

National Congenital Anomaly System

Evaluation of the National Congenital Anomaly System in England and Wales

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Do we really need NCAS at all?

In January, Boyd *et al*¹ drew attention to the shortcomings of the National Congenital Anomaly System (NCAS), and *Archives* now carries a complementary paper (page 368) examining the functionality of the system, measured against the standards suggested by the USA Center for Disease Control. In both reports, NCAS is found wanting. Can it be fixed, should it be fixed, or should it be abolished?

The problems with NCAS are well described in these two papers: very poor ascertainment, and no data on antenatally diagnosed cases, except when fed data by the regional congenital anomaly registers; massively incomplete data fields; and consequently a severely limited capacity to fulfil the role for which it was set up in the wake of the thalidomide disaster. Yet congenital anomaly remains a leading cause of death and disability, perinatally and in infancy. It continues to pose challenges to public health, neonatal medicine, and surgery. Environmental pollutants, prescription drugs, assisted reproduction technologies, and changes in diet and lifestyle all have actual or potential effects on the risk for congenital anomaly, so continuous, accurate anomaly monitoring is of great importance nationally and internationally.

A great strength of the regional registers in England and Wales is that they are run, slightly obsessively, by people who really care about congenital anomaly. These people are part of a regional network of contacts. They use multiple sources of ascertainment, and they are able to record provisional diagnoses (such as those often made antenatally), then follow them up to find the true diagnosis. The participation of informants is active, giving a sense that the register is owned locally by the very people who contribute to it. NCAS in contrast still works on the "black hole" principle: it endeavours to ascertain information from people and institutions too remote to care about it, then fails to engage these people or feed back information to them. Disengagement brings grudging and patchy compliance, and results in

reporting forms (SD56 forms) that are often incomplete and at worst downright inaccurate.

In view of the undoubted effectiveness of the local registries, Misra *et al* call for more of them to cover the whole population, for proper funding, and for them to be the means by which information is fed up to NCAS. No one could quarrel with the idea that the existing registries should be properly and sustainably funded: many run on a shoestring, research money, and goodwill, yet they are the only accurate source for congenital anomaly ascertainment, so it would be little short of a national disaster if they ceased to exist. But the assumption that complete population coverage is necessary for a system of anomaly surveillance is questionable: if over half the population is covered, we need to be sure of the added value of including the rest, unless there is evidence that certain industries, pollution patterns, or other geographical entities are differentially distributed between regions where registers do or do not exist.

Furthermore, and partly in recognition of the limitations of NCAS, higher level structures have evolved that already do much that NCAS would like to do. These are the British Isles Network of Congenital Anomaly Registers (BINOCAR) and the European body, EUROCAT (<http://www.eurocat.ulster.ac.uk/whatis.html>). Through these groupings, collaborative projects covering much larger populations than individual registries can be conceived and executed. In the case of EUROCAT, there is also the facility for undertaking temporal cluster analysis and generating standard reports. EUROCAT succeeds because it is a collaboration, and there is a sense that it is owned by its member registries. NCAS does not have such a relationship with the English and Welsh registries because it is but one part of the Office for National Statistics (ONS).

Taking a radical view, ONS could abolish NCAS, support a set of regional registries (which does not rule out the possibility of extending these to truly national coverage), require them to participate in EUROCAT to standardise coding and data structure, and contract with

EUROCAT to provide standard reports to the ONS that would then be of real value. In addition, the Department of Health could consider promoting legislation to make the notification of anomalies statutory rather than voluntary. By itself, this would be unlikely to improve direct ascertainment for NCAS, but it would certainly help the regional registries.

In principle, the one thing that NCAS could do that is less easily done by individual registries, is to link with the statutory ONS birth and death data. The main problem with this linkage is that, if anomaly cases are tracked through to death, it takes a long time to produce reliable outcome data, and the data are then out of date. It is potentially much quicker and more relevant to ascertain current deaths and analyse these for instances of congenital anomaly. The problem here is that death certificates often make no mention of an underlying anomaly, and, even if they do, this information is commonly not coded as a cause of death by ONS, even when it is the true underlying cause. The issue of the correct description of cause of death is being investigated through the Confidential Enquiry into Maternal and Child Health (CEMACH), so this aspect should ultimately improve, but, in the meantime, the appeal of linking NCAS data to deaths looks greater in theory than in practice.

So, do we really want or need NCAS? Ironically, one of its best achievements was in helping to set up BINOCAR. All of the NCAS functions in Misra's table 1 could be discharged better by the relevant BINOCAR registries working with EUROCAT. I will always give more credence to accurate data on half the population rather than dodgy data purporting to be on the whole population. ONS, doctors, and the public need the regional registries, but do not need NCAS. I vote for abolition.

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Competing interests: MWP is the clinical director of the Regional Maternity Survey Office which runs the Northern Congenital Abnormality Survey (NorCAS).

REFERENCE

- 1 Boyd PA, Armstrong B, Dolk H, *et al*. Congenital anomaly surveillance in England: ascertainment deficiencies in the national system. *BMJ* 2005;330:27.