

South West



Congenital Abnormality Register

Minutes of the SWCAR Steering Committee Meeting

held on

Friday 24 September 2004

between 9.30 – 11.00 am in the

Meeting Room, Level 6, UBHT Education Centre, Bristol.

Present:

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

Ms Julie Chamberlain, Information Assistant, SWCAR

Mrs Cath King, Genetic Nurse Specialist, Royal United Hospital

Ms Aileen McLoughlin, Project Nurse, SWCAR

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

Mrs Sarah Smith, Project Nurse, SWCAR

Mrs Rosie Thompson, Project Manager, SWCAR

1.0 Apologies

Apologies were received from Ms A Philips, Mrs M Brooks, Ms J Ford, Dr J Madar; Dr J Verne, Dr P Turnpenny, Ms C Hammonds, Mr S Savage, Ms M Robson and Ms J Drury.

2.0 Register Report

2.1 Levels of notification

Notification levels for 2002, 2003 and 2004 for each hospital in the Region were produced by AM (see attached) and it was noted that the overall levels were decreasing year on year but RT pointed out that the Register still had more notifications for 2002/2003 to be input and that extra help would be employed to deal with this backlog of data.

PF was concerned that the Register was not being notified of inborn errors of metabolism and suggested contacting Maggie Williams, Acting Biochemist, Southmead Hospital. AM was asked to make initial contact and TO agreed to email her.

Action: AM/TO

Salisbury Hospital, PF felt, ought to be producing notifications similar in number to those from Derriford Hospital. RT explained that she had planned to visit them and follow up on the CEMACH and congenital anomaly notifications.

2.2 2002/03

Due to the backlog of data an information assistant on a 9 month contract would be recruited to work on the retrospective data for 2002/2003. Interviews would take place on 6 October.

Action: RT

2.3 Validation of data

A minimum data set has been established for 2004 notifications and written evaluation guidelines would be drawn up by the end of the year to validate the 2004 data.

Action: RT/AM

2.4 Improving levels of notification

2.4.1 Feedback from Project Nurses

AM reported that St Michael's, Yeovil, Taunton & Somerset, Gloucester Royal, Royal Cornwall, Southmead, Cheltenham, Western General and Royal Devon & Exeter hospitals were now able to automatically print a SWCAR notification form from their STORK system following the birth of a baby with an anomaly. North Devon District hospitals, using the same system, would be able to produce forms from November onwards.

AM reported on the following hospitals:-

Derriford - Notifications were good from the CEMACH Coordinator but not from the midwives. The neonatal unit was very enthusiastic but did not report. Three monthly PAS electronic downloads were being received.

North Devon – Antenatal reporting was good but the Labour Ward was not so reliable but they would have the new STORK form in November. No downloads had yet been received. Stork remote access is in the process of being arranged.

Cornwall – Antenatal reporting was excellent. ANNP's complete paediatric forms for NICU and physiotherapy reporting was also very good. Downloads were being regularly received.

Royal Devon & Exeter – Antenatal reporting was good but the Labour Ward reporting was still being implemented. No downloads had yet been received but this was hoped to change shortly. AM is to chase Steve Roffe, Deputy Information Manager, IMT Services. TO to contact paediatricians.

Action: AM/TO

St Michael's – Antenatal reporting was very good with the Labour Ward also sending notifications and it was felt the paediatric notifications would soon start to follow.

Taunton & Somerset – Antenatal and labour ward reporting was good but to date the neonatal wards had not reported many cases, although they were using the paediatric form.

Torbay – Antenatal reporting was good but reporting from other areas was not happening. AM had planned to visit the hospital at the end of October.

Western General – Antenatal reporting was good. Labour Ward reporting was infrequent as it was a low risk unit. The introduction of the new STORK form should improve notification of terminations.

Bristol Children's Hospital – AM now had access to their cardiac database, HeartSuite, which enabled the Register to follow up on cardiac cases in the Bristol area.

AM explained that she was concerned that no progress had been made with obtaining renal diagnosis letters from the hospital. It was agreed that TO contact Jan Dudley, Nephrologist, to reassure them about the Register. PF suggested the clinicians may be more keen to notify if diagnosis letters were anonymised or sent to a named clinician, either TO or himself. **Action: TO**

SS reported on the following hospitals:-

Bath - No reporting at all.

Cheltenham - Antenatal, Delivery Suite and paediatricians reporting were all very good.

Gloucester – Antenatal reporting was good with some Delivery Suite reporting. No postnatal reporting was currently happening but there was no objection and improvements should be seen.

Southmead – Antenatal reporting was good, with some Delivery Suite reporting, but paediatric reporting was thin.

Swindon – Antenatal and Delivery Suite reporting was good but paediatricians would like forms available on their intranet. Physiotherapists have objected to reporting as they say all relevant data already resides on their Child Health Database.

Yeovil – Antenatal and Delivery Suite reporting was good but paediatricians were still not accessing the paediatric notification forms currently filed on their intranet. **Action: SS**

2.4.2 Paediatric Notification Form

The new simplified Paediatric Notification Form, a shorter version of the Dataform requesting fewer maternal details, has now been in use for several months and approximately 80 forms have been received to date. They have been sent mainly from Royal Cornwall Hospital physiotherapy and neonatal units, Taunton & Somerset Hospital paediatric department and St Michael's Hospital neonatal unit and Southmead. Cheltenham and Gloucester hospitals were happy to continue to use the Dataform to report on paediatric notifications.

2.5 MREC

SWCAR has now been granted ethics approval for data collection from MREC (a copy of the approval letter was recently sent to all members). MREC should be re-applied for every three years. This will be done by BINOCAR.

TO made clear that Royal Devon & Exeter Hospital were now reassured following the approval and although progress was slow, with continued pressure, notifications from them were achievable. AM and TO planned to make contact. **Action: TO/AM**

Royal United Hospital, Bath, who were previously opposed to reporting, were pleased that approval had come through, although there was still some resistance. CK explained the antenatal clinic had everything they required to start reporting but the paediatricians still needed more materials. To get things moving forward CK thought it might be helpful to ask Bath to start notifications from a specified date. PF felt that if there were

any real objections at Bath it was very important to find out the nature of these objections so they could be effectively dealt with.

2.6 Pilot for obtaining consent

RT explained that, as the Register now had MREC approval, it was not necessary to pilot consent. It was thought inappropriate for the newest register to take this on board and that a more established register should follow this up if this is still felt to be necessary. This would be discussed at the next BINOCAR meeting.

2.7 Wessex AnteNatally Detected Anomalies Register (WANDA)

In June, a meeting was held with representatives of the Strategic Health Authority as the Register had asked for guidance from them about the ongoing dispute with WANDA. To date no guidance has been received although two follow up letters have been sent.

TO reiterated to members that all correspondence from SWCAR to WANDA had been conciliatory and that this practice should continue as it was important not to let the relationship between the registers deteriorate as that could prove counterproductive, especially as SWCAR were unable to cope with the additional workload.

The British Isles Network of Congenital Anomaly Registers (BINOCAR) was due to discuss the ongoing disagreement at their conference on 4/5 October 2004.

Action: RT

2.8 Follow On Congenital Abnormalities Longterm (FOCAL)

FOCAL, a body funded by the Birth Defects Foundation, had asked RT to provide data from the Register on diaphragmatic hernias as they were putting together a proposal for following up children with this anomaly.

PF was surprised that this study was being undertaken as he and two colleagues, Baglaj and Glynn, had published a detailed paper in 1998 following up on diaphragmatic hernias in children born at St Michael's hospital and he wondered if a detailed literature search had been undertaken.

RT agreed to raise this point at her next meeting with FOCAL on 9 November and offered to send PF a copy of the FOCAL proposal when she received it.

Action: RT

2.9 Website

AM outlined her initial thoughts on the contents of the new website for the Register.

After discussions, it was agreed the website should start off in a simple format, with an improved look logo which could be expanded over time and that it should be professionally managed and updated as appropriate, although the costs of updating on a regular basis would need to be determined.

The site should contain basic contact details, the code of practice, MREC, PIAG approval, etc, relevant links to BINOCAR, ONS, other registers websites and relevant support groups and also hold individual hospital data on notification levels/anomaly rates in the major hospitals in the Region to be accessed only by the individual hospitals themselves by username and password. Within the hospital area each hospital should be identified by a letter rather than a name.

Security issues were raised and it was agreed that although all SWCAR notification forms should be accessible on the site in a printable format, it was felt at this early stage, the website should not be used to complete notification forms online. Members also felt it should be made clear to notifiers NOT to send confidential information to the Register via email.

AM was asked to get quotes for the initial cost of developing the website together with ongoing costs for maintenance. **Action: AM**

2.10 Annual Regional Meeting

RT asked if members thought that holding an Annual Regional Meeting was still worthwhile. It was agreed that it was and that a half day event with a “big name” would encourage people to attend if it was combined with reporting of the 2002 data and the launch of the new website. However, it was felt that this would not be feasible until the end of next year.

3.0 Any Other Business

There was no other business.

4.0 Date of Next Meeting

The next meeting will be on Thursday 10 March 2005. The time of the meeting and a convenient venue will be determined once it is known which members would like to attend.

Action: JC