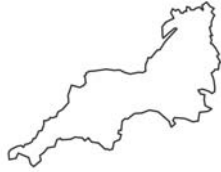


South West



Congenital Anomaly Register

Minutes of the SWCAR Steering Committee Meeting

held on

Wednesday 10th March 2005

between 2 – 4 pm in

Tutorial Room 3, Level 5, UBHT Education Centre, Bristol.

Present:

Prof Peter Fleming (Chair), Infant Health & Developmental Physiology, Bristol University

Ms Julie Chamberlain, Information Administrator, SWCAR

Mr Ed Cross, Information Assistant, SWCAR

Ms Aileen McLoughlin, Co-ordinator, SWCAR

Mr Tim Overton, Consultant in Fetal Medicine, St Michael's Hospital

Mrs Rosie Thompson, Project Manager, SWCAR

Mr Ben Wreyford, Information Assistant, SWCAR

1.0 Apologies

Apologies were received from Mrs M Brooks, Mr D Bryne, Ms J Drury, Ms J Ford, Ms C Hammonds, Ms C King, Dr J Madar, Dr R Martin, Ms A Philips, Ms M Robson, Dr P Turnpenny and Dr J Verne.

2.0 SWCAR Website

A computer room had been booked and this enabled each member to view the new SWCAR website on an individual PC, to interact with the site and provide feedback on first impressions, its ease of use and to have the opportunity to compare other register websites.

AM queried if it was still necessary for each hospital to enter a password to access their own hospital data. PF felt that this was still necessary as numbers of cases in some hospitals were small enough for individuals to be identifiable and TO felt that the information could be inappropriately used, eg, by members of the public, if given unrestricted access. It was also thought that securing the site would also encourage notification. It was agreed that Regional and Strategic Health Authority data involved sufficient numbers and did not require password protection.

To bring the Register in line with the Children's Act it was agreed that the Register should increase the notification age limit for diagnosis from "up until age 16" to "prior to the 18th birthday". PF, however, felt that there would be further consent issues to deal with in the future for older children.

Examples of how other Registers had presented their data were distributed for discussion. As there were few members present at this meeting it was considered more appropriate to hold an additional

meeting in early summer to discuss exactly what data should be presented and in what format on the website. It was thought a good starting point was to follow CARIS, the Welsh Register, and include extra information, if necessary, with a link to their site for those comparing data across the two regions. AM agreed to send out paperwork to other members for feedback.

Action: AM

All present agreed the website was an important development and TO congratulated AM on the excellent work she had achieved with Interactive Design, the web company involved. The new website, www.swcar.org.uk, is due to go live by the end of May 2005.

3.0 Notifications

3.1 Levels of notification

A table was provided of all notifications received in 2004 for each booking hospital split by warning cards, dataforms and paediatric notification forms (copy attached). This data represents notifications received by booking hospital.

3.2 New notifications

SWCAR now has access to the central document server for copies of diagnosis letters. Consultant nephrologists at the Bristol Children's Hospital have recently agreed to provide diagnosis letters to SWCAR for cases of antenatally detected dilated renal pelves. The clinical genetics department have just reached an agreement with the Register to notify on an adapted dataform. Remote STORK access has been gained to North Devon District Hospital and it was still hoped to receive information from BADGER, the St Michael's NICU computer system. Molecular genetics have agreed to report cases of inborn error of metabolism and other conditions diagnosed at their Southmead laboratory. They are also informing the Exeter laboratory about SWCAR with a view to encouraging reporting. Maggie Williams has agreed a list of relevant conditions with TO/PF. They are currently deciding on the most appropriate reporting method. TO added that this was all very encouraging news and that good progress was being made.

AM reported that FUJITSU were taking over IT services in the south west and felt a direct approach should be made to them at an early stage to allow them to focus on the requirements of the Register whilst still in their planning phase. TO agreed to make an approach on behalf of the Register to see whether a representative could attend a development meeting.

Action: TO

4.0 Reporting of Data

4.1 Sample reporting methods from other registers

See paragraph 4 under **2.0 Website**.

4.2 Reporting of SWCAR 2004 data

The Register had been notifying the Office for National Statistics (ONS) since January 2003 and AM asked whether it would now be appropriate to look into the possibility of notifying EUROCAT (the european network of population-based registries for the epidemiologic

surveillance of congenital anomalies) and it was agreed moves should be made towards finding out more.

Action: RT

RT and Nirupa Dattani, Director, NCAS (ONS) have jointly written to Child Health departments in the south west region to request that they notify the Register on SD56 forms rather than notifying ONS directly. SWCAR will then take on complete responsibility for notifying ONS of all south west cases. This will take effect immediately.

Action: AM

5.0 Use of SWCAR data

The Public Health Department in Bristol has requested use of SWCAR data for an exploratory project to investigate the prevalence of reported smoking consumption and alcohol and drug misuse in pregnancy in relation to congenital anomalies. TO explained he was delighted that they had shown an interest and enthusiasm in using the data but wondered if it was practical to start with this particular study. He offered to contact Viv Harrison again to possibly suggest use of different data and to highlight that Central Office for Research Ethics Committees (COREC) approval and NHS Research and Development registration would be required prior to the start of any project.

Action: TO

6.0 SWCAR Newsletter

To encourage interest in the next SWCAR newsletter AM thought it would be more appealing to include a paragraph about a specific anomaly written by an expert in that field. Discussion focused on possible articles about cosmetic hypospadias, the services of the cleft team/Pierre Robin syndrome, abdominal wall defects or possibly something about the recent gastroschisis conference in London.

AM and TO would make contact with Nigel Mercer/Nigel Hawthorne/Mike Saunders of the Cleft Team and Peter Soothill who chaired the gastroschisis conference.

Action: AM/TO

7.0 Any Other Business

There was no other business.

8.0 Date of Next Meeting

The best date for the next meeting from those members who have responded so far is Wednesday 29th June 2005 between 2 – 4 pm in Bristol.

Action: AM