



Congenital Anomaly Register for
Oxfordshire, Berkshire & Buckinghamshire



Dear Colleague

30th March 2015

Re: Closure of CAROBB and the establishment of a new National Congenital Anomaly and Rare Disease Registration Service (NCARDS)

After nine successful years of CAROBB and 23 years of OXCAR I am writing to let you know that things are changing in relation to the notification and registration of congenital anomalies in Oxfordshire, Berkshire, Buckinghamshire, and nationally across England. Public Health England (PHE) are establishing a new National Congenital Anomaly and Rare Disease Registration Service (NCARDS) This will involve the closure of CAROBB and the transfer of the CAROBB register to the Public Health England offices at:

NCARDS
4150 Chancellor Court
Oxford Business Park South
Oxford OX4 2GX

CAROBB is closing on the 31st March 2015. Once the transfer of CAROBB to NCARDS has happened you will receive information about the new processes of notification to the new national register. A letter from PHE is attached for your information.

As CAROBB closes I would like to thank you for your contribution to CAROBB and to OXCAR before that and to reflect on the achievements of the register which would not have been possible without your involvement and contribution of notifications which are the life blood of any register.

The Oxford Congenital Anomaly Register (OXCAR) was established in 1991 at the John Radcliffe Hospital by Dr Tricia Boyd, Clinical Geneticist for Prenatal Diagnosis. The aim of OXCAR was to collect information about fetuses and babies affected by congenital anomalies for women resident in the area with an OX postcode. One of the main goals of the register was to monitor and evaluate the impact of the then newly emerging prenatal diagnosis technologies and in particular to assess the accuracy of antenatal ultrasound scanning used in the screening for structural congenital anomalies.

In 2002 the Department of Health put out a call for competitive bids to fund research active disease registers. With colleagues from the National Perinatal Epidemiology Unit (NPEU) Tricia successfully bid to expand OXCAR to become a fully established population-based based congenital anomaly register covering Berkshire and Buckinghamshire as well as Oxfordshire and CAROBB was created - Congenital Anomaly



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Register for Oxfordshire, Berkshire and Buckinghamshire. With Cath Rounding appointed as Co-ordinator, Tricia as Clinical Director and the move to NPEU CAROBB went from strength to strength and the recent CAROBB team of Jane Forrester–Barker, Kay Randall and Nicole Diggins have continued the improvements and expansion of the register.

Importantly data from CAROBB and OXCAR have: led to 78 peer reviewed publications including papers in The Lancet and the British Medical Journal; contributed to 148 separate projects ranging from local audits to national research programmes and the European collection of congenital anomaly data led by EUROCAT; and countless local presentations supporting local service delivery. Most importantly the findings from the register have been used to support the counselling of parents and prospective parents. None of this would have been possible without the contribution of information from countless colleagues from hospital departments, community services, NHS information services, other organisations and the parents involved in our stakeholder group.

With the transfer to Public Health England and the creation of a new national registration system the opportunity now exist for other areas of England to be as well served by congenital anomalies information as Oxfordshire has been for 23 years and the whole of the CAROBB area for nine years.

Information about CAROBB will continue to remain on the NPEU website:

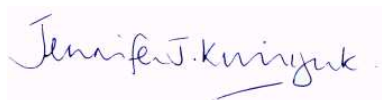
<https://www.npeu.ox.ac.uk/carobb>

If you have any questions about CAROBB please contact Jenny Kurinczuk at:

Jenny.kurinczuk@npeu.ox.ac.uk or 01865 289700

With thanks again for your contribution this important endeavour.

Yours faithfully



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March 2015

Dear Colleague,

National Congenital Anomaly and Rare Disease Registration Service (NCARDRS)

I am writing to update you on changes in congenital anomaly and rare disease registration, which may impact on the arrangements for data flows your Trust currently provides to this service.

To address the national requirements for high quality public health disease surveillance identified by the Chief Medical Officer, Public Health England (PHE) has committed to the expansion of congenital anomaly and rare disease registration from the current 49% coverage to the whole population of England. The register is also central to the UK Rare Disease Strategy and the Department of Health 2020 Vision on Rare Diseases.

From the 1 April 2015 PHE will manage and lead this national service, incorporating the existing seven regional congenital anomaly registers, the National Downs Syndrome Cytogenetic Register (NDSCR) and the British Isles Network of Congenital Anomaly Registers (BINOCAR) hub. In those parts of the country where there is currently no data collection, new regional teams will be established.

Public Health England has received section 251 approval from the Secretary of State via the confidentiality advisory group (CAG) to process confidential patient data obtained without consent for the purpose of congenital anomaly and rare diseases registration, and possesses the necessary legal basis to do this under Regulation 5 of the Health Service (Control of Patient information) Regulations 2002 (as a defined medical purpose). In addition, PHE is has evidence for level 2 of the HSCIC Information Governance Toolkit.

The regional registration team (CAROBB), along with the register, will be moving to PHE offices from the 1st April 2015. Once the team have relocated data providers will be informed of any changes to contact details and a forwarding service will be put in place should any paperwork be sent to the old address. Regional registration staff currently have access to hospital systems (on-site or via remote access) for case ascertainment and completion. This access is covered under existing data sharing agreements and either honorary contracts or

direct employment by the NHS Trust. We would like these arrangements to continue when the regional registry staff transfer into PHE on 1st April and will be in contact with your HR and IT leads separately to discuss the detail of these arrangements.

We believe the information governance arrangements put in place by PHE are sufficient to maintain the existing data flows to NCARDRS, but if you require any further information please contact Victoria Donnelly, Infrastructure Programme Manager, NCARDRS:
Victoria.donnelly@phe.gov.uk 07795 590742

Yours sincerely,



Jem Rashbass
Director, National Disease Registration
Public Health England

cc Caldicott Guardian