



**Australian Government**

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**National Health and Medical Research Council**

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**Office of the Privacy Commissioner**

## **MEDIA RELEASE**

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### **New privacy guidelines for health practitioners on disclosing genetic information**

The National Health and Medical Research Council (NHMRC), in cooperation with the Office of the Privacy Commissioner (OPC), today released new guidelines to assist health practitioners in making decisions about disclosing genetic information to their patient's genetic relatives.

In 2003, a joint inquiry by the Australian Health Ethics Committee and the Australian Law Reform Commission led to an amendment of the Privacy Act regarding the disclosure of genetic information by health practitioners.

The amendment required the development and issuing of these guidelines which have undergone extensive public consultation and been approved under section 95AA of the Privacy Act.

Dr Sandra Hacker AO, chair of the NHMRC's Guidelines Working Party, said the guidelines specify the strict requirements that must be met by health practitioners if they are faced with the difficult decision of having to disclose genetic information without patient consent.

"These new guidelines permit doctors to disclose information to a genetic relative of the patient without the patient's consent, but only in situations where they reasonably believe that disclosure is necessary to lessen or prevent a serious threat to the life, health or safety of the patient's relative," Dr Hacker said.

"It is important to emphasise that doctors can not disclose information to non-genetic relatives, for example husbands or wives, or when there is no threat to the genetic relative."

The Australian Privacy Commissioner, Karen Curtis, has issued a Temporary Public Interest Determination (TPID) which will allow medical practitioners to collect or use the contact details of a patient's genetic relatives in situations where the guidelines permit the disclosure of information.

“It is important to note that the guidelines and TPID do not require disclosure of information, but rather provide the framework for this to occur under the appropriate circumstances,” Ms Curtis said.

“Disclosure of genetic information without consent is only permissible under the Privacy Act if it is in accordance with the guidelines.”

*The use and disclosure of genetic information to a patient’s genetic relative under Section 95AA of the Privacy Act 1988 (Cth) – Guidelines for health practitioners in the private sector’* are available for download at

<http://www.nhmrc.gov.au/publications/synopses/e96syn.htm>

Further information is available from the Office of the Privacy Commissioner:

[www.privacy.gov.au/law/act/genetic](http://www.privacy.gov.au/law/act/genetic)

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