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

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 [2], 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.

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Notes to editors

[1] “Congenital Anomaly Statistics 2010, England and Wales”. British Isles Network of Congenital Anomaly Registers (BINOCAR). Published online at: <http://www.binocar.org/Publications/Reports>

[2] The six 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)
- South West Congenital Anomaly Register (SWCAR)
- 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.

About Queen Mary, University of London

Queen Mary, University of London is one of the UK's leading research-focused higher education institutions with some 16,900 undergraduate and postgraduate students.

Amongst the largest of the colleges of the University of London, Queen Mary is a member of the Russell Group, which represents the 24 leading universities in the UK.

Queen Mary's 3,800 staff deliver world class degree programmes and research across 21 academic departments and institutes, within three sectors: Science and Engineering; Humanities, Social Sciences and Laws; and the School of Medicine and Dentistry.

Queen Mary is ranked 11th in the UK according to the *Guardian* analysis of the 2008 Research Assessment Exercise, and has been described as 'the biggest star among the research-intensive institutions' by the *Times Higher Education*.

The College has a strong international reputation, with around 20 per cent of students coming from over 100 countries. Queen Mary has an annual turnover of £300 million, research income worth £70 million, and generates employment and output worth £600 million to the UK economy each year.

The College is unique amongst London's universities in being able to offer a completely integrated residential campus, with a 2,000-bed award-winning Student Village on its Mile End campus.

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.