

Media release

29 October 2014

Genetic Health Guidelines released today to assist medical practitioners when deciding to use or disclose a patient's genetic information to a relative without consent

NSW Privacy Commissioner Dr Elizabeth Coombs has today issued NSW Genetic Health Guidelines entitled: "Use and disclosure of genetic information to a patient's genetic relatives: Guidelines for organisations in NSW".

The guidelines were developed to accompany the amendments to the *Health Records and Information Privacy Act 2002* (HRIP Act) made in early 2012. These amendments take effect on 1 November 2014 and address the use and disclosure of genetic health information to biological relatives.

The guidelines cover the use and disclosure of a patient's genetic information to a genetic relative without their consent in certain, specific circumstances. These circumstances include those that lessen or prevent a serious threat to the life, health or safety of a genetic relative of the individual to whom the information relates. When disclosing genetic health information, this can include information about relatives that have deceased.

"In this age of increasing knowledge of genetic health conditions, information about a health condition can be a matter not just for the person with the condition but also for their biological relatives. Under the legislative amendments I had the responsibility to develop these Genetic Health Guidelines to give guidance to NSW medical practitioners and other suitably qualified and experienced professional health practitioners. The Guidelines aim to assist health practitioners when making the very difficult decision to disclose genetic health information to a biological relative without the patient's consent," said Dr Coombs.

"The NSW Genetic Health Guidelines were developed in accordance with the legislation and draw upon the National Health and Medical Research Council's Guidelines "Use and disclosure of genetic information to a patient's genetic relatives under s95AA of the Privacy Act 1988 (Cth)" which were previously approved by the Federal Privacy Commissioner. This has ensured consistency in approach," Dr Coombs said.

The NSW Genetic Health Guidelines are available on the IPC website. Access the NSW Genetic Health Guidelines here.

Dr Coombs is available to discuss the Genetic Health Guidelines on Mondays, Wednesdays and Fridays. Please contact Kate Jobling on 0435 961 691 or email ipcinfo@ipc.nsw.gov.au to make your request.

For more information about the release of the Genetic Health Guidelines, please visit www.ipc.nsw.gov.au

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