Data quality issues to be aware of when using the Queensland Perinatal Data Collection to estimate the prevalence of congenital anomalies at birth in Queensland

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Key findings

This report examines the underlying data quality issues relevant to reporting of the number of babies born with congenital anomalies. The key findings are as follows:

- The proportion of babies reported with a form of congenital anomaly increased substantially between 1989/90 to 2010/11.
- There are inconsistent reporting practices across facilities and over time, that need to be taken into consideration when analysing and reporting on congenital anomaly data.
- The reason for an increased number of reported cases may be attributable to changes in some ICD-10-AM codes, and also to the introduction of methods for electronic-submission of data. However not all increases were explained by these factors.

These issues should be considered when using congenital anomaly data to inform policy and planning.

1.0 Background and purpose of the report

The Queensland Perinatal Data Collection (PDC) contains data on all births in Queensland. All public and private hospitals, and private midwifery or medical practitioners who deliver babies outside hospitals, are required to complete the Perinatal Data Collection Form (MR63D), or submit an electronic extract of information related to a birth to the Health Statistics Unit, Queensland Department of Health.

The scope of the collection includes the reporting of any congenital anomalies that were present at birth and detected prior to separation from care[1], and it is the primary source of information for surveillance of and reporting on the epidemiology of congenital anomalies for state and national purposes. The collection classifies the reported congenital anomalies using the British Paediatric Association Classification of Disease, Perinatal Supplement from the start of the collection up until June 2002, and then by International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM).

In recent years, there has been a marked increase in the proportion of babies reported with some form of congenital anomaly in the PDC[2-8]. This technical report provides a summary of investigations undertaken to assess conditions and facilities where these increases occurred and possible data quality factors associated with these increases. The results of this report are intended to inform subsequent analyses and interpretation of data relating to congenital anomalies in Queensland.

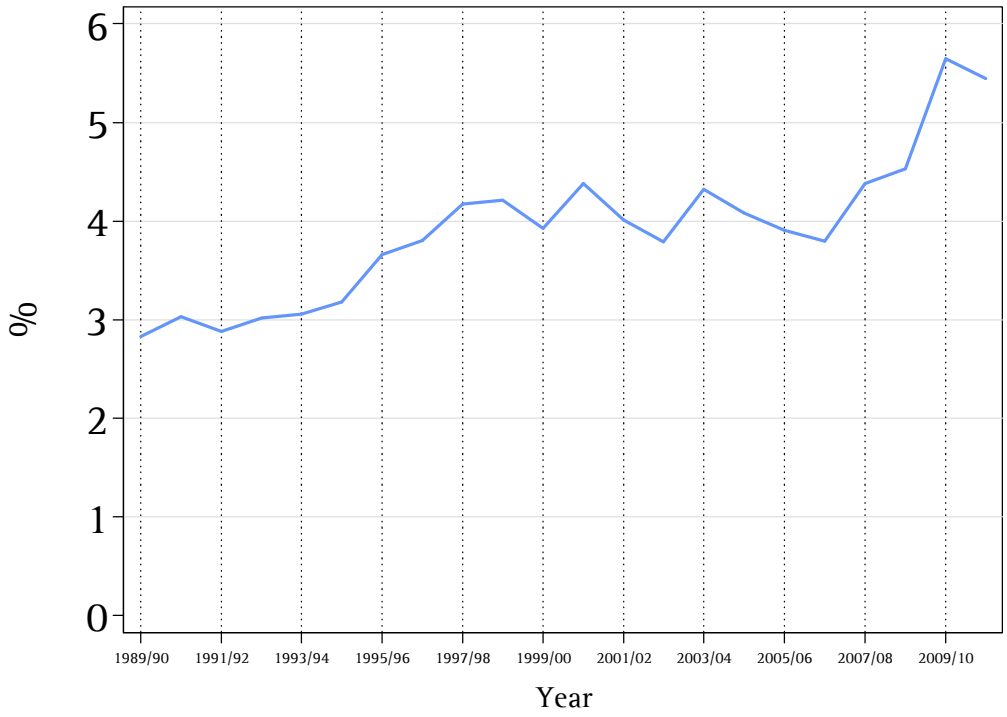
2.0 Methodology

Analyses were conducted by the Health Statistics Unit (HSU), Queensland Health. The data set analysed contained all baby records for births between July 01, 1989 and June 30, 2011.

3.0 Overall trend in congenital anomalies and trends by facility

Between 1989/90 to 2010/11, there were 45,101 babies recorded with at least one form of congenital anomaly out of 1,134,319 births. Figure 3.1 shows the trend during this period. The proportion has increased from approximately 2.8% in 1989/90 to 5.4% in 2010/11. While the proportion fluctuates, a clear upward trend, especially in recent years can be observed from the graph.

Figure 3.1. Trend of proportion of babies recorded with a congenital anomaly, Queensland, 1989/90 – 2010/11

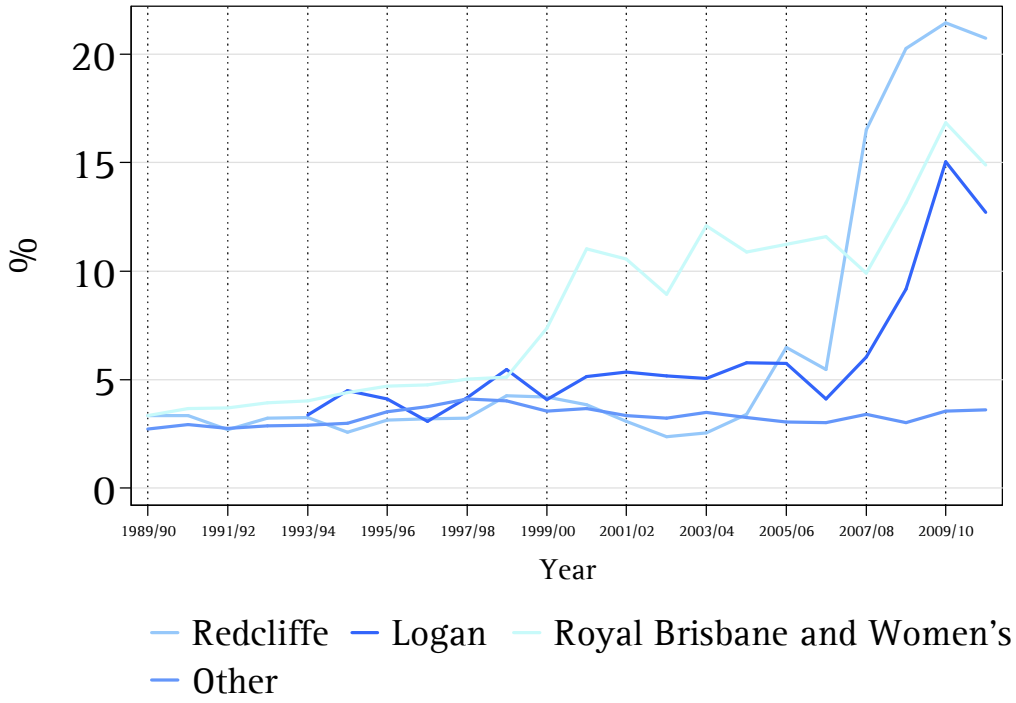


Source: Queensland Perinatal Data Collection

The pattern, however, changes dramatically when it is plotted by the place of birth. Figure 3.2 shows that there are unnatural spikes observed at three facilities – Logan, Redcliffe, and Royal Brisbane and Women's* Hospitals, while the proportion stayed relatively flat when these facilities were excluded. Redcliffe showed the most significant change, from 3.3% of the babies reported to have at least one congenital anomaly in 1989/90 to 20.7% in 2010/11. It is unlikely that the true prevalence of congenital anomaly at birth would change so significantly in such a short time period, and that the changes would be observed only at selected facilities. As such, further investigations were conducted to determine the possible reasons for the inconsistent pattern.

* Includes both the Royal Brisbane and Women's Hospital (until 2003: Royal Women's Hospital) and the Royal Brisbane and Women's Hospital Birthing Centre

Figure 3.2. Trend of proportion of babies recorded with a congenital anomaly by facility, Queensland, 1989/90 – 2010/11



Source: Queensland Perinatal Data Collection

3.1 Type of conditions

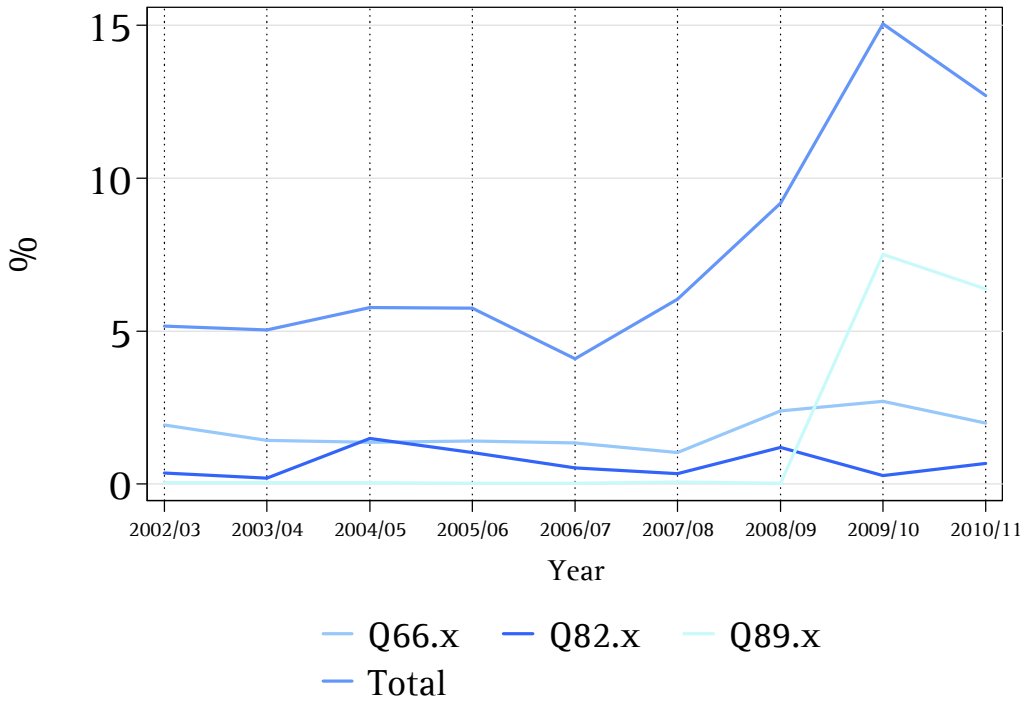
At Logan Hospital, while a gradual increase was observed over the years, a sudden jump in the reported proportion of babies with a congenital anomaly was observed between 2007/08 (6.0%) and 2008/09 (9.2%), and a much bigger spike was evident in 2009/10 (15.0%) (Figure 3.2). The types of congenital anomalies reported were investigated to determine the conditions that may have led to the increase. Between 2007/08 and 2008/09, while the increase was observed across a range of conditions, there was a marked increase in the number of babies reported with *Q66.x – Congenital deformities of feet*, in particular *Q66.0 Talipes equinovarus*. The increase was also observed in Redcliffe and Royal Brisbane and Women's Hospitals. A further investigation found that the increase is likely to have been related to changes in the ICD-10-AM definition for this condition. From the sixth edition of the ICD-10-AM, which was implemented in the PDC from July 2008, a fifth digit code was introduced which allowed more detailed classification of the condition (Table 3.1). Prior to this, it was noted (personal communication) that at least one of the hospitals was coding positional talipes to *M21.67 – Other acquired deformities of ankle and foot*. Since this is not a congenital anomaly code, these babies would not have previously been included in congenital anomaly reporting.

Table 3.1 Changes in ICD-10-AM code for Talipes equinovarus, fifth and sixth editions

ICD-10-AM edition	ICD-10-AM code	Description
Fifth (2006/07-2007/08)	Q66.0	Talipes equinovarus
Sixth (2008/09-2009/10)	Q66.00	Talipes equinovarus, unspecified
	Q66.01	Structural talipes equinovarus
	Q66.02	Positional talipes equinovarus

The more extreme spike was observed between 2008/09 and 2009/10. An investigation revealed that there was a sudden increase in the number of babies reported with *Q89.89 - Other specified congenital malformations* at Logan, from no cases in 2008/09 to 264 cases in 2009/10 (Figure 3.3). Furthermore, more than half of the total number of babies recorded with Q89.89 between 2002/03 to 2010/11 (844 cases) in Queensland were recorded in Logan during 2009/10 and 2010/11 (491 cases). Similarly, Mater Hospitals[†] experienced a spike in the number of babies reported with Q89.89 in 2007/08, from almost no cases in 2006/07 to more than 80 cases. The records from these two hospitals constituted more than 98% of the babies recorded with Q89.89 between 2002/03 and 2010/11. While this sudden increase did not have a noticeable effect on the overall number of babies reported with a congenital anomaly for Mater, the effect was apparent for Logan.

Figure 3.3. Trend of proportion of babies born at Logan Hospital with selected congenital anomaly, 2002/03 – 2010/11



Source: Queensland Perinatal Data Collection

For Redcliffe and Royal Brisbane and Women's, the change in the diagnosis pattern was not as obvious. While both hospitals showed most apparent increase for *Q66.x – Congenital deformities of feet* and *Q82.x – Other congenital malformations of skin*, the increase in the recording of congenital anomalies was scattered across different conditions.

3.2 Implementation of electronic submission systems

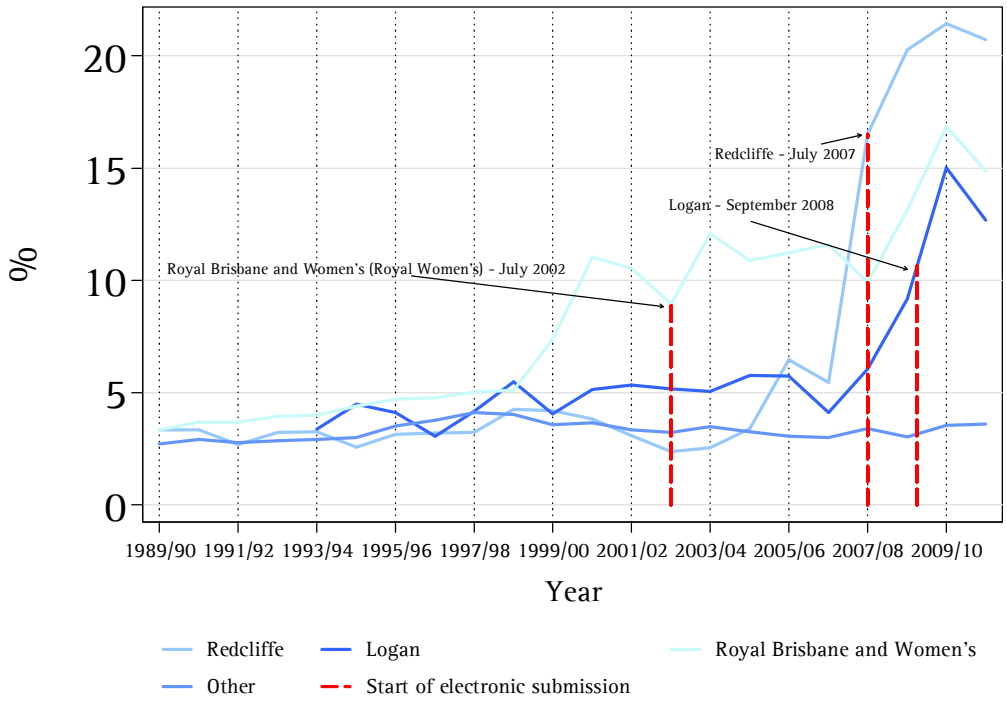
In Queensland, a number of hospitals have implemented an electronic system to submit birth information, replacing the submission of data using a paper form (MR63D). Currently there are 5 main systems used in Queensland, and each hospital has initiated their use of electronic submission at

[†] Includes Mater Mothers' Hospital, Mater Women's & Children's Private Health Services, Mater Misercordiae Women's & Children's Private Health Service (Women's Campus) (until June 2008)

different time points. The system used and the timing of implementation for each hospital is shown in Appendix A.

For Redcliffe Hospital, there is a strong correlation between the increase in reporting of congenital anomalies and the implementation of electronic submission of perinatal records. Redcliffe Hospital initiated their electronic submission in July 2007, which corresponds to the sudden spike observed between 2006/07 and 2007/08 (from 5.5% to 16.5%) (Figure 3.4). While this does not explain their nearly two-fold increase between 2004/05 and 2005/06 (3.4% to 6.5%), it appears that the implementation of the electronic submission system had an effect on the number of cases reported. A similar pattern was also observed for Logan Hospital, where electronic data submission commenced in September 2008.

Figure 3.4. Trend of proportion of babies born with a congenital anomaly by facility and the timing of start of electronic submission, Queensland, 1989/90 – 2010/11



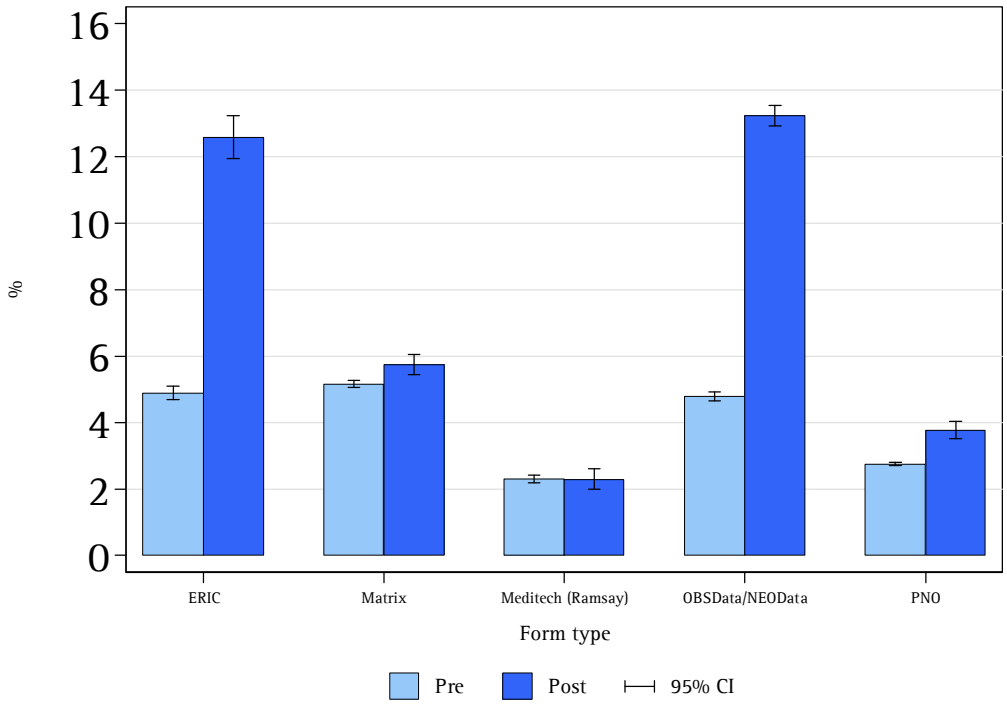
Source: Queensland Perinatal Data Collection

However, there was no obvious relationship between the spikes in reporting and the introduction of electronic submission for Royal Brisbane and Women's hospital. While the electronic system was implemented in July 2002, there was a clear increase between 1998/99 (5.1%) and 2000/01 (11.0%) and from 2007/08 (9.9%) to 2008/09 (13.1%) and then to 2009/10 (16.9%). The reason for the increase for this hospital is unclear, and further investigation is required to determine what may have led to the increases observed over time.

As shown in Appendix A, Royal Brisbane and Women's and Redcliffe Hospitals share the same electronic submission system (*OBSData/NEOData*), and Logan Hospital uses a system (ERIC) that is not used by other sites within Queensland for perinatal data reporting purposes. It was of interest to assess if the introduction of the various electronic systems had any impact on the reporting of congenital anomalies. Figure 3.5 shows the difference in the proportion of babies recorded with at least one form of congenital anomaly before and after the implementation of electronic submission and by the type of

system used[‡]. While the most extreme increases were observed at facilities utilising ERIC (i.e. Logan Hospital) and OBSData/NEOData (i.e. Redcliffe and Royal Brisbane and Women's Hospitals), the combined facility group that used Matrix (Townsville and Mater Hospitals) and Perinatal Online (PNO) also showed increases. Only sites utilising Meditech showed no increase following the move to electronic reporting.

Figure 3.5. Proportion of babies reported to have at least one form of congenital anomaly by timing of the implementation of electronic submission and by form type[§], Queensland, 1989/90 – 2010/11[**]



Source: Queensland Perinatal Data Collection

The cause of this increase in the number of babies reported with a congenital anomaly after the introduction of electronic submission systems is not clear. One hypothesis is the ease of populating information using the electronic system compared with the paper form. Figure 3.6 shows a part of the MR63D form, with the sections relevant to the reporting of congenital anomalies indicated with red rectangles. The space provided for reporting of congenital anomalies is limited, and the form does not

[‡] Note that different sites implemented the system at different dates. Since the only available data on the date of implementation at each site were month and the year, it was assumed that any birth on or after the first day of the month of implementation of the system was considered as "post" the introduction of electronic submission at the site. While the comparison could be made based on the date of discharge of the baby rather than their date of birth, date of birth was used for simplicity as the differences made were minimal.

[§] Babies born in Royal Women's Hospital (closed in 2003) were included with Royal Brisbane and Women's Hospital Babies born in Kirwan Hospital for Women (closed in 2001) were included as part of births in The Townsville Hospital Babies born in Mater Misercordiae Women's & Children's Private Health Service (Women's Campus) (closed in 2008) were included with Mater Women's & Children's Private Health Services

[**] Due to the timing of the implementation and the period of data included in this study, births at particular hospitals may only be included in "pre-electronic submission" group. That is, if a hospital introduced their electronic submission on or after July 2011 or have not yet implemented an electronic system, they do not have any data included as submitted using an electronic system.

provide guidance on the possible anomalies that may be reported. With an electronic system such as PNO, a reference list of possible congenital anomalies can be presented (Figure 3.7), which may guide medical staff in determining the congenital anomalies that are reportable, which may increase the likelihood of conditions being recorded. This may especially apply for minor conditions which in the past may have been overlooked or considered to be non-reportable conditions.

Thus, while the magnitude of the effect may be different, the implementation of an electronic submission system may not only have affected the three facilities but also other facilities in Queensland. Nonetheless, the rates of increase at the three facilities identified in this report were far greater than increases that occurred at other sites and mean that fair comparisons cannot be made across different sites and time periods.

Figure 3.6. An extract of part of the Queensland Perinatal Data Collection Form (MR63D), with sections relevant to the reporting of congenital anomalies indicated with red rectangles

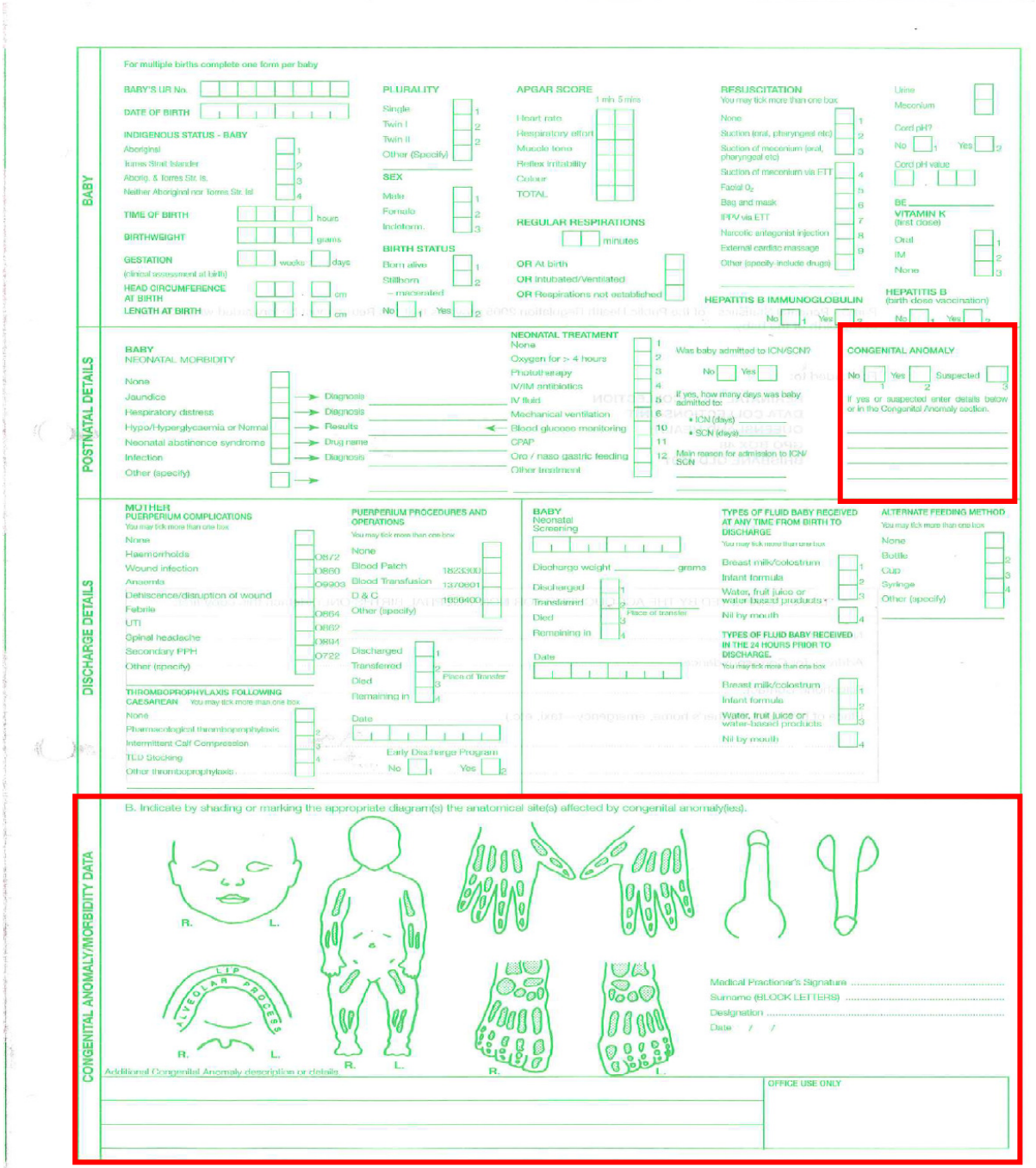
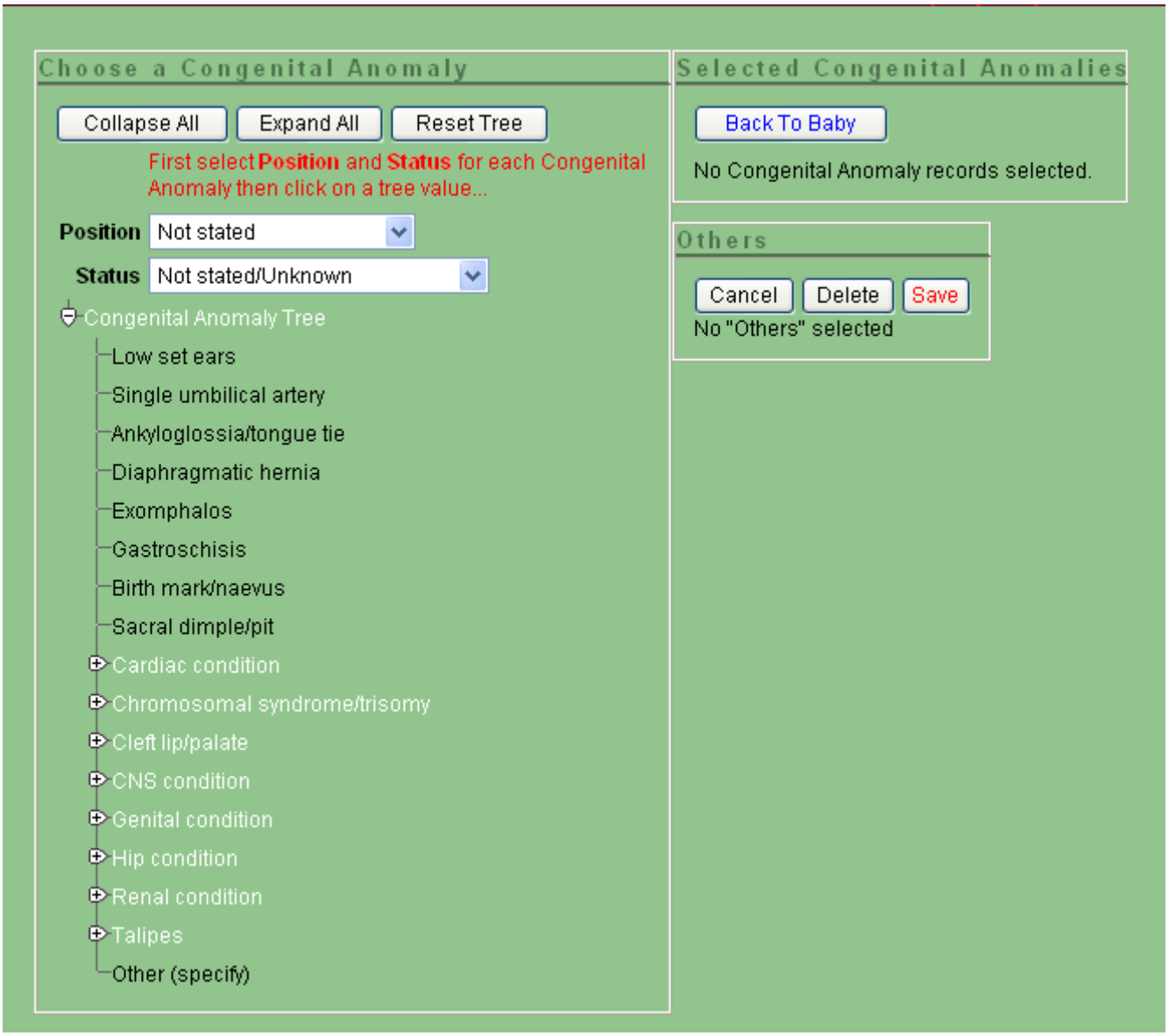


Figure 3.7. A screenshot of the Perinatal Online (PNO) application, in the module where congenital anomalies are reported



3.3 Implications of the inconsistent reporting

An obvious implication of these results is that interpretation of the trend is difficult, especially at the broad level of reported number of babies having any form of congenital anomaly. While a clear increase in the proportion can be observed, it may be misleading to conclude that there are changes in the prevalence of congenital anomalies at birth from the data, as the overall annual rate has been affected by coding and data collection mechanism changes.

Another artefact of the increases observed at selected facilities is that while a significant proportion of births in Queensland occur at one of these three hospitals, the demographic characteristics of mothers giving birth at these facilities are not representative of the general demographic characteristics of mothers giving birth in Queensland. Thus, having an inflated proportion of congenital anomalies at these hospitals relative to other facilities results in an inflated rate of CAs within the population

serviced by these facilities and valid comparison cannot be made across different populations within the State.

Table 3.2 shows the proportion of mothers who gave birth to a baby with a form of congenital anomaly by Indigenous status for 2009/10 and 2010/11. The result suggests that the relative risk of non-Indigenous mothers giving birth to babies having a congenital anomaly was higher than for Indigenous mothers ($p < 0.001$) (Figure 3.8).

Table 3.2. Proportion of mothers who gave birth to a baby with congenital anomaly by Indigenous status, Queensland, 2009/10 – 2010/11

	Presence of congenital anomaly		
Indigenous status	**Yes**	**No**	**Total**
Indigenous	320 (4.6%)	6,615 (95.4%)	6,935 (100.0%)
Non-Indigenous/Not stated	6,539 (5.7%)	108,907 (94.3%)	115,446 (100.0%)
Total	6,859 (5.6%)	115,522 (94.4%)	122,381 (100.0%)

Source: Queensland Perinatal Data Collection

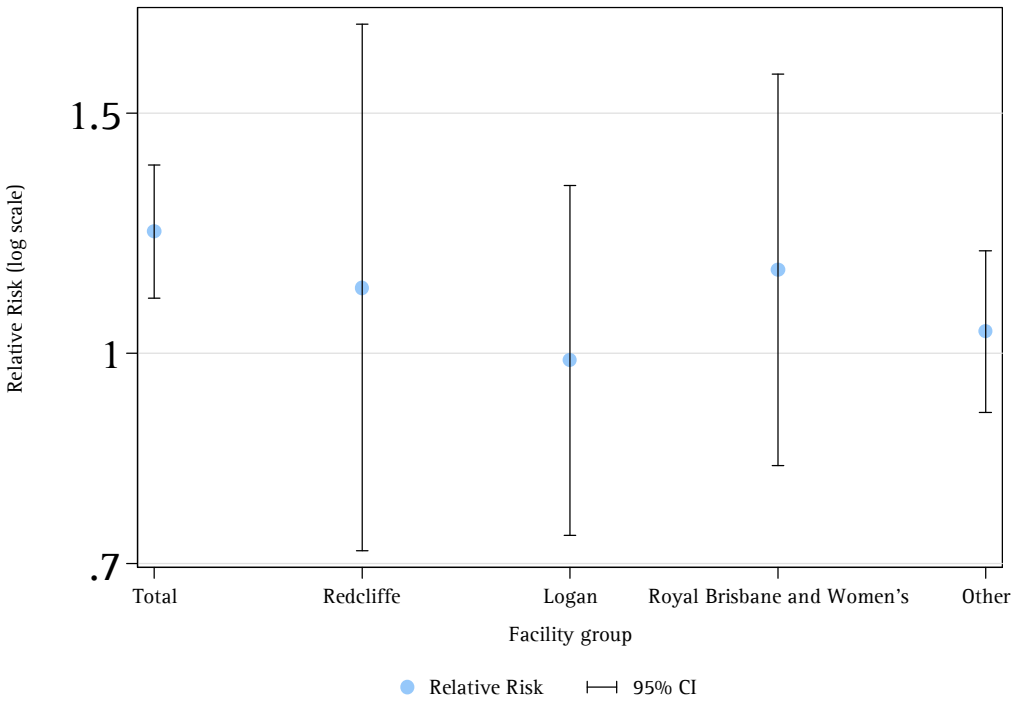
This result, however is strongly influenced by the fact that there is a lower than average rate of births to Indigenous mothers at the three facilities of concern. Table 3.3 shows the proportion of Indigenous mothers by facility. It is evident that the proportion of Indigenous mothers is much lower at these three facilities than at the remainder of facilities combined. This means that since most of the mothers who gave birth at these facilities were non-Indigenous, the spikes observed are more likely to affect the rates for non-Indigenous mothers as a whole than the Indigenous mothers. In fact, when the relative risks were calculated by stratifying by facility of birth, the difference was no longer statistically significant across all three hospitals, and other facilities combined (Figure 3.8).

Table 3.3. Number and proportion of mothers by Indigenous status and selected facility, Queensland, 2009/10 – 2010/11

Facility	Indigenous	Non-Indigenous/Not stated	Total
Redcliffe	105 (3.3%)	3,080 (96.7%)	3,185 (100.0%)
Logan	326 (4.6%)	6,718 (95.4%)	7,044 (100.0%)
Royal Brisbane and Women's	255 (2.8%)	8,929 (97.2%)	9,184 (100.0%)
Other	6,249 (6.1%)	96,719 (93.9%)	102,968 (100.0%)
Total	6,935 (5.7%)	115,446 (94.3%)	122,381 (100.0%)

Source: Queensland Perinatal Data Collection

Figure 3.8. Relative risk of non-Indigenous mothers giving birth to a baby with at least one form of congenital anomaly compared to Indigenous mothers by place of birth, Queensland, 2009/10 – 2010/11



Another example of the impact of this coding inconsistency is on analysis of overall congenital anomaly rates by the remoteness of the usual residence of the mother. When the proportion of mothers giving birth to babies with congenital anomaly was compared by area of usual residence, it was found that mothers who usually reside in areas categorised as Major City based on ARIA+ were nearly twice as likely to give birth to a baby with a congenital anomaly as those who usually reside in non-Major City areas (Table 3.4, Figure 3.9). However, since these three hospitals are located in an urban area of the State, it is likely that the increased recording of congenital anomalies would have more influence on those mothers who live in the areas categorised as Major City.

Table 3.4. Proportion of mothers who gave birth to a baby with congenital anomaly by ARIA+, Queensland, 2009/10 – 2010/11

	Presence of congenital anomaly		
ARIA+	Yes	No	Total
Major City	5,030 (6.9%)	67,869 (93.1%)	72,899 (100.0%)
Non-Major City	1,769 (3.7%)	46,480 (96.3%)	48,249 (100.0%)
Total	6,799 (5.6%)	114,349 (94.4%)	121,148 (100.0%)

Source: Queensland Perinatal Data Collection

Table 3.5 shows the distribution of the ARIA+ of usual residence of the mothers by facility. Clearly, most of the mothers who gave birth at these hospitals were from the Major City category. Thus, the spikes observed at those facilities are more likely to have an impact on the rate reported for the mothers

giving birth to babies with a reported congenital anomaly. Figure 3.9 displays the relative risk stratified by place of birth and ARIA+ of usual residence. The two-fold higher relative risk for mothers who usually reside in Major City areas was not observed when stratified by the place of birth. While the significantly higher relative risk for facilities combined as "Other" was observed, when Mater hospitals (another tertiary paediatric centre located in a metro area of Brisbane that also showed a sudden, though less pronounced, increase in congenital anomalies coded as '*Other specified congenital malformations*') were removed, the relative risk was no longer significant for this group. These examples provide a classic demonstration of a phenomenon known as "*Simpson's paradox*" whereby results are highly dependent on the way data are aggregated.

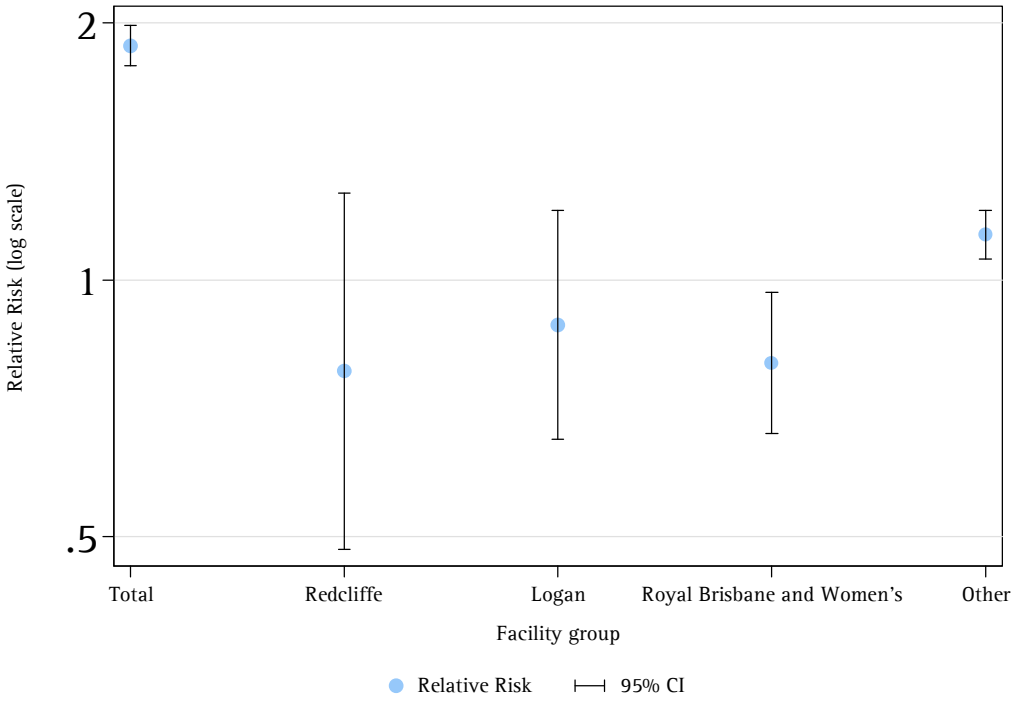
Table 3.5. Number of mothers by ARIA+ of usual residence of the mother and selected facility, Queensland, 2009/10 – 2010/11

Facility	Major City	Non-Major City	Total
Redcliffe	3,120 (98.0%)	63 (2.0%)	3,183 (100.0%)
Logan	6,773 (96.2%)	268 (3.8%)	7,041 (100.0%)
Royal Brisbane and Women's	8,549 (93.7%)	578 (6.3%)	9,127 (100.0%)
Other	54,457 (53.5%)	47,340 (46.5%)	101,797 (100.0%)
Total	72,899 (60.2%)	48,249 (39.8%)	121,148 (100.0%)

Source: Queensland Perinatal Data Collection

In addition, it is important to note that analyses making use of usual residence information in the PDC should be done with caution. The usual residence of the mother recorded in the data is the "last known address" of usual residence[1]. If from an antenatal visit a mother was advised to give birth at a tertiary hospital, she may temporarily relocate to a place closer to the hospital where she plans to give birth, especially if her usual residence is in a rural area. This may give scope for possible inconsistency in the recording of address, as her "new address" may be recorded as her usual residence, resulting in an underestimation of the proportion of mothers who reside in a non-metro location. The data for Royal Brisbane and Women's Hospital, one of the tertiary perinatal centres in Queensland, showed that the proportion of mothers who gave birth to babies with at least one form of congenital anomaly was higher for those who resided in areas categorised as non-Major City than for those who resided in areas categorised as Major City (Figure 3.9). This makes sense, given that mothers of babies with congenital anomalies detected prior to birth may be referred to this hospital from non-metro areas. However the level of difference may be greater if the analyses are done based on the usual residence at the time of conception. This data is, however, unavailable within the collection.

Figure 3.9. Relative risk of mothers who usually resided in a Major City area giving birth to a baby with at least one form of congenital anomaly compared to mothers who live in other areas, by place of birth, Queensland, 2009/10 – 2010/11



While the differences over time and among facilities are evident, it is not clear what the true prevalence of congenital anomaly at birth in Queensland is. The introduction of electronic systems and other factors may have allowed the end-user to correctly assign congenital anomalies, which may not have been translated to the collection correctly in the past. Thus, the currently reported number of cases at the three facilities showing large increases may reflect the true prevalence, which historically has been under-reported. That is, it may not be correct to conclude that the reported number of cases in the recent period for the hospitals showing a sudden increase constitutes over-reporting of congenital anomalies.

Nonetheless, both longitudinal and cross sectional analyses using the Queensland Perinatal Data Collection for reporting on congenital anomalies will be affected by the inconsistency in recording of congenital anomalies across sites and over time. This will also affect the national data that incorporates the Queensland Perinatal Data Collection, so will also have an impact on the validity of inter-state and international comparisons.

In order to minimise the impact of this inconsistent reporting, it may be necessary to introduce more detailed guidelines regarding the collection and/or reporting of congenital anomalies in Queensland. At a minimum, it is recommended that the grouping "born with at least one form of congenital anomaly" is not used to assess the prevalence of congenital anomaly at birth or for intra-state comparisons. Instead, it is recommended that subsets of 'reportable conditions' which are available nationally and internationally[9] [10] be used for reporting in Queensland as they contain conditions that have been less affected by changes in reporting systems and coding.

4.0 Conclusion

This report outlined some of the data quality issues that surround the surveillance of congenital anomalies using the PDC. Any analyses using this data should incorporate consideration of the underlying data quality issues.

5.0 Acknowledgement

The authors would like to thank Dr. David Cartwright and Mr. James Muller from the Royal Brisbane and Women's Hospital, Sandra Martyn from the Statistical Standards and Strategies Team, Health Statistics Unit, Colleen Morris from the Statistical Collection and Integration Team, Health Statistics Unit, the Queensland Maternal and Perinatal Quality Council and the Queensland Congenital Anomaly Sub-Committee for their valuable comments.

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7.0 Appendix A

The type of electronic system used for submission for Perinatal Data Collection and the timing of implementation by facility

Facility ID	Facility Name	Form Type	Start of electronic submission
00003	Mater Mothers' Public	Matrix	Jul-09
00015	Ipswich	Perinatal Online	Aug-11
00016	Redcliffe	OBSData/NEOData	Jul-07
00028	Redland	Perinatal Online	May-11
00029	Logan	ERIC	Sep-08
00030	Caboolture	Perinatal Online	Oct-09
00049	Nambour	Perinatal Online	Sep-09
00062	Bundaberg	Perinatal Online	Dec-09
00068	Gympie	Perinatal Online	Oct-09
00069	Hervey Bay	Perinatal Online	Nov-09
00070	Kingaroy	Perinatal Online	Sep-10
00091	Chinchilla	Perinatal Online	Apr-11
00092	Dalby	Perinatal Online	Sep-10
00093	Goondiwindi	Perinatal Online	Sep-10
00100	Stanthorpe	Perinatal Online	Sep-10
00104	Toowoomba	Perinatal Online	Jan-12
00105	Warwick	Perinatal Online	Apr-11
00112	Charleville	Perinatal Online	Apr-11
00113	Cunnamulla	Perinatal Online	Apr-11
00119	Roma	Perinatal Online	Apr-11
00120	St George	Perinatal Online	Apr-11
00133	Biloela	Perinatal Online	Mar-10
00134	Blackwater	Perinatal Online	Aug-10
00135	Emerald	Perinatal Online	Aug-10
00136	Gladstone	Perinatal Online	Mar-10
00141	Rockhampton	Perinatal Online	Mar-10
00143	Theodore	Perinatal Online	May-11
00144	Capricorn Coast	Perinatal Online	Jun-10
00145	Woorabinda	Perinatal Online	Jan-12
00156	Longreach	Perinatal Online	Aug-10
00172	Mackay	Perinatal Online	May-10
00174	Proserpine	Perinatal Online	Sep-09
00191	Ayr	Perinatal Online	Mar-11
00192	Bowen	Perinatal Online	Mar-11
00193	Charters Towers	Perinatal Online	Mar-11
00196	Ingham	Perinatal Online	Oct-12
00200	Townsville	Matrix	Dec-10

Facility ID	Facility Name	Form Type	Start of electronic submission
00201	Royal Brisbane and Women's	OBSData/NEOData	Jul-02
00211	Atherton	Perinatal Online	Jul-10
00214	Cairns	Perinatal Online	Jul-10
00222	Innisfail	Perinatal Online	Jul-10
00223	Mareeba	Perinatal Online	Jul-10
00226	Thursday Island	Perinatal Online	Oct-10
00227	Tully	Perinatal Online	May-11
00246	Mount Isa	Perinatal Online	Apr-10
00313	St. Andrews (Ipswich)	Meditech (Ramsay)	Sep-09
00318	Mater Women's & Children's Private	Matrix	Jul-09
00320	North West Private Hospital	Meditech (Ramsay)	Nov-09
00331	Pindara Private Hospital	Meditech (Ramsay)	Nov-09
00370	Mater (Redland)	Matrix	Dec-09
00420	Cairns Private Hospital	Meditech (Ramsay)	Sep-09
00441	John Flynn Gold Coast Private	Meditech (Ramsay)	Oct-09
00943	Boigu Island Primary Health Care Centre	Perinatal Online	Jan-12
00949	Saibai Island Primary Health Care Centre	Perinatal Online	Jan-12
00989	Townsville Hospital Birthing Centre	Matrix	Dec-10
00990	Toowoomba Hospital Birth Centre	Perinatal Online	Jan-12
00994	Royal Brisbane & Women's Birthing Centre	OBSData/NEOData	Jul-02
00995	Mackay Base Hospital Birthing Centre	Perinatal Online	May-10