## **HEALTH LEGISLATION AMENDMENT BILL 2012**

**PROOF** 

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## Bill introduced on motion by Ms Jillian Skinner, read a first time and printed.

## **Second Reading**

**Mrs JILLIAN SKINNER** (North Shore—Minister for Health, and Minister for Medical Research) [12.01 p.m.]: I move:

That this bill be now read a second time.

I am pleased to bring before the House the Health Legislation Amendment Bill 2012. The bill makes a number of minor amendments to the Health Practitioner Regulation (Adoption of National Law) Act 2009, the Health Records and Information Privacy Act 2002 and the Poisons and Therapeutic Goods Act 1966. The amendments will help ensure the continued smooth operation of these Acts. I will turn first to the amendments to the Health Records and Information Privacy Act set out in schedule 1.2 to the bill. The Health Records and Information Privacy Act regulates the collection, use and disclosure of health information and applies to both the public and private sector. The private sector in New South Wales is also bound by the Commonwealth Privacy Act 1988.

Genetic information is considered health information and is regulated by the general principles in the Act. However, genetic information poses some specific issues of concern in today's world. A patient's genetic information, including whether the patient has a genetic disease or has a genetic predisposition to a disease will often be of significance to the patient's genetic relatives. This is because the patient's genetic relatives often carry the same genes and therefore face the same genetic risks as the patient. Because of the relevance genetic information may have on a patient's relatives, genetic services in New South Wales advise individuals during pre-test counselling that there may be a need for them to inform other at-risk family members of genetic test results. While most patients agree, a small number of patients fail or refuse to disclose their genetic information.

These types of cases cause complex ethical issues. When a patient's genetic information indicates the patient either has a genetic disease, or has a strong genetic predisposition to developing a serious disease, there are ethical arguments that clinicians should be able to disclose health information to a genetic relative even without the patient's consent. These arguments are particularly strong when providing the information would allow a genetic relative to take steps to identify his or her own level of risk and take any appropriate preventative action, such as regular screening for the particular disease in order to allow for early diagnosis and treatment. In some cases, such early treatment can be lifesaving. However, while there are possible benefits to disclosing such information without consent, there are other interests to take into consideration. These include the need to protect the patient's privacy and confidentiality and the need to recognise that negative impacts may flow from such a disclosure. This may include adversely impacting on family dynamics or causing distress to relatives if they have knowledge of a genetic risk that they would prefer not to be

made aware of, particularly if there is no current treatment or preventative options available.

While the disclosure of genetic information to a genetic relative without consent is a serious and contentious ethical question, the form of privacy law in New South Wales as currently drafted does not enable the complexities of the question to be addressed. Rather, genetic information is treated in the same way as any other health information. This effectively means that such disclosure without consent can occur only when there is a serious and imminent threat to life, health or safety. However, the serious and imminent test will rarely, if ever, allow disclosure of genetic information to a genetic relative without consent. While many treatable and serious genetic disorders may pose a serious, and potentially fatal, risk or threat of harm, they are likely also to have a slow onset of many years and so are unlikely to meet the requirement that the threat be imminent.

This contrasts with the position at the Commonwealth level under the Commonwealth Privacy Act. The Commonwealth Act allows, but does not mandate, an organisation to use and/or disclose genetic information without the patient's consent if and only if the organisation reasonably believes that the use or disclosure is necessary to lessen or prevent a serious threat to the life, health or safety—whether or not the threat is imminent—of a genetic relative of the patient; the use or disclosure is conducted in accordance with guidelines approved by the Commonwealth Privacy Commissioner; and in the case of disclosure the information is disclosed to a genetic relative of the patient.

The Commonwealth Privacy Commissioner has approved guidelines which were developed by the National Health and Medical Research Council [NHMRC]. The guidelines impose a number of conditions on clinicians when they are deciding whether or not to disclosure the information. Thus, the authorising clinician is to first take all reasonable steps to obtain consent from the patient. The clinician is required also to consider all the ethical issues and to consult with other experienced clinicians. Further, the National Health and Medical Research Council guidelines make clear that if a disclosure occurs, only information that is necessary to communicate the risk of harm should be disclosed and, where possible, the patient should not be identified.

By recognising the ethical issues associated with genetic information and by establishing a limited but appropriate framework in which genetic information can be disclosed without consent, the Commonwealth Act is considered the better model to deal with the contentious ethical issues associated with genetic information. The bill therefore seeks to amend the Health Records and Information Privacy Act to establish a similar framework in New South Wales in respect of genetic information. The amendment to the Act will allow, but not require, an organisation to use and disclose a patient's genetic information without consent only if the organisation reasonably believes that the use or disclosure is necessary to lessen or prevent a serious threat to the life, health or safety—whether or not the threat is imminent—of a genetic relative of the person to whom the information relates; the use or disclosure is conducted in accordance with guidelines approved by the New South Wales Privacy Commissioner; and in the case of disclosure the information is disclosed to a genetic relative of the individual.

This amendment will bring New South Wales into line with the Commonwealth Privacy Act. The Office of the New South Wales Privacy Commissioner has been consulted and supports the proposed amendment. The decision to use or disclose a patient's genetic information to a genetic relative without consent will always be a difficult one for clinicians as they try to

juggle the competing interests of a patient's desire for privacy and confidentiality and a relative's possible need to be provided with important and possibly lifesaving genetic information. The amendment to the Health Records and Information Privacy Act recognises these sometimes competing interests and establishes an appropriate framework in respect of the use and disclosure of genetic information without consent.

I turn to the amendments to the Health Practitioner Regulation (Adoption of National Law) Act, which are set out in schedule 1.1 to the bill. The Health Practitioner Regulation National Law (New South Wales) is set out in the schedule to the Adoption Act and provides for the implementation in New South Wales of the National Accreditation and Registration Scheme for health professionals. In implementing the National Registration and Accreditation Scheme, New South Wales agreed to adopt national registration for health practitioners, but elected to retain its own State-based complaints scheme involving health professional councils and tribunals and the independent Health Care Complaints Commission. It is to the New South Wales specific provisions relating to the complaints management scheme in the Adoption Act and the National Law that the bill makes a number of minor amendments.

The first amendment is to section 6A of the Adoption Act, which is amended to remove an "Impaired Registrants Panel" from the definition of an "adjudication body". An adjudication body is a body that can impose conditions on the registration of a health professional, or cancel, or suspend a health practitioner's registration. However, an Impaired Registrants Panel is not a body that can impose conditions on the registration of a health professional, or cancel, or suspend a health practitioner's registration; rather, the panel recommends the imposition of conditions. As such, it is not appropriate for the panel to be included in the definition of the "adjudication body". The remainder of the amendments relate to New South Wales specific provisions of the national law and are designed to ensure that the complaints management scheme continues to operate smoothly and effectively in New South Wales.

The amendments include inserting, at proposed section 3A, a new objectives and guiding principles provision. The new section 3A will ensure that the protection of the public is the paramount consideration when complaints management functions are exercised in New South Wales. The bill amends sections 150 (7), 169B(1) (c), 172B (1) (b) and 174A (2) (b) of the national law to provide a consistent criteria of the qualifications of a lay or community member of a New South Wales specific body under the national law. The bill will amend these sections to provide that, to be eligible as a community or lay member for New South Wales bodies, a person must be a person who is not, and has never been, registered as a practitioner or student in the relevant profession, but may be a person who is, or was, registered in another health profession. The amendment will bring the eligibility criteria for community members for New South Wales bodies into line with the eligibility criteria for community members of the national boards.

The bill will insert a new section 143A into the national law to clarify that a mandatory notification under the national law is taken to be a complaint for the purposes of the Health Care Complaints Act 1993. Amendments also are made in the bill to division 8 of part 8 of the national law to strengthen and streamline a number of the review processes under the New South Wales specific provisions of the national law. The bill amends sections 146B, 148E, 149A and 152I of the national law to clarify that the Professional Standards Committee, a health profession council, a health profession tribunal or an Impaired Registrants Panel can direct a health practitioner or student to undergo psychological counselling, and amends clause 2 of schedule 5 to clarify that a notice of intention to enter

premises of a registered health practitioner can be given either by the assessor or by a person on behalf of the assessor. Section 244A is also amended to allow a health professional council to issue an evidentiary certificate relating to a person's historical registration status.

Finally, I turn to the amendments to the Poisons and Therapeutic Goods Act, which are set out in schedule 1.3 to the bill. Following the commencement of the National Registration and Accreditation Scheme, consequential amendments were made to the Poisons and Therapeutic Goods Act to ensure that nurse practitioners, optometrists and midwives, who were appropriately endorsed under the national law, were able lawfully to possess, use, supply or prescribe appropriate scheduled medicines under the Poisons and Therapeutic Goods Act. Podiatrists should have been included in the consequential amendments but were inadvertently omitted. To rectify that oversight, the bill amends a number of sections of the Poisons and Therapeutic Goods Act to ensure that podiatrists who are endorsed under the national law are able to possess, use, supply or prescribe appropriate scheduled medicines under the Poisons and Therapeutic Goods Act. I commend the bill to the House.

Debate adjourned on motion by Dr Andrew McDonald and set down as an order of the day for a future day.