

## Summary of Australian Electoral Commission's "Supply of Elector Information for Use in Medical Research", January 2011

The Australian Electoral Commission (AEC) has recently undertaken a review of the information it provides about access to data from the Commonwealth electoral Roll for the purposes of research.

Revised information is now available at:

[http://www.aec.gov.au/Enrolling\\_to\\_vote/About\\_Electoral\\_Roll/medical\\_research.htm](http://www.aec.gov.au/Enrolling_to_vote/About_Electoral_Roll/medical_research.htm)

Researchers and Ethics Committees should familiarize themselves with the full document. The following points are provided to highlight some of the key aspects of the AEC's position and how/where these should be addressed in ethics applications.

1. Prior to 2004, copies of the Commonwealth electoral Roll could be purchased from the AEO and used for any purpose. In 2004 the Electoral Act was amended to tighten privacy protections. A public version of the Roll can be 'inspected' on a computer terminal at AEO premises, but no copies or images may be taken. Not all addresses and categories of electors are included in the public version. Medical researchers would usually require information from the 'protected version' of the Roll, which includes all electors and also additional information such as sex and age range. This information comes within the scope of "personal information" as defined in the *Privacy Act 1988*.
2. The primary purpose of the Commonwealth electoral Roll is to register eligible voters. The AEC can only disclose personal information from the Roll for another purpose where this is authorized by law. The NHMRC [Guidelines Under Section 95 of the Privacy Act 1988](#) permit the disclosure of personal information for the purposes of medical research, providing certain conditions are met.
3. Researchers applying for ethical approval of their research must set out a number of matters, including:
  - in Module One, Section E (for CAF applications), or the Victorian Specific Module, Section 3 (for NEAF applications)**
    - why identifiable "personal information" is needed from this source.
    - the amount of data needed (i.e. number of records involved). Note that the AEC considers the number of records significant: the larger the data-set being requested, the larger the 'privacy breach'.
    - a list of the Information Privacy Principles (IPPs) that may be breached. This can be done by checking the relevant privacy principle boxes in the table provided in the 'Disclosure of information' section of the module.
    - reasons why the public interest in the research substantially outweighs the public interest in adhering to the IPPs, and sufficient information to support these claims.
    - mechanisms and procedures for the secure storage of data, and to protect against further use or disclosure of the Roll extract.
  - in the Participant Information and Consent Form**
    - advice to the electors/potential participants about complaints mechanism to the HREC and the Office of the Australian Information Commissioner (i.e. contact details for both).
4. The above matters must also be addressed in any subsequent requests to access additional records – i.e. in amendments to approved research projects. The amendment documentation should therefore include a revised Privacy section of the relevant module.
5. The final decision about whether personal information will be disclosed from the Commonwealth electoral Roll for a specific research project lies with the AEC, regardless of whether the HREC has approved the disclosure.
6. The AEC is not empowered to, *and will not*, undertake data-matching activities; for e.g. to update address details for participants in previously approved research. PICFs that include 'consent' from participants for such data-matching are not considered by the AEC to be sufficient authority.
7. Applications to the AEC to access information from the Commonwealth electoral Roll should include a copy of the HREC approval, research proposal or protocol, and the relevant module covering privacy. AEC processing fees apply. Refer to the [AEO website](#) for further information.