Technical notes on QH_CONG_ANOM: Congenital anomalies in terminations of pregnancy at less than 20 weeks gestation

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Key findings

This report examines the completeness and accuracy of a new data collection which was implemented to record information about early terminations of pregnancy where one or more congenital anomaly was detected in the fetus. The key findings are as follows:

- As at June 30 2008, the collection had 279 rows of data representing 253 episodes of care
- Fetus number and ICD-10 diagnostic code were missing on 30 records (11%).
- Data values on all fields fell within allowable limits.
- The mother's originating record was located on QHAPDC in all cases, although there were delays in availability. Corrections to the mother's originating record triggers corresponding corrections to the congenital anomalies table.
- The generation of counts from this table has highlighted some potential limitations including:
    - The absence of information about sex of the fetus
    - The over-utilisation of two ICD-10-AM codes (Q998 and Q999)
- There is also a risk of double-counting some terminations, although this can be avoided by the user applying appropriate levels of scrutiny

Any decisions based on these data need to be made in the context of such limitations.

1.0 Background and purpose of the report

In July 2007, Queensland Health established a new collection linked to the Queensland Hospital Admitted Patient Data Collection (QHAPDC). This records information about terminations of pregnancy (TOP) that take place prior to 20 weeks gestation and where one or more congenital abnormalities are detected. The primary goal of the collection is to improve surveillance of congenital anomalies in Queensland by supplementing information obtained from the Queensland Perinatal Data Collection (QPDC). The QPDC only records information on births and fetal deaths (including TOP) where gestational age is greater than 20 weeks and/or birth weight is greater than 400 grams.

This report provides an overview of the data and summarises quality issues that arose during the first twelve months of data collection. Key variables on the collection were examined to evaluate the completeness of data. Counts were generated from the collection in order to identify any potential limitations in applying the data to the surveillance of congenital anomalies in Queensland.

2.0 Methodology

Analyses were conducted by the Health Statistics Centre (HSC), Queensland Health. The data set analysed contained all records collected from July 01, 2007 to June 30, 2008. At this time, the table consisted of 7 variables and 279 rows of data.

Variables extracted for these analyses were:

Year:	Financial year
Fclty_id:	Facility number
Fclty_unique_id:	Episode of care number
Foetus_no:	Unique number for each fetus in a multiple birth
Cong_code:	ICD code to identify the congenital anomaly reported
Origin:	Denotes (W)orking and (F)inal records
Partition_key	Episode of care end date

3.0 Overview of the table and its structure

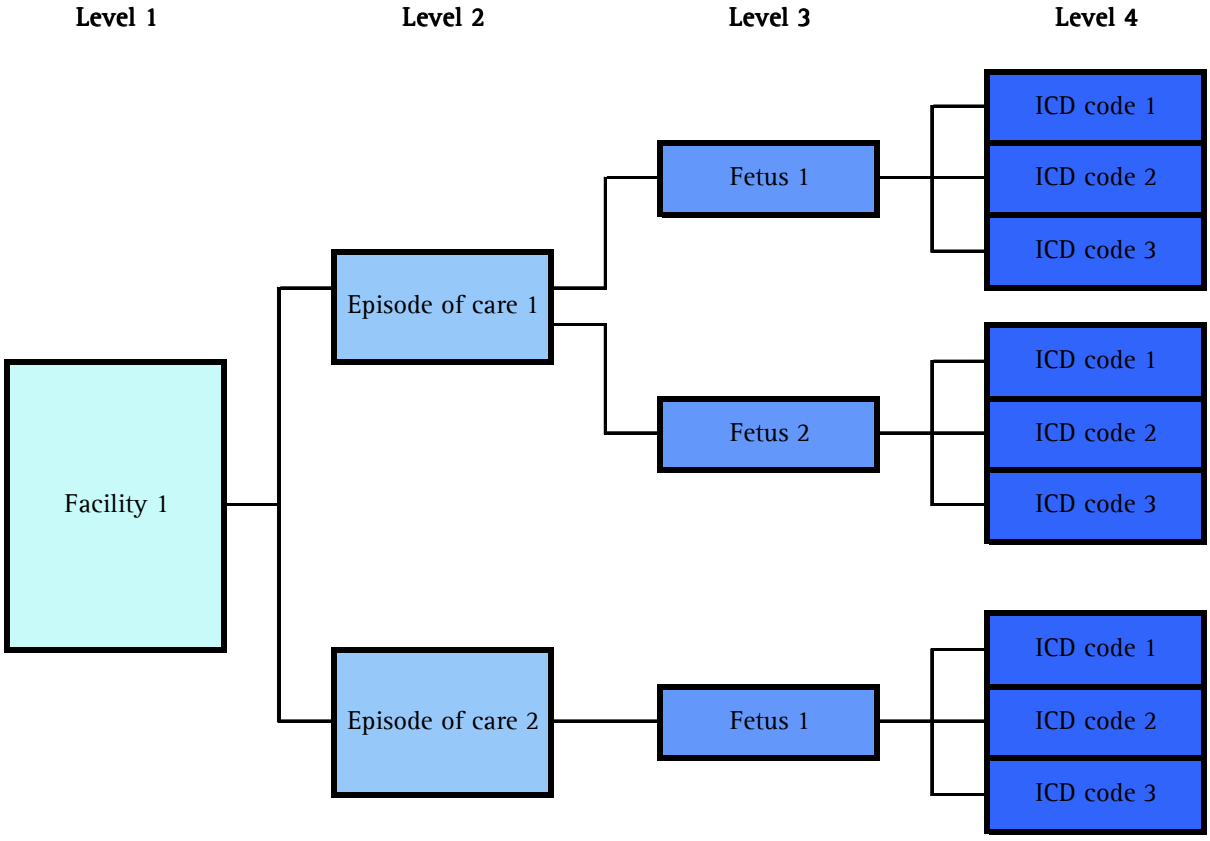
The table is generated using trigger codes that appear in the mother's record within the QHAPDC system (see Table 3.1). Once any given record is flagged, information about the congenital anomalies detected is sought from the admitting facility. A separate record is then created in QH_CONG_ANOM for the fetus. The facility identifier and the episode of care code fields can be used to link the record back to the mother's original record in the QHAPDC. This allows maternal characteristics to be evaluated.

Table 3.1 ICD-10-AM trigger codes used to generate a record in QH_CONG_ANOM.

Trigger code ICD-10AM range(s)	Description
0350-0356, 0358, 0359	Maternal care for known/suspected fetal abnormality or damage
0310, 0311, 0312	Complications specific to multiple gestation
0336, 0337	Maternal care for known/suspected disproportion
0360-0366, 0369	Maternal care for other known/suspected fetal problems
0430, 0431, 0438	Placental disorders
At least one ICD-10AM code from:	
0040-0049	Medical abortion
0050-0059	Other abortion
0060-0069	Unspecified abortion
At least one ICD-10AM code from:	
0090	Duration of pregnancy < 5 completed weeks
0091	Duration of pregnancy 5-13 completed weeks
0092	Duration of pregnancy 14-19 completed weeks

The table is minimalist in nature and only contains those items that allow for the enumeration of individual fetuses and for the description of all congenital anomalies that were detected in each fetus. The core data items are the date of the record, facility identifier and episode-of-care number, fetus number and an ICD code diagnostic field. It is a hierarchical table, with higher levels representing the episode of care in which the TOP was performed. Multiple rows are permitted for each episode of care to accommodate the termination of more than one fetus within a pregnancy, while multiple rows for each fetus allow the reporting of more than one congenital anomaly. The hierarchy of the table is illustrated in Figure 3.1.

Figure 3.1 The hierarchial structure of QH_CONG_ANOM from the highest (Level 1) to lowest (Level 4) of the table hierarchy



Prepared by: Statistical Analysis Unit, Health Statistics Centre, Queensland Health Ph: 3224 2953 (Jan 16, 2009)

4.0 Results

4.1 Completeness

As at June 30, 2008 the table contained 279 rows of data which represented 253 episodes of care. The following data items were fully populated – FCLTY_ID, FCLTY_UNIQUE_ID and YEAR. The items FOETUS_NO and CONG_CODE contained missing values on 30 rows. In total, 23 of the incomplete records (77%) had dates between April 1, 2008 and June 30, 2008. This suggests that the process used to populate the table (i.e. referral back to the mother's admitting facility following a trigger) is leading to some delays in the completion of data collection.

4.2 Consistency

All records had dates within the range July 2, 2007 to June 29, 2008. A valid facility identifier was assigned in all cases. Where fetus number was assigned, the value

entered was '1' in the majority (99%) of cases (indicating the termination of a single fetus). The values '2' and '3' were used on two and one episode of care, respectively. A code in the range Q00-Q99 (Congenital malformations, deformations and chromosomal abnormalities) was given in 97% of cases where an ICD-10-AM was allocated. The remaining codes included D181 and M91730 (lymphangioma), G10 (Huntington's chorea) and G710 (muscular dystrophy).

4.3 Consistency with the mother's record

The congenital anomalies data was extracted in November 2008 and was linked to other QHAPDC tables that existed as at November 2008 in order to extract the mother's originating record. The mother's record was not available in the QHAPDC for a number of episodes of care, and this was attributed to the processes that allow QHAPDC records to be maintained and corrected. We have since attempted to link the congenital anomalies data extracted in November 2008 to current QHAPDC tables (February 2009) to establish whether this assumption was valid.

The mother's originating record was identified on QHAPDC in February 2009 for all 253 episodes of care. An ICD-10-AM code of O04 or O05 was assigned to the principal diagnosis field in 247 episodes of care (98%). The principal diagnosis code was O35 in 4 cases and O36 in one case: an ICD-10-AM code of O04 or O05 appeared in an "Other Diagnosis" field for these five cases. The duration of pregnancy code was available for all 253 episodes of care. This was O091 (5-13 completed weeks) in 30%, and O092 (14-19 weeks) in 70% of cases.

In one case, the mother's principal diagnosis was listed as O021 (Missed abortion) along with a further diagnosis code of O092 (Duration of pregnancy 14-19 completed weeks). This combination should not trigger a record in the congenital anomaly table and the combination did not exist in the appraisal conducted in November 2008. We completed a search of the updated (February 2009) congenital anomalies table and established that the record had since been deleted. The Data Collections Unit advise us that the system is programmed to edit the congenital anomalies table whenever a triggering record is altered.

4.4 Generating counts

At the time of preparation, it was recognised that the data set was capturing multiple episodes of care for some terminations. This typically occurred when a woman was discharged following the procedure, but returned some time later for treatment of a complication arising from the termination. Failure to investigate this may result in double counting some terminations. Double counting in the denominator (i.e. all TOP prior to 20 weeks gestation on the QHAPDC) should also be investigated.

The sex of the fetus is not recorded on the QHAPDC for terminations of pregnancy. Thus, incidence rates for congenital anomalies cannot be estimated separately for males and females when TOP (at gestation < 20 weeks) are included in the numerator and/or denominator. Similarly, incidence rates cannot be accurately estimated for

any congenital abnormality that is sex-specific, such as hypospadias, which only affects male fetuses.

The Queensland Perinatal Data Collection (QPDC) records terminations of pregnancy where the fetus is at least 20 weeks of age and/or 400 grams birth weight. Thus, sex-specific incidence rates can be estimated with reasonable accuracy using the QPDC. Our immediate experience is that estimated rates are higher when early TOP are not included in the numerator and denominator, but the difference is not substantial. However, our caveat is that the impact of this is likely to be higher for congenital anomalies (and particularly for severe anomalies) that can be detected early in the pregnancy through screening tests.

The QHAPDC congenital anomaly table covers the time period from conception to 20 weeks gestation. When combined with the QPDC, the time frame for surveillance of congenital anomalies in Queensland is extended to include the period from conception to the end of the birth episode. Under QPDC rules, the birth episode ends when the baby is discharged from hospital, dies or is 28 days of age (which ever occurs soonest). However, congenital anomalies which are diagnosed after the birth episode are not captured by this system. This stands in contrast to other Australian states which require congenital anomalies to be notified up to one year of age (New South Wales), five years of age (South Australia), six years of age (Western Australia) or 15 years of age (Victoria). Thus, estimates may differ slightly from those reported in other states due to this exclusion.

Preliminary findings suggested that two codes (Q998: Other specified chromosomal abnormalities; and Q999: Chromosomal abnormality, unspecified) may have been over-utilised during the first year of data collection. This matter was discussed with the admitting facilities, who reported that they referred to the mother's chart in an effort to identify the congenital anomaly. However, there were occasions where the information contained on the chart was not sufficient to describe the chromosomal anomaly beyond a code of Q998 or Q999. This issue is currently being reviewed by the Data Collections Unit of Queensland Health. In the meantime, rates for specific chromosomal anomalies (e.g.: Down syndrome) maybe somewhat higher than is reported from these data and we advise caution when reporting data on chromosomal anomalies in Queensland.