

# Supply of Elector Information for Use in Medical Research

## General

The Australian Electoral Commission (AEC) recognises the importance of the conduct of medical research that is undertaken in accordance with the requirements of relevant Commonwealth laws which ensure that the privacy of individuals is protected and that the public interest in the medical research is properly considered against the privacy breach that necessarily results when “personal information” is provided by the AEC to third parties. However, at all times it must be remembered that the primary purpose of the Commonwealth electoral Roll is to register the entitlement of Australian citizens to vote in federal elections and that medical research is only an ancillary use of this “personal information”.

## Privacy Act

The AEC is a Commonwealth “agency” and is subject to the provisions contained in the *Privacy Act 1988* which regulate the collection, storage, use and disclosure of “personal information”. The AEC is also subject to the specific provisions contained in the *Commonwealth Electoral Act 1918* (Electoral Act) dealing with the use and disclosure of information from the Commonwealth electoral Roll. The information contained on the Commonwealth electoral Roll includes the name and address of electors together with some other identifiers and therefore comes within the scope of the definition of “personal information” in subsection 6(1) of the *Privacy Act 1988* which provides that:

**“personal information** means information or an opinion (including information or an opinion forming part of a database), whether true or not, and whether recorded in a material form or not, about an individual whose identity is apparent, or can reasonably be ascertained, from the information or opinion.”

Information Privacy Principle (IPP) 11 regulates the disclosure of “personal information” by Government agencies such as the AEC. That IPP provides that a record keeper that has possession or controls a record containing “personal information”, shall not disclose that information unless a specified exception applies (see IPP 11.1 in section of the *Privacy Act 1988*). There is no specific exception for disclosure of “personal information” for the purposes of medical research, although there is an exception where the disclosure is

authorised by law (IPP 11.1(d)). IPP 11.3 provides that a person, body or agency to whom personal information is disclosed under IPP 11.1 must not use the information for a purpose, other than the purpose for which it was provided to the disclosing agency. The information contained in the Commonwealth electoral roll was provided for the express purposes of the conduct and facilitation of Commonwealth elections, not for the purpose of medical research. Accordingly, any disclosure by the AEC of the “personal information” from the Roll for the purposes of medical research would ordinarily constitute a breach of IPP 11.

However, section 95 of the *Privacy Act 1988* has the effect that, where the AEC discloses “personal information” from the Roll in accordance with the Guidelines issued by the CEO of the National Health & Medical Research Council (NH&MRC Guidelines), that disclosure will not constitute a breach of IPP 11. This constitutes an authorisation under law for the purposes of IPP 11.1.

## Electoral Act

The Electoral Act contains a comprehensive regime of provisions that regulate the persons and organisations that the AEC is lawfully able to disclose information from the Commonwealth electoral Roll, the information that is able to be included in each extract from the electoral Roll that is disclosed and the permitted uses that can lawfully be made of that information. The relevant provisions are contained in Part VI of the Electoral Act and in particular sections 90A, 90B, 91A and 91B.

The Electoral Act authorises the AEC to collect “personal information” for inclusion in the Commonwealth electoral Roll. This information includes the name and address of all eligible persons who are electors in addition to a range of other information about these electors including their age, sex and other contact details (see sections 83 and 90B). To be an eligible person entitled to appear on the electoral Roll, the person must be 18 years of age and an Australian citizen (see section 93). Accordingly, with the exception of some British subjects who enrolled prior to 26 January 1984, the Commonwealth electoral Roll does not include details of all Australian residents.

The current regime for accessing the Commonwealth electoral Roll was inserted by the *Electoral and Referendum Amendment (Access to the Electoral Roll and Other Measures) Act 2004* (Amendment Act). Prior to these amendments, copies of the Commonwealth electoral Roll could be purchased from the AEC and used for any purpose. However, on 21 July 2004, this ceased to be lawful and the AEC was prohibited from continuing such action. The Second Reading Speech to the Bill that became the Amendment Act (see House of Representatives Hansard of 1 April 2004 page 27929 particularly at page

27930) made it clear the new regime was to cover the field in relation to access to the Commonwealth electoral Roll and the then Minister stated that:

*“The bill will amend the roll access provisions to improve clarity, remove contradictions and improve privacy protections. Access to roll information will be set out in a tabular form. The tables will include all information that is currently provided for in the Electoral Act. They list who is entitled to roll information, what information they are entitled to and how often they will receive it...”*

Other safeguards to the Commonwealth electoral Roll are contained in sections 390 (immunity from subpoenas), 390A (immunity from search warrants) and section 47A of the *Freedom of Information Act 1982* (third party enrolment information is an exempt document).

The Amendment Act also introduced a range of criminal offences that apply to the use and disclosure of the “protected information” from the Commonwealth electoral Roll where this was not for a permitted purpose. The offence in subsection 91A(1) of the Electoral Act for the unauthorised use of Roll information carries a penalty of 100 penalty units (i.e. \$11,000) while the offence in subsection 91B(2) of the Electoral Act for the unauthorised disclosure of Roll information carries a penalty of 1,000 penalty units (i.e. \$110,000). This level of penalties indicates the seriousness that the Commonwealth Parliament regarded such breaches of the Electoral Act and the sensitivities about the “personal information” held by the AEC as part of the database behind the Commonwealth electoral Roll.

## The Commonwealth electoral Roll

The Commonwealth electoral Roll is stored and maintained as an electronic data-base (see section 111 of the Electoral Act) that contains a range of “personal information” about all eligible persons who are electors. To be an eligible person entitled to appear on the electoral Roll, the person must be 18 years of age and an Australian citizen (see section 93). With the exception of some British subjects who enrolled prior to 26 January 1984, the Commonwealth electoral Roll does not include details of all Australian residents or persons under the age of 18 years.

Under section 90A of the Electoral Act, a public version of the Commonwealth electoral Roll is required to be made available by the AEC for public inspection at premises occupied by the AEC during office business hours. Accordingly, any person (including medical researchers) has a legal right to attend an AEC office and to inspect the public version of the Commonwealth electoral Roll. However, there are some limitations on the right to inspect the public version of the Commonwealth electoral Roll. First, no copies or images of the Roll are able to be taken. It is only a right to inspect the Roll. Second, the

public version of the Commonwealth electoral Roll is accessible only on a computer terminal at AEC premises. Third, the public version of the Commonwealth electoral Roll that can be inspected does not include the address details of all eligible electors with “silent electors” (see section 104) and certain other categories of electors being excluded.

The information that is sought from the AEC by medical researchers is not the public version of the Commonwealth electoral Roll which only contains the name and address of electors who have enrolled to vote at a federal election (see section 83). The information sought by medical researchers includes protected “personal information” under item 2 of the table in subsection 90B(4) of the Electoral Act which includes the sex and age range of electors. Subsection 90B(5) of the Electoral Act limits the age ranges that can be lawfully disclosed by the AEC to medical researchers to an age range of at least 2 years. This protected information is subject to safeguards (including penal sanctions) on its further disclosure or misuse under sections 91A and 91B of the Electoral Act.

Regulation 9 of the Electoral and Referendum Regulations 1940 provides that a “permitted purpose” for the use of the Commonwealth electoral Roll for the purposes of the offences contained in sections 91B of the Electoral Act includes the supply of the protected information for use in:

- the conduct of medical research in accordance with the ‘Guidelines Under Section 95 of the Privacy Act 1988’, issued by the National Health and Medical Research Council in March 2000; or
- the provision of a public health screening program:
  - approved by the Secretary of the Department of Health and Aged Care, and
  - conducted in accordance with the Guidelines for the Conduct of Public Health Screening Programs with particular reference to Privacy and the Management of Personal Information issued by the Department of Health, Housing, Local Government and Community Services on 1 December 1993.

## NH&MRC Guidelines

The NH&MRC Guidelines can be accessed at <http://www.nhmrc.gov.au/files/nhmrc/file/publications/synopses/e26.pdf>. These Guidelines require that any proposals by a medical researcher to a Human Research Ethics Committee (HREC) must set out a number of matters including the reasons why identifiable “personal information” is needed, the source of the data, the amount of data

needed and a list of the IPPs that may be breached (see section 14 of the *Privacy Act 1988*). The proposal must also set out the reasons why the public interest in carrying out the proposed research in question outweighs, to a substantial degree, the public interest in adhering to the IPPs and provide sufficient information to enable the HREC to weigh-up the public interest considerations (see paragraphs 2.2, 2.3 and 2.4). Also, if the AEC subsequently agrees to release the “personal information” from the Commonwealth electoral Roll, paragraph 2.6 of the NH&MRC Guidelines requires the researcher to advise the elector of a number of matters including the complaints mechanism to the HREC and the Office of the Australian Information Commissioner about the proposed use of the “personal information”. This information must be included in the proposal to the HREC and the protocols that are developed to support the medical research.

It is apparent that if the AEC agrees to the disclosure of the “personal information” from the Roll to be used in medical research then IPP 11.1 and 11.3 will be breached. The “personal information” was collected for the purpose of the conduct of an election – not for the purpose of medical research. Accordingly, the requested disclosure by the AEC to a medical researcher will be in breach of IPP 11.1 and 11.3 and this must be clearly identified in the proposal from the medical researcher.

Under Part 3 of the NH&MRC Guidelines, the HREC is then required to determine whether the public interest in the medical research outweighs the public interest in the protection of the elector’s privacy. This will be based on the contents of the proposal that the medical researchers have prepared a lodged with the HREC together with any additional advice and expertise that the HREC acquires to ensure that it complies with paragraph 3.4 of the NH&MRC Guidelines. The AEC is of the view that the larger the data-set that is requested in the proposal then the larger the privacy breach that will be committed if the AEC agrees to comply with the request. The disclosure of the “personal information” by the AEC to the medical researcher under IPP 11.1 and 11.3 are the two matters which must be considered by an HREC in accordance with paragraphs 3.1. to 3.3 of the NH&MRC Guidelines. In addition, the HREC decision must be recorded in accordance with the requirements of paragraph 3.4 which includes that the HREC identify “the number of records involved”. One of the effects of this requirement is that any subsequent requests to the AEC for additional records of “personal information” must also be considered and approved by the HREC.

It is also noted that the NH&MRC Guidelines themselves clearly reflect that the final decision on the disclosure of “personal information” from the Commonwealth electoral Roll in these matters rests with the AEC. Paragraph 1.3 of the NH&MRC Guidelines states that:

*“Agencies may always decline to disclose personal information for use in medical research even where the medical research has been approved by an HREC in accordance with these guidelines.”*

The above statement in the NH&MRC Guidelines when combined with the discretionary power given to the AEC in subsection 90B(4) of the Electoral Act results in there being no Parliamentary intention that the AEC should grant every request from a medical researcher for access to “personal information” contained in protected versions of the Commonwealth electoral Roll. The AEC is not bound by decisions made by the NH&MRC on specific research projects or by decisions made by HRECs on individual proposals. The AEC will weigh up a number of matters including the other election related work on hand, the size of the data-sets being sought, the methodological link between the medical research proposal and the personal information that was being sought from the AEC and other possible sources of relevant information that may be available outside the AEC.

## Data-matching

The AEC receives many requests from medical researchers asking the AEC to undertake data-matching activities to match lists of previous participants in earlier studies with the current address details of those persons on the Commonwealth electoral Roll. The lists provided to the AEC include the name, previous address and date of birth of the participants. There is no power in the Electoral Act (or relevant Privacy legislation) for such data-matching action to be undertaken by the AEC. Subsections 90B(5) and (7) of the Electoral Act specifically limit what information the AEC can lawfully disclose for the purposes of medical research so that it can only be an age range (of at least 2 years) and is unable to include the actual date of birth information of electors for the purposes of medical research.

Further, previously issued information sheets given to participants in the earlier studies by researchers (whether as part of the initial invitation to participate or subsequently signed by the participant) do not provide the AEC with any legal authority that overrides the limitations set out in the Electoral Act. Unfortunately, these information sheets are usually several years old and do not show that any informed consent to the subsequent disclosure of this information by the AEC is current so as to comply with the Information Privacy Principle Guidelines issued by the Privacy Commissioner (now part of the Office of the Information Commissioner) in relation to dealing with informed consents (see <http://www.privacy.gov.au/law/apply/guidance>). Accordingly, all requests for data-matching will be refused.

Even if it could be argued that such data-matching could be lawfully undertaken under the Electoral Act by the AEC, any proposals lodged with a HREC that are relied upon to

support such access requests would also be required to address the privacy breach involving IPP 10.1 as the AEC is being asked to “use” the Roll for a purpose other than for which the “personal information” was collected.

## Applying to the AEC

Applications for access to the Commonwealth electoral Roll for the purposes of conducting medical research should be directed to: The Freedom of Information Officer, Legal Services Section, Australian Electoral Commission, PO Box 6172, KINGSTON ACT 6172.

You will be asked to forward a copy of the appropriate HREC approval to the AEC and any relevant proposal to the HREC on which that approval is based. However, it should again be noted that the final decision regarding release of elector information rests with the AEC, even when the study has received the appropriate approval. The AEC may seek further details concerning your study in order to satisfy itself in relation to the appropriateness of the release of elector information. The AEC may also seek the advice of the Privacy Commissioner.

The Federal Privacy Handbook issued by the Privacy Commissioner (now known as the Office of the Australian Information Commissioner) defines medical research as “*systematic investigations for the purpose of adding to generalised medical knowledge pertaining to human health and includes epidemiological research*”. This is the definition that is generally applied by the AEC in making decisions regarding whether or not a particular proposal amounts to “*medical research*” for the purposes of subsection 90B(4) of the Electoral Act.

Under provisions of the Electoral Act the AEC can provide elector name, address, sex and age-range information for use in medical research and public health screening programs. Please note that whilst age-range information can be provided in a minimum of two-year spans, the AEC would normally only provide it in five or ten year spans. If age-range spans of less than five years are required, justification will need to be provided.

The FOI officer for the AEC can be contacted on (02) 6271 4511 to discuss details to assist in making an application.

## Format

The format and type of extraction can be discussed with the AEC's Roll Products and Services Unit on (02) 6271 4666, or by email [help.rollmanagement@aec.gov.au](mailto:help.rollmanagement@aec.gov.au). Formal approval of your request will still be required before any processing can commence.

## Media

The AEC provides data on CD-ROM. If this does not suit your needs, please contact Roll Products and Services Unit on (02) 6271 4666, or by email [help.rollmanagement@aec.gov.au](mailto:help.rollmanagement@aec.gov.au) to discuss alternative media options.

## Extract types

The Commonwealth electoral Roll is organised on the basis of the 150 Divisions in the House of Representatives and the 6 States and 2 Territories for the purposes of Senate elections. This is to facilitate the extraction of the certified lists of electors which are used in elections. The AEC is not able to extract data from the Commonwealth electoral Roll on the basis of postcodes, census district or any other subcategory as any additional use of programming resources will incur substantial costs provided that such resources were even available. Under subsection 90B(7) of the Electoral Act the AEC is able to charge a fee that covers the costs of providing the requested information. This fee will also include the AEC costs in both examining the requests and the administration of each request (e.g. the drafting and issuing of safeguard agreements).

The following extracts are taken from the most recent backup file of the AEC's Roll Management System. Please contact the Roll Products and Services Unit for information regarding the latest backup.

There are two types of extracts available:

- EX02 Elector Extract by Age Ranges contains details of electors in a minimum of 2 year age ranges by Federal Division. The extract may include electors from all Federal Divisions or from nominated Federal Divisions within a State or Territory.
- EX03 Random Elector Extraction provides a basic random sample of electors from a State or Territory or from a range of Federal Divisions. Sample size, age range and gender may be nominated.

## Data format

There are two standard choices of data format that affect the addresses in the data supplied:

- Formatted addresses - contains address as four lines of text, pre-formatted into a form suitable for printing directly onto an envelope or mailing label; or

- Unformatted addresses - contains individual data items for each piece of the address and it is left up to the user to format them for use. This format is not suitable for printing directly onto an envelope or mailing label.

## Cost

An estimate of the processing costs will be provided, on request, at the time we receive the details of your request.

## Conditions

Before we provide any elector information, an agreement protecting the data from unauthorised use must be signed by the person in charge of the study and returned to the AEC. One of the issues that must be addressed and considered at the time of the proposal lodged with the HREC is whether or not any subcontractors (e.g. telemarketing companies, Sensis for telephone matching, etc) are to be used outside the research team. Because the Commonwealth electoral Roll information that may be disclosed includes “protected information”, the disclosure to subcontractors will be unauthorised in breach of section 91B of the Electoral Act unless the approvals obtained from both the HREC and the AEC clearly include such use of subcontractors. In this situation the subcontractors will be required to sign separate safeguard agreements the contents of which will be determined by the AEC.

## Time frames

The AEC will endeavour to respond to requests as soon as possible. However, the AEC gives priority to its core business. Consequently, the AEC is unable to guarantee the supply of an extract by a specified date.

## Payment

The AEC will forward an invoice for payment prior to the despatch of the data. Payment is required prior to the despatch of the data. Once the provision of the data extract is approved by the AEC, the Roll Products area of the AEC will contact you to arrange payment and safe delivery of the data.

## Checklist

1. Is the extract from the Commonwealth electoral Roll the appropriate source of data to be used in the research?
2. Have other potential data-sources been examined, particularly where the medical research involved persons who are resident in only one State or Territory (e.g. State or Territory Government Instrumentalities, State or Territory Electoral Commissions, the

National Exchange of Vehicle and Driver Information System maintained by all State and Territory registration authorities)?

3. Has the proposal to the HREC addressed all of the matters contained in the NH&MRC Guidelines?

4. Has the HREC decision recorded the matters contained in the NH&MRC Guidelines?

5. Are there mechanisms in place to notify participants of the matters set out in paragraph 2.6 of the NH&MRC Guidelines?

6. Are there mechanisms and procedures in place to protect the Roll extract from further use or disclosure given the penalties in section 91B of the Electoral Act?