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Evaluation of the National Congenital Anomaly System in England and Wales

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Objective: To evaluate the National Congenital Anomaly System (NCAS).

Methods: The NCAS in England and Wales based at the Office for National Statistics and the various regional registers that exchange data with it were examined, based on guidelines for evaluating public health surveillance systems, published by the Centres for Disease Control (CDC). Data relating to congenital anomaly notifications received from 1991 to 2002 were analysed.

Main outcome measures: The main outcome measures were based on CDC standards and included the level of usefulness of the system, simplicity, flexibility, data quality, acceptability, sensitivity, representativeness, timeliness, and stability of the system.

Results: The NCAS has two main tiers: the “passive” system of voluntary notifications and the anomaly registers, but many reporting sources within these. It receives about 7000 notifications a year. It is inflexible and has variable data quality. The voluntary nature of reporting affects the system’s acceptability. The sensitivity as compared with two regional registers (Trent and Wales) is about 33%. The congenital anomaly registers reporting to the NCAS achieve high levels of coverage and completeness. From 2003, they cover 42% of all births and account for the major proportion of the notifications.

Conclusions: The NCAS serves the important function of monitoring birth defects in England and Wales, but is not currently operating in a timely or effective way. It should be adapted to meet its main objectives more effectively. More regional anomaly registers should be instituted and existing registers supported through central funds.