



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
PO Box 6021
Parliament House
Canberra ACT 2600
Email: jscem@aph.gov.au

12 May 2011

Dear Chair,

Supplementary submission – Medical research under the Commonwealth Electoral Act 1918 (Cth)

Thank you for the invitation to make a supplementary submission to the Joint Standing Committee on Electoral Matters (the Committee).

As we noted in our appearance before the Committee on 13 April 2011, we fully support and respect the integrity of the Commonwealth electoral roll and recognise the importance of governance arrangements to control when and how the roll may be accessed.

Nonetheless, as detailed in our original submission of 10 February 2011, we believe that the Australian Electoral Commission's (AEC) current interpretation of "medical research" under the *Commonwealth Electoral Act 1918 (Cth)* (CEA) is overly restrictive. Medical researchers are consequently often unable to access electoral roll data that will assist them to conduct research that has the potential to improve both the health and quality of life of Australians.

To address this issue, we propose a new process by which medical researchers can apply to access the Commonwealth electoral roll. We believe that this process will achieve two outcomes. It will preserve public confidence in the integrity of the electoral roll against inappropriate disclosure of elector information. It will also allow for a fully informed and independent determination about whether or not a research proposal constitutes "medical research".

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

Section 90B(4), item 2 of 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. While the CEA does not currently define "medical research", the AEC generally utilises the definition of "medical research" set out in the Federal Privacy Handbook issued by the Office of the Federal Privacy Commissioner.¹

¹ 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". Federal Privacy Commissioner. (1998). *Federal Privacy Handbook: federal privacy law and practice*, paragraph 40-040.

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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* issued by the National Health and Medical Research Council (the NHMRC Guidelines) under section 95(1) of the *Privacy Act 1988* (Cth).² The NHMRC 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.

Proposed approval process for access to the electoral roll for medical research purposes

Approval by a Human Research Ethics Committee

We endorse the current AEC requirement that the release of electoral roll data for medical research purposes should only be to applicants who have had their proposed medical research project approved by a HREC in accordance with the NHMRC Guidelines.

This is a rigorous and systematic process, which requires researchers to explicitly take privacy considerations into account and justify why their proposed research is in the public interest. Given this, we note that medical researchers would have no difficulty meeting additional privacy requirements considered appropriate by the AEC, such as requiring third parties to execute Deed Polls in which they undertake to preserve privacy according to the standards determined necessary by the AEC.

Definition of “medical research”

Presently, once research has been approved by a HREC in accordance with the NHMRC Guidelines, researchers seeking access to the electoral roll on medical research grounds will then apply to the AEC. In response, the AEC will make a determination as to whether or a not a study constitutes “medical research” under the CEA.

As noted, the AEC generally utilises the definition of “medical research” from the Federal Privacy Handbook when making this determination. This is a purposefully narrow definition intended to capture only a limited range of research. This has been remarked upon by the Australian Law Reform Commission (ALRC) who sought to do away with “medical” research as a sub-category. We also believe that the current definition is too narrow and that “medical research” should be given a broader interpretation. The ALRC has stated:

... In response, the OPC Review stated that ‘the *Privacy Act* is not intended to restrict important medical research’^[7] and made the following recommendation: As part of a broader inquiry into the *Privacy Act* ... the Australian Government should consider ... how to achieve greater consistency in regulating research activities under the *Privacy Act*.^[8]

While it is possible to argue that the term ‘research’ is broad enough to include the compilation or analysis of statistics, this is not universally accepted. The NPPs refer to research, *or* the compilation or analysis of statistics. This wording tends to infer

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



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that research does not include the compilation or analysis of statistics. The National Statement does not refer to the compilation or analysis of statistics, but HRECs are asked to review research proposals consisting of the compilation or analysis of statistics or including statistical elements. In order to put the matter beyond doubt, the ALRC recommends that the *Privacy Act* should state expressly that the term 'research' includes 'the compilation and analysis of statistics'.³

Further relevant recommendations may be found in Attachment A.

Medical research involves more than clinical research or the testing of drugs. It also involves research that has a "public health" focus and research that is otherwise regarded as having consequences for public health. Such research may examine the features of populations relevant to health and is conducted for the purpose of protecting or improving the health of a population. It is this category of research that is more likely to seek access to the electoral roll to obtain a randomly selected sample of electors that is reliably representative of the Australian population. No other database is accessible to researchers for this purpose.

Prima facie, research should be considered to be "medical research" if funded by the NHMRC or an equivalent reputable funding body such as the National Heart Foundation. If such research is judged by the AEC to not satisfy its understanding of "medical research", then the AEC should provide reasons for this determination.

A list of other reputable funding bodies could be drawn from the Australian Competitive Grants Register maintained by the Commonwealth Government. The names of relevant competitive granting bodies derived from this list are noted in Attachment B to this submission.

Appeal process

In order to enhance the transparency and fairness of the AEC's decision making process, it is also crucial that there be an opportunity for applicants to seek the review of a decision made under section 90B(4), item 2 of the CEA.

There is currently no ability for an applicant to seek internal review of a decision made under this section within the AEC. There also appears to be no option for an applicant to appeal this decision to the Administrative Appeals Tribunal (AAT). This was confirmed in a recent email to Monash University from the AAT. A copy of this email is included as Attachment C to this submission.

We believe that the inability of an applicant to seek an independent review of a decision about whether or not a research proposal is "medical research" detracts from the integrity of the decision making process.

Therefore, we submit that any AEC determination made under section 90B(4), item 2 of the CEA be subject to a two stage review process. First, an applicant should have the

³ See further: Australian Law Reform Commission. (2008). *Australian Privacy Law and Practice: ALRC Report 108, paragraphs 65.67-65.68*. Accessed at: <http://www.alrc.gov.au/publications/65.%20Research%3A%20Recommendations%20for%20Reform/definition-research>



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opportunity to seek internal review of the AEC's decision through a Medical Review Committee. We propose that this Committee be made up of AEC staff with expertise in electoral law and researchers with medical and public health expertise who could be drawn from the Council of the NHMRC. The Committee would be required to assess the applicant's research proposal and the accompanying HREC application to ascertain if it constitutes "medical research". The Committee may request further information from AEC officers or the research applicant. If the Committee is unable to reach a decision by majority, then the ultimate determination will be made by the Australian Electoral Commissioner. If the Australian Electoral Commissioner decides that a research proposal is not "medical research", we further submit that the applicant should have the option of appealing this decision to the AAT.

We consider that this new process will both maintain public confidence in the Commonwealth electoral roll and enhance the AEC's decision making in this regard. It will more properly reflect current medical research practice and will offer the opportunity to obtain an independent review of the AEC's decision. Most importantly, the proposed process will operate to protect the integrity of the electoral roll and prevent inappropriate disclosure of elector information because it enables the AEC's views to be fully taken into account at all stages of the decision making and review process.

Yours sincerely,

A handwritten signature in black ink that reads 'Bebe Loff'.

Associate Professor Bebe Loff
Director
Michael Kirby Centre for Public Health and Human Rights



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ATTACHMENT A

Recommendation 65-9 The research exception to the 'Use and Disclosure' principle should provide that an agency or organisation may use or disclose personal information where all of the following conditions are met:

- (a) the use or disclosure is necessary for research;
- (b) it is unreasonable or impracticable for the agency or organisation to seek the individual's consent to the use or disclosure;
- (c) a Human Research Ethics Committee—constituted in accordance with, and acting in compliance with, the *National Statement on Ethical Conduct in Human Research* as in force from time to time—has reviewed the proposed activity and is satisfied that the public interest in the activity outweighs the public interest in maintaining the level of privacy protection provided by the *Privacy Act*;
- (d) the information is used or disclosed in accordance with the Research Rules, to be issued by the Privacy Commissioner; and
- (e) in the case of disclosure—the agency or organisation reasonably believes that the recipient of the personal information will not disclose the information in a form that would identify the individual or from which the individual would be reasonably identifiable.

Recommendation 66-3 The Research Rules, to be issued by the Privacy Commissioner, should address the circumstances in which, and the conditions under which, it is appropriate to collect, use or disclose personal information without consent in order to identify potential participants in research.



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ATTACHMENT B

COMMONWEALTH

Cancer Australia
National Health and Medical Research Council

NON COMMONWEALTH

Australian Rotary Health
Diabetes Australia Research Trust (DART)
Juvenile Diabetes Research Foundation
Leukaemia Foundation
Motor Neurone Disease Research Institute of Australia
National Breast Cancer Foundation
National Heart Foundation of Australia
Prostate Cancer Foundation of Australia
VicHealth (Victorian Health Promotion Foundation)



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ATTACHMENT C

Policy & Research Section <Research@aat.gov.au> 19 April 2011 10:07

Dear Associate Professor Loff

I refer to your letter of 14 April 2011. While we are unable to provide you with legal advice about your particular query, I can provide you with some general information which may be of some assistance to you.

The Administrative Appeals Tribunal (AAT) can review a range of Australian Government decisions if an Act or other legislative instrument specifically states that the AAT can review the decision. A list of the decisions that the AAT can review can be accessed at: <http://www.aat.gov.au/LegislationAndJurisdiction/JurisdictionList.htm>.

As you have noted in your letter, the AAT has the power to review certain decisions under the *Commonwealth Electoral Act 1918*. Section 121 sets out the decisions which may be reviewed by the AAT. This section does not refer to section 90B, and accordingly it does not appear that a decision made under 90B(4) is reviewable. However, a conclusive determination of whether or not the AAT can review a decision can only be made by the AAT once it has received an application for review.

I hope this information is of assistance.

Kind regards,

Kelly Burke

Legal & Policy Officer | Policy & Research Section
Administrative Appeals Tribunal
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