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## HIMJ: Reviewed articles

### Validating notifications of pregnancy terminations for birth defects before 20 weeks gestation

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#### Abstract

The Victorian Perinatal Data Collection Unit (PDCU) maintains a Birth Defects Register (BDR), including data on terminations of pregnancy for birth defects before 20 weeks. This study aimed to validate the completeness of reporting, and accuracy of diagnoses provided by hospitals on these terminations.

From 1995-1999, 13 hospitals notified 321 terminations to the PDCU. An additional 41 cases were found through this study. For matched cases ( $n=273$ ), 199 (73%) had comparable diagnoses, 21 (8%) had different and 53 (19%) had additional diagnoses. Discrepancies arose because of problems with correct identification of relevant cases and lack of understanding of the importance of including all information on multiple birth defects.

**Keywords:** Birth defects; termination of pregnancy; validation of data; quality control

#### Introduction

The Perinatal Data Collection Unit (PDCU) is responsible for maintaining a Birth Defects Register (BDR) which collects data on all fetuses, babies, and children with birth defects since 1982, irrespective of the age at diagnosis. Notification is voluntary and the PDCU is reliant upon the goodwill of many health professionals for completeness of the BDR.

An integral part of the BDR is the follow-up of terminations of pregnancy for birth defects before 20 weeks gestation. Since 1995 all hospitals with obstetric beds have annually been requested to supply information on any such termination. Most hospitals select their own cases and send the information to the PDCU. However, the question has arisen as to how complete is the number of notifications and how accurate are diagnoses. The importance of these data to research and planning means that it is necessary to determine their quality and completeness.

#### Aim

The aims of the study were as follows:

- To validate the completeness of the notifications of terminations of pregnancy for birth defects before 20 weeks gestation.
- To validate the accuracy of the diagnosis provided by hospitals on the termination of pregnancy form.

- To determine why variations in the reporting of notifications of terminations of pregnancy for birth defects before 20 weeks gestation may occur.

### **Methodology**

A sample of hospitals was selected to participate in the study, looking at the terminations of pregnancy before 20 weeks gestation for birth defects in the years 1995-1999. The hospitals were selected on the basis of having had at least five terminations in any one of the study years, or if there were large variations in the number of notifications received from a hospital during the study period.

A health information manager (HIM) at each hospital was asked to run a report on all admitted episodes, which were coded using the following diagnosis codes:<sup>[1]</sup>

ICD-9-CM: 635.0 - 635.9 '*Legally induced abortion*'

**and** 655.0 - 655.9 '*Known or suspected fetal abnormality affecting management of mother*'

in the period 1 January 1995 to 30 June 1998

ICD-10-AM: O04.0 - O04.9 '*Medical Abortion*',

**and** O35.0 - O35.9 '*Maternal care for known or suspected fetal abnormality and damage*' **and** O09.0 - O09.2 '*Duration of pregnancy < 20 completed weeks*'

in the period 1 July 1998 to 31 December 1999. (See [Discussion](#) for details of a necessary refinement to this code list identified later.)

A HIM student and a supervising HIM reviewed hospital medical records and completed a termination of pregnancy notification form. This is the same form used by hospitals in the initial reporting episode. The diagnoses recorded were then coded using the British Paediatric Association Classification of Diseases.

Data were abstracted from the BDR on all terminations of pregnancy for birth defects less than 20 weeks gestation between 1995 to 1999 using SPSS version 9.0. Two separate databases were created, one for BDR data, and the other for data obtained from the hospitals during the validation study. The records in each database were then merged and matched using common variables: hospital code, mother's name, unit record number, mother's date of birth, and date of termination. Any records that could not be matched this way were then checked for potential matches in other hospitals using mother's date of birth, date of termination, and diagnoses.

The cases that matched were then compared to reveal any discrepancies between the diagnoses previously reported to the BDR and the diagnosis recorded during the validation. These cases were separated into:

- those whose diagnoses were the same or similar (ie, 74109 spina bifida, unspecified, with hydrocephalus, was

considered to be the same as 74105 spina bifida, lumbar, with hydrocephalus);

- those with different diagnoses;
- those where extra diagnoses were notified to the BDR;
- those where extra diagnoses were discovered during the validation;
- those with some diagnoses that were the same, but which also had additional diagnoses from both the BDR and the validation study.

## Results

During 1995-1999, 321 individual cases of terminations for a birth defect before 20 weeks gestation were reported to the BDR by the 13 hospitals in the study. Two hundred and seventy-three (89%) of these were matched to cases retrieved for the validation study, leaving 48 (15%) cases from the BDR that could not be matched. There were an additional 41 cases discovered as a result of the validation study that had not previously been notified to the BDR, giving a total of 362 cases. Therefore, overall agreement between the BDR and the validation study was 75% (Table 1).

### 1: Notifications of hospital-based terminations of pregnancy for birth defects before 20 weeks gestation

	Number	Per cent									
In both BDR & Validation Study	273	75.4	In BDR only	48	13.3	In Validation Study only (ie, missing from BDR)	41	11.3	<b>Total</b>	<b>362</b>	<b>100</b>

Between hospitals, the percentage agreement varied dramatically, with the lowest being 25%, and the highest 89% (Table 2).

### 2: Case comparison by hospital (number & percentage agreement)

Hospital	Matched cases	Not reported to BDR	Reported to BDR only	Total	Agreement
Hospital 1	16	1	5	22	73%
Hospital 2	9	4	3	16	56%
Hospital 3	33	0	4	37	89%
Hospital 4	15	0	2	17	88%
Hospital 5	45	2	4	51	88%
Hospital 6	51	2	10	63	81%
Hospital 7	10	3	3	16	63%
Hospital 8	19	3	0	22	86%
Hospital 9	3	8	1	12	25%
Hospital 10	11	5	0	16	69%
Hospital 11	22	5	2	29	76%
Hospital 12	11	1	2	14	79%

Hospital 13	28	7	12	47	60%
<b>TOTAL</b>	<b>273</b>	<b>41</b>	<b>48</b>	<b>362</b>	<b>75%</b>

Private hospitals made up the greatest proportion of notifications (54%), but the percentage agreement for both private and public hospitals was relatively similar (75% and 76%, respectively) (Table 3).

<b>3: Notifications by hospital type (private or public)</b>					
<b>Sector</b>	<b>Matched cases</b>	<b>Not reported to BDR</b>	<b>Reported to BDR only</b>	<b>Total</b>	<b>Agreement</b>
Private	146	26	23	195	75%
Public	127	15	25	167	76%
<b>TOTAL</b>	<b>273</b>	<b>41</b>	<b>48</b>	<b>362</b>	

The proportions previously unreported to the BDR, by year, are as follows: 1999 – 27%, 1998 – 24%, 1997 – 17%, 1996 – 10% and 1995 – 22%.

Of the 48 cases (13%) that had been reported *previously* to the BDR, but were unable to be matched to notifications retrieved during the validation study, 40 (83%) had been previously reported by a hospital, and only 8 (17%) were notified solely from another source (ie, laboratory). Therefore, 40 cases that should have been picked up during the validation study, as the data originally came from the hospital, were not picked up.

Of the 41 cases that had not previously been reported to the BDR but were found during the validation study, the majority comprised either terminations performed for a chromosomal abnormality (29%) or for neural tube defects (anencephaly and spina bifida; 37%).

Of the cases that were matched ( $n=273$ ), 199 (73%) had a diagnosis that was the same, or very similar, 21 (8%) had a different diagnosis, and the remaining 53 (19%) cases had additional diagnoses that were reported by either the BDR or the validation study or both (Table 4).

<b>4: Diagnosis comparison between matched cases</b>											
<b>Hospital</b>	<b>Same diagnoses</b>		<b>Different diagnoses</b>		<b>Additional BDR diagnoses</b>		<b>Additional study diagnoses</b>		<b>Additional diagnoses different</b>		<b>Total</b>
	<b>No.</b>	<b>%</b>	<b>No.</b>	<b>%</b>	<b>No.</b>	<b>%</b>	<b>No.</b>	<b>%</b>	<b>No.</b>	<b>%</b>	
Hospital 1	11	68.8	3	18.8	1	6.3	0	0	1	6.3	16
Hospital 2	7	77.8	1	11.1	0	0	1	11.1	0	0	9
Hospital 3	22	66.7	4	12.1	2	6.1	3	9.1	2	6.1	33
Hospital 4	8	53.3	1	6.7	1	6.7	4	26.7	1	6.7	15
Hospital 5	40	88.9	3	6.7	2	4.4	0	0	0	0	45
Hospital 6	37	72.5	3	5.9	2	3.9	7	13.7	2	3.9	51

Hospital 7	7	70	1	10	0	0	1	10	1	10	10
Hospital 8	15	78.9	0	0	3	15.8	1	5.3	0	0	19
Hospital 9	3	100	0	0	0	0	0	0	0	0	3
Hospital 10	3	27.3	1	9.1	2	18.2	5	45.5	0	0	11
Hospital 11	16	72.7	1	4.6	4	18.2	0	0	1	4.5	22
Hospital 12	7	63.6	1	9.1	2	18.2	1	9.1	0	0	11
Hospital 13	23	82.1	2	7.1	3	10.7	0	0	0	0	28
<b>TOTAL</b>	<b>199</b>	<b>72.9</b>	<b>21</b>	<b>7.7</b>	<b>22</b>	<b>8.1</b>	<b>23</b>	<b>8.4</b>	<b>8</b>	<b>2.9</b>	<b>273</b>

Of all the cases notified, only 21 had codes that were completely different. This means that 252 cases had *primary* diagnoses that were the same, but 53 of these cases had additional diagnoses. It can be inferred, therefore, that 92% of cases were correctly notified to a reasonable degree.

Of the cases where additional diagnostic information was reported by the BDR, 60% were reported by two sources: the hospital and a laboratory. Thirty-five percent were reported by the hospital only, and 5% by a laboratory only.

### Discussion

The results of this validation study show that 85% ( $n=273$ ) of the notifications for terminations of pregnancy for a malformation before 20 weeks gestation that were in the BDR between 1995-1999 were able to be matched to cases retrieved during the validation process, leaving 15% that are still being under-reported ( $n=41$ ).

Of additional concern are the cases that were notified previously to the BDR by hospitals ( $n=48$ ), and that were not retrieved during this validation study. However, a small number of records (less than 10) were not available at the time of the study, which may account for some of the unmatched 48 cases.

An analysis by hospital type does not show any marked differentiation in notification between private and public hospitals (75% and 76%, respectively). However, some hospitals have much better rates of notification than others (for example, Hospital 3 = 89% versus Hospital 9 = 25%). This seems to indicate that the problem may be related to how the records are initially retrieved. If restricted ICD codes are used to select the relevant cases, then some patients may be missed.

For example, in undertaking this study, HIMs were asked to run a report using a specific selection of diagnosis codes. It was noted during the study that the ICD-10-AM code O09.9 'Unspecified duration of pregnancy' was not among the codes given to hospitals. Due to this oversight, some cases of termination with an unspecified gestation may not have been included in the validation, and may account for some of the 48 cases that had been notified previously to the BDR but were not included in this validation study.

Also, during this study a problem was identified in the interpretation of the codes provided for abstracting the relevant cases. While hospitals were given specific instructions on the codes to be used (ie, *medical abortions and maternal care for known or suspected foetal abnormality and damage and duration of pregnancy less than 20 completed weeks*) it was not specified that cases should fulfil **all of these criteria** to be included. Therefore, at some hospitals where we expected only 15 records to be retrieved there were over 100, because cases that filled **any** of the code criteria were pulled (ie, a medical-induced abortion **or** a patient admitted for maternal care for a known or suspected foetal abnormality/damage **or** a pregnancy of less than 20 completed weeks). This highlights the necessity of being extremely clear and specific when requesting cases to be retrieved. It also explains how discrepancies in previous years may have arisen.

While 1999 had the largest proportion of cases not previously reported (27%), it did not vary significantly from any of the previous years, with each of the preceding years comprising anywhere from 10% to 24% of the additional 41 cases identified through the validation study. Therefore, reasons for discrepancies cannot be linked to the year of termination.

Also, the nature of the diagnosis does not appear to affect notification rates, with chromosomal cases only slightly less likely to be missed than neural tube defects (29% and 37%, respectively).

The comparison of diagnosis codes between cases previously notified to the BDR and those abstracted during the validation study also shows that great care needs to be taken when completing the notification forms. Although 73% of cases had the same diagnosis, and 92% had the same primary diagnosis, it is in the area of additional and supplementary conditions that more care needs to be taken.

Several reasons for the discrepancies in diagnoses were considered:

- The PDCU often receives supplementary notification of terminations of pregnancies for birth defects from the cytogenetic laboratories. These may not always be available in the medical record at the time the notification is being completed.
- Information missing from the medical record at the time of the original extraction for the PDCU (such as pathology reports), and therefore omitted from the BDR notification, may have been filed subsequently and thus included in the diagnoses for the validation study.
- HIMs from the PDCU involved in the study may have been more rigorous in their completion of the notification forms and the inclusion of ancillary birth defects than hospital-based HIMs doing their routine work.
- HIMs may not be aware of the need to include all the manifestations of a syndrome along with the main syndrome name and/or chromosomal anomaly.

Several recommendations may be made based on the findings of this study. Firstly, in the letter sent to HIMs each year requesting the notification of terminations of pregnancy for birth defects before 20 weeks gestation, the specific ICD-10-AM diagnosis codes and selection criteria for cases should be included and clearly explained. Secondly, the level of reporting of complete diagnoses could be improved by advising HIMs of the extent to which additional diagnoses are relevant, such as minor birth defects that are part of particular syndromes. The inclusion of a copy of pathology or other test results (if applicable) with the notification form also assists PDCU staff in abstracting additional diagnoses not deemed relevant by the person making the notification.

In future, we will endeavour to have an annual validation of a different sample of hospitals so as to be able to assess accurately the quality of information maintained on terminations of pregnancy for birth defects before 20 weeks gestation.

### **Conclusion**

This validation study has been a valuable means of assessing the completeness and accuracy of the number of notifications and the diagnoses that are notified for hospital-based terminations of pregnancy for birth defects before 20 weeks gestation. It was found that a high percentage of cases were notified to the PDCU for terminations of birth defects occurring in the years 1995 - 1999. Most hospitals had a good annual notification rate, but there were some that could make improvements.

A similar finding was noted regarding the diagnoses reported. Most hospitals were accurate in their notification of the type of malformation as the reason for termination. The figures on additional diagnoses that were not originally notified to the PDCU indicate that perhaps HIMs are undervaluing the importance of notifying all birth defects, not just the primary syndrome or its manifestations. Overall, the reporting of correct diagnoses by most hospitals was quite good, although there is certainly room for improvement.

**Note from the authors:** Validation of our large data collection is an ongoing concern for the PDCU, and it is important for our results to be published so that those using our data can be aware of its strengths and limitations.

### **Reference**

Riley M, Halliday J (2000). *Birth Defects in Victoria 1983-1998*, Perinatal Data Collection Unit, Victorian Department of Human Services, Melbourne.

[1] It was necessary to specify two sets of codes, one set for ICD-9-CM and one set for ICD-10-AM, as Victoria changed from ICD-9 to ICD-10 on July 1, 1998.

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