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## Neural Tube Defects in Queensland: 1 July 2007 to 30 June 2010

Stuart Howell
Health Statistics Centre, Queensland Health

Neural tube defects (NTD) are a significant public health concern in Australia and are typically associated with high rates of mortality and morbidity<sup>1</sup>. Most NTD are diagnosed early in pregnancy and many affected women opt for a termination of pregnancy. The fetal death rate is high in pregnancies affected by NTD and, while some fetuses survive, these individuals may experience significant lifetime morbidity and disability.

This report describes the epidemiology of neural tube defects in Queensland for the three year period 2007/2008 to 2009/2010. The data are sourced from the Queensland Hospital Admitted Data Collection (QHAPDC: terminations of pregnancy prior to 20 weeks duration) and the Queensland Perinatal Data Collection (QPDC: live births and fetal deaths of at least 20 weeks gestation or 400 grams in birth weight). In combination, these sources allow for the best available surveillance of diagnosed congenital anomalies from conception to the end of the perinatal period. However, it is recognised that this does not provide full surveillance, as events such as spontaneous abortions are not captured. Two forms of NTD are described: anencephaly, which is the absence of major parts of the brain, skull and scalp; and spina bifida, in which the vertebrae that cover the spinal cord have one or more openings in the middle, allowing exposure and/or protrusion of nervous tissue and coverings.

Table 1: Neural tube defects in Queensland (2007/2008 to 2009/2010)

Measure	2007/	2008/	2009/
	2008	2009	2010
Incidence (per 10,000 fetuses) [n]	9.7 [73]	9.9 [76]	8.1 [62]
Live births (per 10,000 live births) [n]	2.8 [17]	2.9 [18]	1.9 [12]
Fetal deaths (per 10,000 fetal deaths) [n]	465.1 [18]	434.8 [19]	705.0 [27]
Total births (per 10,000 live births and fetal deaths) [n]	5.8 [35]	5.9 [37]	6.3 [39]
Early TOP (per 10,000 early TOP) [n]	26.6 [38]	27.0 [39]	16.6 [23]
Percent terminated (%)	52.1	51.3	37.1

Sources: Queensland Hospital Admitted Patient Data Collection (extracted August 2011);

Queensland Perinatal Data Collection (extracted August 2011; 2010 data was preliminary at the time of extraction)

There were 211 fetuses affected by neural tube defects in Queensland between 2007/2008 and 2009/2010. This corresponds to an incidence of 9.3 affected fetuses per 10,000 fetuses. Of these, 47.4% of fetuses (n=100) were terminated prior to 20 weeks duration. Neural tube defects were detected in 64 fetal deaths and in 47 live births. This corresponds to a fetal death rate of 530.2 affected fetuses per 10,000 fetal deaths and a live birth rate of 2.6 affected fetuses per 10,000 live births.

The incidence of neural tube defects declined between 2007/2008 and 2009/2010 (Table 1, Figure 1) from 9.7 to 8.1 affected fetuses per 10,000 fetuses. There was also a decline in live birth rates as well as in the proportion of fetuses that were terminated early in the pregnancy (<20 weeks duration). Fetal death rates increased over the study period.

<sup>&</sup>lt;sup>1</sup> Abeywardana S & Sullivan EA 2008. Neural tube defects in Australia. An epidemiological report. Cat. No. PER 45: AIHW National Perinatal Statistics Unit.

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Table 2: Anencephaly in Queensland (2007/2008 to 2009/2010)

Measure	2007/	2008/	2009/
	2008	2009	2010
Incidence (per 10,000 fetuses) [n]	4.9 [37]	5.1 [39]	4.1 [31]
Live births (per 10,000 live births) [n]	0.5 [3]	0.6 [4]	0.3 [2]
Fetal deaths (per 10,000 fetal deaths) [n]	180.9 [7]	183.1 [8]	365.5 [14]
Total births (per 10,000 live births and fetal deaths) [n]	1.6 [10]	1.9 [12]	2.6 [16]
Early TOP (per 10,000 early TOP) [n]	18.9 [27]	18.7 [27]	10.9 [15]
Percent terminated (%)	73.0	69.2	48.4

Sources: Queensland Hospital Admitted Patient Data Collection (extracted August 2011);

Queensland Perinatal Data Collection (extracted August 2011; 2010 data was preliminary at the time of extraction)

There were 107 fetuses affected by anencephaly over the study period, yielding an incidence of 4.7 affected fetuses per 10,000 fetuses. Survival was generally poor - 65% of fetuses were terminated at prior to 20 weeks duration, while a further 27% were recorded as fetal deaths. While there were 9 live births during the period, these babies died shortly after they were born. The incidence of anencephaly has declined between 2007/2008 and 2009/2010, from 4.9 to 4.1 affected fetuses per 10,000 fetuses (Table 2, Figure 1). While the total birth rate has increased over the study period, this seems to be due to an increase in the number of fetal deaths (Table 2). The proportion of fetuses terminated decreased over time.

Table 3: Spina bifida in Queensland (2007/2008 to 2009/2010)

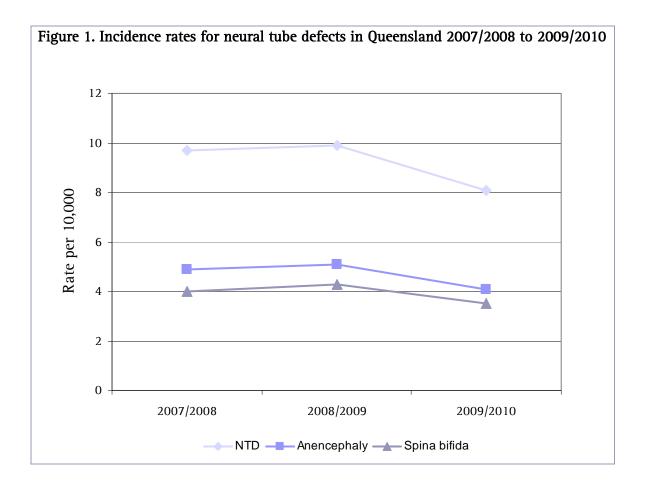
Measure	2007/	2008/	2009/
	2008	2009	2010
Incidence (per 10,000 fetuses) [n]	4.0 [30]	4.3 [33]	3.5 [27]
Live births (per 10,000 live births) [n]	1.8 [11]	2.3 [14]	1.5 [9]
Fetal deaths (per 10,000 fetal deaths) [n]	284.2 [11]	228.8 [10]	313.3 [12]
Total births (per 10,000 live births and fetal deaths) [n]	3.6 [22]	3.9 [24]	3.4 [21]
Early TOP (per 10,000 early TOP) [n]	5.6 [8]	6.2 [9]	4.3 [6]
Percent terminated (%)	26.7	27.3	22.2

Sources: Queensland Hospital Admitted Patient Data Collection (extracted August 2011);

Queensland Perinatal Data Collection (extracted August 2011; 2010 data was preliminary at the time of extraction)

There were 90 fetuses affected by spina bifida in Queensland between 2007/2008 and 2009/2010, which is equivalent to an incidence rate of 4 affected fetuses per 10,000 fetuses. Of these, 23 fetuses (25.6%) were terminated at prior to 20 weeks duration. Spina bifida was detected in 33 fetal deaths and 34 live births, yielding a death rate of 273.4 affected fetuses per 10,000 fetal deaths and a live birth rate of 1.8 affected fetuses per 10,000 live births. The incidence of spina bifida declined between 2008/2009 and 2009/2010 (Table 3, Figure 1), as did the live birth rate, total birth rate and the proportion of fetuses terminated at prior to 20 weeks duration. Fetal death rates increased over the same period.

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## Related publications:

Stat Bite # 19: Maternal characteristics in pregnancies affected by neural tube defects in Queensland: 1 July 2007 to 30 June 2010
Stat Bite # 14: Trisomy 21 (Down Syndrome) in Queensland: 1 July 2007 to 30 June 2010
Stat Bite # 18: Maternal characteristics in pregnancies affected by Trisomy 21 (Down Syndrome) in Queensland: 1 July 2007 to 30 June 2010