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Linking AWPS and CARIS data to estimate perinatal mortality in Wales due to congenital anomalies

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Objectives

The All Wales Perinatal Survey (AWPS) collects mortality data on perinatal, neonatal and infant mortality in Wales up to a year of age. The Congenital Anomaly Register and Information Service (CARIS) collects clinical data on all congenital anomalies in foeti, infants and children in Wales. This was the first attempt to link the AWPS and CARIS databases.

Approach

The AWPS database coded stillbirths, terminations and deaths by the clinic-pathologic classification until 2012, assigning each case a survey number. The CARIS database started collecting data from 1998. Thus, the common period between 1998 and 2012 (15 years) was chosen for this study.

Using CARIS as the main dataset, AWPS data were matched against the CARIS database using NHS numbers, along with soft linking on date of birth, maternal date of birth, and postcode. The unique AWPS survey number and coding was then added to the matched record within the CARIS dataset. This final âĂŸlinkedâĂŹ dataset was used to look at trend data.

Results

Between 1998 and 2012 a total of 20,574 cases were recorded in the CARIS database. After excluding cases where no gestation or date of death were recorded, and including deaths between >19 weeks' gestation up to 365 days after birth, there were 1306 foetal losses/terminations, 231 stillbirths, and 662 livebirths (total 2,199) records left in the CARIS database who died with congenital anomalies. In the comparable period, using the same criteria, there were 6,909 records identified in the AWPS database. Of those, 1,765 had a recorded lethal congenital anomaly. By using the above criteria, a total of 2,039 cases in the CARIS database were linked to the AWPS database. 241 cases in the CARIS database and 151 cases in the AWPS database could not be linked by the above methods.

Analysing the CARIS cases alone showed that consistently more than 80% of foeti are live-born, and survive. Chromosomal (22%), cardiovascular (21%) and brain (15%) anomalies are the most common congenital anomalies in the linked cases, which contribute to infant mortality. This pattern has remained largely unchanged over the study period.

Conclusion

Using NHS numbers and soft linking, the majority of CARIS cases were linked to AWPS cases. Although both these databases should closely reflect each other, missing cases suggest there is scope for improvement in data collection. Sharing of data could also improve the quality of both databases.

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