

Consultative Council on Obstetric and Paediatric Mortality and Morbidity

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Dr Robert Hall
Director of Public Health and Chief Health Officer
Department of Human Services
18/120 Spencer St
Melbourne 3000

Dear Dr Hall

Re: Discussion Paper on Review of the Health Act 1958

The following submission addresses Section 5, Health Information, comment 26:

Should the new Act contain more specific provisions requiring:

- *Regular provision of specified information relevant to statutory functions of consultative councils?*

This response is written from the viewpoint of the Birth Defects Advisory Committee, a subcommittee of the Consultative Council on Obstetric and Paediatric Morbidity and Mortality (CCOPMM).

As shown in Section 5.3, CCOPMM is mandated under Section 162F91)⁵⁵ of the Health Act

b) to conduct a perinatal data collection unit for the purpose of:

- ii) indentifying and monitoring trends in respect of perinatal health including congenital abnormalities*
- iv) providing information to the medical profession for research into the epidemiology of perinatal mortality and disorder including congenital abnormalities;*
- and*
- v) establishing and maintaining a register of congenital abnormalities*

Note that the use of the words 'congenital abnormalities' are now replaced with 'birth defects'

Background

Since 1983, the Birth Defects Register (BDR) has been located within the Perinatal Data Collection Unit, Public Health Division, DHS. There are over 3500 notifications (referring to approximately 2500 babies) of birth defects each year in Victoria, through a voluntary notification system. There are multiple sources of notification to the BDR.

The largest source of notification is the Perinatal Morbidity Statistics Form, completed usually by midwives and which is the basis of the mandatory data collection on every birth in Victoria. On this form is a section asking about birth defects, which can be completed when a problem is recognisable at birth or in the short period of stay in hospital under midwifery care. In 2002, the midwives notified 48% of birth defects. There are many birth defects that are not recognised by the midwives, such as some cardiac defects, the signs and symptoms of which may only appear after discharge from the place of birth.

Other important sources are hospital inpatient listings from which 34% of notifications are received. Two major paediatric tertiary centres and some speciality outpatient units such as cardiology supply these listings. Other sources include pathology (cytogenetic) laboratories (7%), maternal and child health nurses (3%), autopsy reports (2%) and death certificates (5%).

Currently, almost all birth defects that fall into the registrable categories go through the hospital inpatient system at some stage, because they require surgery, genetic counselling, and/or medical management. Minor birth defects are generally excluded from the collection.

Functions of the Birth Defects Register - why is it important to collect these data?

The monitoring and surveillance that is done through having a birth defects register allows for:

- 1) Recognition of clusters or significant changes in prevalence of birth defects, and an ability to respond to community concerns about perceived 'clusters' or increased numbers.
- 2) Provision of epidemiological information to Government and non-government organisations responsible for planning health care facilities for those with birth defects.
- 3) Assessment of the effectiveness of primary preventative programs such as the Statewide folate education program for the prevention of neural tube defects.
- 4) Provision of information for studies to increase knowledge of aetiology and preventability of birth defects.

The need for mandatory notification of birth defects:

Since 1984, public health care facilities and individuals have been willing and able to provide the data on birth defects to the PDCU. There has always been policy on and strict adherence to privacy and confidentiality within the PDCU, which has facilitated this process. However, with increasing privatisation of hospitals, prenatal screening services and diagnostic laboratories (pathology, DNA, and cytogenetics), there is local, interstate and overseas evidence that there may be problems in continued supply of information. The overriding threat to the BDR arises from the current tensions that exist between privacy and data collection for public health surveillance. This relates particularly to hospital disclosure of information to CCOPMM and the fact that health service providers are not required by law to provide data, although under new legislation (section 162FA, June 2004), they are authorised to.

Both SA and NSW have mandatory notification of birth defects and WA is in the process of obtaining this. It is timely to consider how Victoria could be aligned with

these jurisdictions, modelling the process on national and international experience.

Who to mandate?

- 1) Diagnostic laboratories i.e. pathology services, cytogenetics and DNA. This mechanism is in place for notification of infectious diseases
- 2) Prenatal screening facilities i.e. an ultrasound service functioning outside of a hospital setting
- 3) Hospitals. i.e organisations rather than individuals, as with PDCU birth notifications.

Who not to mandate?

- 1) Midwives - they are covered through use of the Perinatal Morbidity Statistics Form.
- 2) Maternal and Child Health nurses - they are often not in a position to access accurate clinical diagnoses.
- 3) Individual practitioners - they are currently contacted for relevant information during the process of follow-up by the PDCU as required.

Categorisation of birth defects, detected prenatally, at or after birth:

Notifications should include:

- 1) Structural malformations
- 2) Congenital neoplasms and infections
- 3) Diseases of the blood
- 4) Metabolic disorders (e.g. phenylketonuria)
- 5) DNA diagnosable single gene disorders (e.g. cystic fibrosis, thalassemia major)
- 6) Chromosomal abnormalities
- 7) Developmental delay

There is some overlap between these categories, and there will be an increasing number of conditions recognised under Category 5.

Goal and objectives of revision of legislation

The goal of the legislation is to enable the monitoring and surveillance of all birth defects in Victoria.

The objectives of the legislation are

- the collection of the information in a timely and accurate fashion,
- the maintenance and storage of the collection with the utmost care and attention to privacy and confidentiality,
- the provision of unidentified data for research purposes,
- epidemiological analysis of the data to identify indicators of public health problems,
- provision of information to those that can effect change and
- provision and distribution of information in a manner accessible to the general public as well as those in public health.

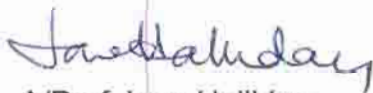
Recommendations

- 1) There should be mandatory reporting to CCOPMM of birth defects by hospitals, diagnostic laboratories and prenatal screening facilities.

- 2) Birth defects should include all those identified during pregnancy, at birth, and at any age up to 15 years.
- 3) Categories of notifiable birth defects should be listed in the legislation relating to notifiable scheduled medical conditions, with specific examples detailed in the regulations if necessary.
- 4) Amend the legislation relating to CCOPMM so as to include reference to both births and birth defects where appropriate.

The Birth Defects Advisory Committee are happy to be involved in any further discussions about this submission and other relevant parts of the legislative review.

Yours sincerely



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Epidemiologist in charge
Victorian Birth Defects Register



A/Prof Agnes Bankier
Chair
Birth Defects Advisory Committee