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## **Report finds one in 50 babies has birth defect and highlights worrying gaps in regional monitoring**

More than one baby in every 50 is born with a birth defect (congenital anomaly) according to the latest annual report by the British Isles Network of Congenital Anomaly Registers (BINOCAR) – significantly more common than previously reported estimates of around one in 80.

The study\* – led by researchers at Queen Mary, University of London and commissioned by the Healthcare Quality Improvement Partnership (HQIP) – is the most up-to-date and comprehensive of its kind, bringing together existing data in England and Wales from 2005 to 2009.

However, the report's authors remain concerned that data for substantial parts of the country, including London, are not currently monitored, meaning large regional increases in birth defects could go unnoticed and their causes not investigated.

“This is a major issue,” commented Joan Morris, Professor of Medical Statistics at Queen Mary, University of London and editor of the report. “It is essential we know how many babies are being born with anomalies and how good their survival is across the whole country, so we can identify ways to reduce the occurrence of anomalies and plan for the care of these babies.”

This national report includes data from five regional registers and two disease specific national registers<sup>†</sup>. Three additional registers exist and it is hoped that with further funding they will contribute data to future reports. Currently there are no registers in London and the South East, the North West and East Anglia.

Professor Elizabeth Draper from the University of Leicester who is Chair of BINOCAR commented: “This report is important, not least because it highlights the need to increase the number of regional registers in England. We are very grateful for the ongoing support from HQIP, but to provide national coverage will require a sustained commitment of additional resources. Funding for national surveillance of congenital anomalies is being considered as part of the surveillance program in Public Health England and we hope it will be in place by April 2013.”

The number and types of birth defects have been monitored since the thalidomide epidemic in the 1960s. Under the original system, cases were notified to the Office for National Statistics by doctors, nurses, midwives and health visitors. Since the 1980s, regional registers have been established in some parts of the country to actively collect data from hospitals, 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. This report collates data from five regional registers, which together cover 28 per cent of the population of England and Wales, leaving the vast majority of birth defects unreported.

- Previous estimates, based on data from the Office for National Statistics, suggested that 1.3 per cent of babies have a birth defect. The new report indicates that the figure is more than two per cent.
- The researchers estimate that there were at least 14,500 babies born with birth defects in England and Wales in 2009.
- The most common defect was congenital heart disease, which affects at least five in 1,000 births. Some cases require major operations and around six per cent of babies born with a heart defect will die before the age of one.
- Neural tube defects, such as spina bifida, affect one in 1,000 babies, many of these may be prevented by women taking folic acid supplements before becoming pregnant.
- Gastroschisis – a defect where the intestines develop outside the abdomen – affect 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 are at greater risk.
- Over half of all major birth defects were detected during pregnancy.

**Ends**

#### **Notes to editors**

\*Congenital Anomaly Statistics 2009, England and Wales, British Isles Network of Congenital Anomaly Registers (BINOCAR)

†The five BINOCAR regional registers contributing to the report are:

- Congenital Anomaly Register and Information Service for Wales (CARIS)
- Congenital Anomaly Register for Oxfordshire, Berkshire and Buckinghamshire (CAROBB)
- East Midlands and South Yorkshire Congenital Anomalies Register (EMSYCAR)
- Northern Congenital Abnormality Survey (NorCAS)
- Wessex Antenatally Detected Anomalies Register (WANDA)

The two disease specific national registers contributing to the report are:

- National Down Syndrome Cytogenetic Register (NDSCR)
- Cleft lip and palate (CRANE) database.

For more information on BINOCAR visit [www.binocar.org](http://www.binocar.org).

**About HQIP:** The Healthcare Quality Improvement Partnership (HQIP) is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. Its aim is to promote quality improvement, and in particular to increase the impact of clinical audit in England and Wales. HQIP hosts the Department of Health contract to manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP). The programme comprises 40 clinical audits that cover care provided to people with a wide range of medical, surgical and mental health conditions.