accepted.

It was considered that in some regions of New Zealand, having two Maori representatives on the regional committee may be over representative. In some areas it may be more appropriate to include more Pacific Island people or, indeed represent our multicultural society especially in the Auckland area.

Conflicts of Interest

Declaring conflict of interest for committee members is important and where appropriate, withdrawing from the relevant ethical discussions/decisions should be strictly adhered to.

Terms and Conditions of Employment

Some respondents felt that it would be better that the committee elects the chairperson rather than have the Ministry appointing this person.

It was good to see that there is provision for the removal of non-functioning members as well as for misdemeanours. However, concern was expressed that there was no mention of past criminal



convictions. It is not enough for us to assume that these people would not be selected in the first place, as in any voluntary organisation a police check should perhaps be considered.

Duties and Responsibilities

A more prescriptive statement is required regarding attendance and this should be measurable, e.g. 80 - 90% of all meetings.

In general NCWNZ believes that all meetings should, where practicable, be held in open session. Researchers should have to justify why any hearing should be held in a closed meeting. If this does not happen it could lead to all meetings thus being closed.

Confidentiality and Information Sharing

While it is agreed that the details of applications should be kept confidential, NCWNZ also believes that the ethical issues surrounding informed patient consent, privacy and confidentiality are crucial for research reviews.

Decision-making Process

NCWNZ agree that achieving a consensus decision on all ethical matters will be very difficult in practice. However, this needs to be strived for wherever possible.

It is noted that abstentions on strong personal and moral grounds should not affect approval processes.

NCWNZ believes that there should be a clear statement regarding appeal processes.

Expert Advice and Consultation

Respondents agree that to maintain credibility, the ethics committees need power to co-opt people with expertise in particular fields if no current committee member has experience in the field being researched.

Gathering expert advice when needed is important and should also include awareness of child health perspectives, as well as women's health and disabled people's perspectives.

Training

NCWNZ believes that training for committee members is important and needs to be ongoing.

Reporting Requirements

While there is concern expressed in these documents about safeguarding information under the Privacy Act 1993 and/or the Health Information Privacy Code 1994, NCWNZ is concerned that there are many instances where information is not forthcoming. Frequently this legislation has been applied in circumstances for which it was not intended.

NCWNZ would like to thank you for this opportunity to comment on these discussion documents which were clear, well set out and apart from those areas where we have made comment, thorough. We look forward to the final outcome.

Beryl Anderson
National President

Catherine Gurnsey
Convener, Health Standing Committee.