The Royal New Zealand
College of General Practitioners

5 February 2015 Ref: JMK28-15

National Ethics Advisory Committee Secretariat
PO Box 5013
Wellington 6145

Dear Sir/Madam

Cross-sectoral ethics arrangements for health and disability research

Thank you for asking the Royal New Zealand College of General Practitioners (RNZCGP) to comment on the National Ethics Advisory Committee (NEAC) discussion paper on *Cross-sectoral ethics arrangements for health and disability research*.

The RNZCGP is the professional body and post-graduate educational institution that sets standards for general practice, providing research, assessment, post-graduate training and on-going education and support for general practitioner and general practice. Fellows of the RNZCGP provide advice and expertise to government and within the wider health sector. The RNZCGP aims to improve the health of all New Zealanders by supporting and strengthening high quality care and standards in general practice. The RNZCGP has a focus on ensuring high quality patient centred clinical care is delivered in CORNERSTONE® accredited general practices by vocationally registered general practitioners.

The College funds and supports research through its Research and Education Charitable Trust and through the publication of the *Journal of Primary Health Care*, a peer-reviewed research journal designed to meet the information needs of GPs, practice nurses, community pharmacists and other primary health care practitioners – as well as the patients and communities we serve.

The RNZCGP understands that NEAC is seeking feedback on existing cross-sectoral ethics arrangements for health and disability research.

College submission

The College is concerned that there are gaps in the current cross-sectoral ethics arrangements for health and disability research, and that these gaps mean that primary care practitioners have difficulty in accessing ethical support and review.

In 2013 the RNZCGP sought comment from two primary care researchers about ethics arrangements. The first commented that recent changes "to the HDECs have been very bad for us". When asked for clarification, the researcher advised that:

> *The big problem for us is essentially that most of our research is now out of scope for HDECs as they have been restructured to concentrate on RCTs [Randomised Controlled Trials]. If it's not an RCT, essentially we have to find somewhere else to get ethics review. If you're attached to a university it can go through university ethics review (although they are poorly set up for human research). If you're not attached to a university, there's nowhere to go.*

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The second researcher commented along similar lines and stated that:

> *From my point of view the new arrangements have really not helped the researchers who are involved in observational research, qualitative research or health services research … which are … often the methodologies used in general practice. The current ethics committees seem reluctant to consider studies using these research methodologies leaving many who have no University attachments (again common in general practice) to have nowhere to go to have their research reviewed from an ethical perspective. Some system to review low risk, but important, research ideas is desperately needed if general practice research is to be encouraged.*

We also note that Professor Andre van Rij, Professor of Surgery at Otago University, made similar comments in an August 2012 article in *New Zealand Doctor.* Professor van Rij was quoted as saying "One of our concerns is that observational studies that relate to vulnerable people will not be reviewed, and they should be reviewed."

New Zealand has a long and proud history of primary care research. In our view, current arrangements do not support primary care and may inhibit future research in this important area.

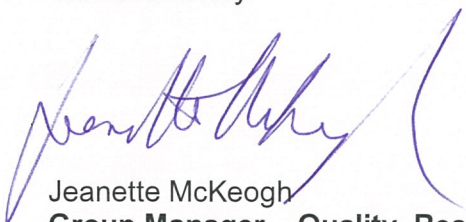
The College submits that, as part of its review, NEAC:

- Takes steps to ensure that researchers in the primary care sector (and in particular those not affiliated to a university) are able to access to ethics committee review
- Ensures that ethics committees consider all primary care research that is important or involves vulnerable people, irrespective of the methodology.

We hope these comments are of assistance to you. If you have any questions or comments, please do not hesitate to contact the College's policy team (policy@rnzcgp.org.nz).

Your consultation paper asks submitters to advise whether they are willing to allow their details to be released under the Official Information Act 1982. The RNZCGP consents to the release of all information contained in this submission.

Yours sincerely



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