New initiatives in the surveillance of congenital anomalies in Queensland 2007-2008

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The surveillance of congenital anomalies in Queensland has traditionally relied on data from the Queensland Perinatal Data Collection (QPDC). While this has provided useful insights, it is limited to evaluating congenital anomalies where the live birth or fetal death occurs after at least 20 weeks gestation and/or 400 grams in birth weight. Terminations of pregnancy (TOP) prior to 20 weeks gestation are not included in the QPDC. Early detection of congenital anomalies may result in TOP among screenable conditions. Thus, incidence rates of congenital anomalies in Queensland may be under reported, particularly among conditions with high rates of TOP.

In July 2007, Queensland Health established a data collection linked to the Queensland Hospital Admitted Patient Data Collection (QHAPDC) in an effort to overcome this limitation. The collection records information about TOP that take place prior to 20 weeks gestation and where one or more congenital anomalies are detected. The goal of the collection is to supplement the information provided by the QPDC, hence allowing more accurate estimates of the incidence of congenital anomalies in Queensland. A technical report on the collection is now available (see related publications).

A preliminary evaluation of the data collection was completed in December 2008 using the first twelve months of data. The primary purpose of the evaluation was to assess the value of the collection in contributing to the health surveillance activities of Queensland Health, and to this end, the results from selected congenital anomalies are presented. In summary:

- The proportion of cases terminated prior to 20 weeks gestation varies according to the specific congenital anomaly considered (Figure 1). This ranged from 27.6% for spina bifida to 89.3% for anencephaly.
- 135 cases would not have been counted in the categories displayed in Figure 1 if TOP (<20 weeks gestation) had been excluded. This represents 61.1% of the total number of cases for those categories in Queensland during 2007-2008.
- The incidence rates for congenital anomalies increased once TOP (<20 weeks gestation) were included (Figure 2). This increase ranged from less than 1 case per 10,000 fetuses for encephalocele to 7.9 cases per 10,000 fetuses for Trisomy 21.

These data show that the inclusion of TOP (<20 weeks gestation) leads to more accurate estimates of the incidence of congenital anomalies in Queensland. This will be particularly true for congenital anomalies that are associated with higher rates of TOP.

**Related publications:**
- Neural tube defects in Queensland (2007-2008)
- Trisomy 21 (Down Syndrome) in Queensland (2007-2008)
- Technical notes on QH_CONG_ANOM: Congenital anomalies in terminations of pregnancy at less than 20 week gestation

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1 This is based on summing cases in six categories: anencephaly, spina bifida, encephalocele, Trisomy 13, Trisomy 18 and Trisomy 21. All neural tube defects were not included in the count as this represents an aggregation of the first three categories.
**Figure 1: Proportion of pregnancies terminated prior to 20 weeks gestation for selected congenital anomalies in Queensland (2007-2008)**

(1) All neural tube defects represent the aggregate of anencephaly, spina bifida and encephalocele

*Source: Queensland Hospital Admitted Patient Data Collection, Queensland Health (extracted November 2008)*

**Figure 2. Incidence rates for selected congenital anomalies in Queensland (2007-2008): a comparison of rates that include and exclude early terminations of pregnancy (TOP)**

(1) All neural tube defects represent the aggregate of anencephaly, spina bifida and encephalocele

*Source: Queensland Admitted Patient Data Collection, Queensland Health – TOP prior to 20 weeks gestation (extracted November 2008)*

*Queensland Perinatal Data Collection, Queensland Health – Live births and deaths in fetuses of at least 20 weeks gestation or 400 grams birth weight (extracted November 2008)*