

Lack of nationwide surveillance may lead to clusters of congenital anomalies going unnoticed

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One baby in every 45 was born with a congenital anomaly in 2010 according to the second annual report by the British Isles Network of Congenital Anomaly Registers (BINOCAR), released today (Thursday).

The report [1] by researchers at Queen Mary, University of London collates data from six regional registers, one more than for 2009, taking the national coverage to 35 per cent of the births in England and Wales and leaving the vast majority of congenital anomalies unreported. Examples of congenital anomalies include heart and lung defects, Down syndrome, neural tube defects such as spina bifida, and limb malformations such as club foot.

Commissioned by the Healthcare Quality Improvement Partnership (HQIP), the study is the most up-to-date and comprehensive of its kind, bringing together existing data in England and Wales from 2006 to 2010. However, the editor of the report, Professor Joan Morris, from the Wolfson Institute of [Preventive Medicine](#), part of Queen Mary, University of London, said: "We remain concerned that data for substantial parts of the country, including London, are not currently monitored, meaning large regional increases in congenital anomalies could go unnoticed and their causes not investigated. Currently there are no registers in London, the South East, the North West and [East Anglia](#)."

With formal responsibility for national surveillance of congenital

anomalies likely to be met under the single national authority of Public Health England (PHE), there is an opportunity to expand the current system to provide national coverage. Professor Elizabeth Draper from the University of Leicester, who is Chair of BINOCAR, commented: "This important report again highlights the value of the existing regional registers. We are grateful for the ongoing support from HQIP to help maintain existing surveillance arrangements, and we will continue to work closely with them and PHE to implement full national coverage in the near future."

The number and types of congenital anomalies have been monitored since the thalidomide epidemic in the 1960s. Since the 1980s, regional registers have been established in some parts of the country to actively collect data from hospital, laboratories and health records. In the intervening years, lack of strategic funding coupled with a lack of support at national level has led to the closure of the national system and some of the regional registers. The creation of a stable system of funding for an entire surveillance network would make it possible to fulfil the potential that the existing registers offer for public health, service planning, clinical audit, outcomes monitoring, research and other purposes.

The main findings from today's report are:

- 2.2% of babies had a [congenital anomaly](#) in England and Wales in 2010.
- The prevalence of congenital anomalies in England and Wales was consistent with those in other European registers.
- The researchers estimate that there were at least 16,000 babies born with congenital anomalies in England and Wales in 2010.
- The most common anomalies were congenital heart defects, which affected at least five in 1,000 births. Some cases required

major operations and around seven per cent of babies born with a heart anomaly died before the age of one.

- [Neural tube defects](#), such as spina bifida, affected one in 1,000 babies; many of these may have been prevented by women taking folic acid supplements before becoming pregnant as well as in early pregnancy.
- Gastroschisis – an anomaly where the intestines develop outside the abdomen – affected one in 1,000 babies. Regional monitoring has shown that this condition has become more common in some areas including Wales and that babies born to younger mothers were at greater risk. Gastroschisis was more likely in England and Wales than in other European registers.
- Over half of all major congenital anomalies were detected during pregnancy.
- Mothers who were between 25 and 29 years of age had the lowest prevalence for all anomalies. The prevalence was higher in the under-20 age group and considerably higher in the 40 and over age group.

More information: [1] "Congenital Anomaly Statistics 2010, England and Wales". British Isles Network of Congenital Anomaly Registers (BINOCAR).

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