

School of Public Health and Preventive Medicine
Faculty of Medicine, Nursing and Health Sciences

Mr Daryl Melham MP
Chair
Joint Standing Committee on Electoral Matters
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Dear Chair,

Medical research under the Commonwealth Electoral Act 1918 (Cth)

We wish to draw the attention of the Joint Standing Committee on Electoral Matters (the Committee) to the detrimental impact that the overly restrictive interpretation of the *Commonwealth Electoral Act 1918* (Cth) (CEA) is having on the current conduct of Australian medical research.

Medical research offers many benefits for the health of Australians. It saves lives and improves people's quality of life by developing new means of medical treatment, enhancing the diagnosis of illness and improving health service delivery.¹ Further, medical research also delivers excellent value for money and is viewed by over 90 per cent of the Australian population as playing an important role in Australia's future.²

However, medical researchers are currently being denied access to electoral roll data – which is crucial to the progress of their research - due to the Australian Electoral Commission's (AEC) view of what constitutes "medical research" under the CEA.

Requirements to release electoral roll information for "medical research" purposes under the CEA

The CEA provides that electoral roll information may be given to any organisation that conducts medical research on request of the relevant organisation and on payment of the appropriate fee.³ While the CEA does not define "medical research", the AEC utilises the definition of "medical research" from the Federal Privacy Handbook issued by the Office of the Federal Privacy Commissioner⁴ when making decisions regarding the disclosure of elector information for medical research purposes.⁵

The release of electoral roll data for medical research under the CEA is limited to "permitted purposes." These include the conduct of medical research in accordance with the Guidelines for the Protection of Privacy in the Conduct of Medical Research (the NHRMC Guidelines) issued by the

¹ National Health and Medical Research Council. (2010). *Annual Report 2009-2010*. Accessed at http://www.nhmrc.gov.au/files_nhmrc/file/publications/synopses/nh144_nhmrc_annual_report_0910.pdf

² Lateral Economics. (2010). *The Economic Value of Australia's Investment in Health and Medical Research: Reinforcing the Evidence for Exceptional Returns*. Accessed at: <http://researchaustralia.org/Publications%20Special%20Reports/The%20Economic%20Value%20of%20Australia%20Investment%20in%20Health%20and%20Medical%20Research%20October%202010.pdf>.

³ Item 2, section 90B(4) *Commonwealth Electoral Act 1918 (Cth)* (CEA).

⁴ The Federal Privacy Handbook defines "medical research" to be "systematic investigations for the purpose of adding to generalised knowledge pertaining to human health and includes epidemiological research". See further: Federal Privacy Commissioner. (1998) *Federal Privacy Handbook: federal privacy law and practice*, paragraph 40-040.

⁵ Australian Electoral Commission website. *Supply of Elector Information for Use in Medical Research*. Accessed at: http://www.aec.gov.au/Enrolling_to_vote/About_Electoral_Roll/medical_research.htm

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National Health and Medical Research Council (NMHRC) under section 95(1) of the *Privacy Act 1988* (Cth).⁶

The NHRMC Guidelines permit Commonwealth agencies to disclose personal information without infringing privacy legislation if the proposed medical research has been approved by a properly constituted Human Research Ethics Committee (HREC) in accordance with the Guidelines.

Inability to access electoral roll data for medical research purposes

Recently, a study led by me at Monash University (Monash) was denied access to electoral data by the AEC. This study seeks to establish the views of the Australian population on privacy and participation in epidemiological research. The study is funded by the NHMRC (through its Medical Research Endowment Fund) and has been approved by the University HREC in accordance with the NHMRC Guidelines. In our view, the study meets the requirements of the CEA. We have recently sought an opinion from the NHMRC as to whether, in its view, our research was medical research. The NHMRC has confirmed that it is their view that our research is medical research. Unless the AEC's decision is changed, this study will not be able to proceed despite the investment of over 12 months' funded preparatory work. We are aware that researchers at other universities around Australia have had a similar experience to Monash.

Legislative proposal to amend the CEA

We note that it is at the AEC's discretion whether or not to release electoral roll information for medical research purposes under the CEA.⁷ We also acknowledge that not all proposed medical research studies will necessarily fulfil the legislative requirements. However, it is of some concern that NHRMC funded medical research projects that, in our view, fulfil these requirements are unable to access electoral roll data and are consequently unable to proceed.

To overcome this problem and to clarify when a research study does fulfil the necessary requirements for "medical research", we propose an amendment to the CEA. That is, where research has been funded by the NHMRC, the AEC can regard the "medical research" criterion as being fulfilled. The NHMRC is unable to fund research that is unrelated to health or medical research.

We also propose that other health and medical research funding bodies such as the National Heart Foundation could be added to a schedule created by regulation. In situations where there is doubt about whether a proposal from these funding bodies is medical research, the AEC could refer these proposals to the NHMRC for advice.

As the Australian Government's key agency for supporting and funding health and medical research, the NHMRC is the most appropriate arbiter for determining whether research proposals constitute "medical research". As noted, the CEA already requires that medical research proposals must fulfil criteria listed in Guidelines created by the NHMRC. The proposed amendments would be a logical extension of that provision. By contrast, determining whether a matter ought to be "medical research" would appear to be outside the AEC's expertise.

The idea for the proposed legislative amendments originates from the AEC itself. In a 2002 submission to the Committee, the AEC acknowledged its difficulties in determining whether certain NHMRC funded studies met the CEA's definition of "medical research". In such cases, the AEC indicated that it sought advice from the NHMRC. However, the AEC also stated that a more formal process should be in place. This would involve the NHMRC being required to advise the AEC that medical research projects complied with the necessary CEA requirements before the AEC released

⁶ Section 91A(2A)(c) CEA; Regulation 9 *Electoral and Referendum Regulations 1940* (Cth).

⁷ Item 2, section 90B(4) CEA; Paragraph 1.3 NHRMC Guidelines.

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any electoral roll data. The AEC indicated that it would be consulting with the NHMRC on this issue but the result of this consultation is unknown.⁸

Such an amendment would also be consistent with the existing CEA provision for public health screening programs. This states that, before the AEC can release electoral roll data for public health screening programs, the relevant program must be approved by the Secretary of the Department of Health and Ageing.⁹

On this basis, we urge that the Committee as part of its current *Inquiry into the 2010 Election* recommend to Parliament that an amendment be made to the CEA regarding disclosure of elector information for medical research purposes. That is,

1. Research funded by the NHMRC is automatically regarded as medical research;
2. Where there is doubt, an opinion be sought from the NHMRC; and
3. A schedule be created by regulation in which the names of other funders of health and medical research could be added.

Introducing this amendment will provide certainty and clarity for both the AEC and medical researchers. The AEC will not be called upon to make decisions beyond its realm of expertise, and medical researchers - who fulfil the necessary CEA requirements - will be able to proceed with their critical work.

We would welcome the opportunity to appear before the Committee to give further evidence on these matters.

Yours sincerely,

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Director

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⁸ Submission of the Australian Electoral Commission to the Commonwealth Joint Standing Committee on Electoral Matters, (2002). *Inquiry into the 2001 Election*, Attachment D, p. 16. Accessed at <http://www.aph.gov.au/house/committee/em/elect01/subs/partd.pdf>

⁹ Section 91(2A)(c) CEA; Regulation 9(b)(i) *Electoral and Referendum Regulations 1940* (Cth).