



Minutes of the SWCAR Steering Committee Meeting

held on

Friday 12 March 2004

between 10am – 12pm in

the Meeting Room, Level C, St Michael's Hospital, Bristol.

Present:

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

Ms Julie Chamberlain, Information Assistant, SWCAR

Ms Chrissie Hammonds, Sonographer, Southmead Hospital

Mrs Cath King, Genetic Nurse Specialist, Royal United Hospital

Ms Angie Knight, Antenatal Screening Midwife, Southmead Hospital

Ms Aileen McLoughlin, Project Nurse, SWCAR

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

Ms Alison Philips, Sonographer, Torbay Hospital

Mrs Sarah Smith, Project Nurse, SWCAR

Mrs Rosie Thompson, Project Manager, SWCAR

PF was in attendance as Chair for agenda items 1.0, 2.0, 2.1, 2.2.1 and 2.5.

TO took over as Chair for the other items.

1.0 Apologies

Apologies were received from Mrs Maggie Brooks, Mr Dominic Byrne, Prof Alan Emond, Ms Jenny Ford, Mr L Osobo, Mr Rob Martin, Dr John Madar and Dr Julia Verne.

It was noted that Dr Consolato Sergi, Consultant Paediatric Pathologist, St Michael's Hospital, has left his position and that Dr Margaret Evans, Consultant Perinatal Pathologist, would be pleased to attend future meetings in his place.

2.0 Register Report

2.1 Levels Of Notification

RT reported that notification levels still varied between hospitals. Cheltenham & Gloucester hospitals had a good record of sending warning cards and follow up data forms. However Royal Cornwall Hospital sent in a large number of warning cards with little follow up. This was an area AM was working to improve.

Following co-operation from IT departments across the region, the Register has received electronic downloads of confirmed cases from St Michael's, Taunton, Cheltenham, Gloucester, and Torbay hospitals. Data was expected shortly from Great Western Hospital, Swindon and Royal Devon & Exeter Hospital.

The Register was now concentrating on acquiring cytogenetic data and post mortem reports for 2002 cases. After this, validation of the 2002 data would begin and the first annual report would be published. RT was pleased with the Register's progress to date.

2.2 Improving Levels Of Notification

2.2.1 Feedback from Project Nurses

SS and AM presented their feedback to the Committee. (copies of slides are attached to these minutes).

The positive aspects of the hospital visits had raised awareness of the Register, eg, reporting of the incidence of particular conditions, their applications and who was notifying the Register from where. Despite this, the presentations had a varied attendance record, especially with paediatricians, and midwives due to their 12 hour shifts. It was noted often the same people, with an interest in the Register, would attend.

AM mentioned that a case controlled study entitled 'Recreational drug use; a major risk factor for gastroschisis' by Liz Draper was due to be published in April 2004. TO asked if he could be notified of the name of the journal in which the study would be published.

Action: AM

Antenatal reporting was generally good and the Central Delivery Suites were well organised in certain hospitals. Paediatric reporting was poor as was postnatal ward reporting where there was none, despite efforts by the project nurses. Unfortunately, Trust Co-ordinators were too busy to take on the role of co-ordinating notifications.

Collection of data retrospectively had proved time consuming and a continuation of gathering data in this manner would have staffing implications in the long term.

AM and SS emphasised the need to look into the removal of the large number of reported cases of positional talipes and 'cosmetic' hypospadias from the database. PF stressed particular caution with cases of positional talipes, which could not be diagnosed at less than six weeks old. It was thought prudent to record all cases at this stage and to screen them at a later date, possibly after one year. It was decided that the Executive Group should look into this matter further.

Action: EXEC GP

AM explained that she has been working with EDS to produce a detailed quote to enable staff in 10 hospitals to automatically print a version of the Register's data form from their STORK system following the delivery of a baby with a congenital anomaly. PF and TO were very enthusiastic about this and felt that the quote for £2275 was reasonable in order to cut down the workload on hospital staff. PF stressed it would be welcome on neonatal units where missing forms were a particular problem. **Action: AM**

The committee congratulated the two project nurses on their efforts to date.

2.2.2 Paediatric Notification Form

RT had designed a new Paediatric Notification Form to achieve improvement of notification rates from paediatricians by providing them with a shorter form to complete. TO asked if this form should be piloted and it was explained that the project nurses were currently doing this at the Royal United Hospital, Bath as well as the Royal Cornwall and Taunton hospitals. CK asked if it would be possible to notify committee members in advance of such pilots taking place as she had been approached about the pilot by a colleague at the Royal United Hospital, Bath and was unaware of its existence. This was agreed.

CK felt some resistance may be encountered surrounding issues with consent possibly in relation to information about family history but TO felt that paediatricians then had the option to leave that part of the form blank.

2.3 MREC

RT has made an application for MREC approval for the BINOCAR network of registers, including SWCAR, none of whom have ethics approval for data collection. This was required as some consultants have requested approval prior to allowing notifications to the Register. It was thought that approval would not be granted until May.

2.4 Pilot For Obtaining Consent

This was being undertaken as the Register must provide evidence to PIAG of the difficulties of obtaining consent. Antenatal and paediatric departments at Taunton had agreed to come on board to pilot consent. RT and TO would work on the details of the pilot and once this had been agreed it would be presented to Bath for their approval. **Action: RT & TO**

2.5 Wessex AnteNatally Detected Anomalies Register (WANDA)

For the benefit of some members present TO ran through the background to this matter, which had been ongoing for some time. He explained that he had more recently received an email from WANDA refusing to provide the Register with any data at all, despite having previously agreed to provide anonymised data.

PF thought that too much time and energy had already been wasted in dealing with this issue without success. He believed the best way forward was to contact Dr Diana Wellesey at WANDA acknowledging the difficulties they faced. Nonetheless, it should be re-emphasised that SWCAR has been commissioned by the SHA to collect data for Dorset and South Wiltshire and as this obligation could not be fulfilled the Register would need to inform them of this. WANDA would then be faced with either providing data to the Register or, alternatively, providing data directly to the SHA themselves.

RT was concerned that SWCAR would have to return some funding and that the matter would come to a standstill once again if Dr Diana Wellesey was not forced to act. RT agreed to make contact with the Head of Children's Services at the SHA to pave the way and TO agreed to assist.

Action: RT & TO

2.6 Postmortem Reports

This item was postponed until Dr Margaret Evans, Consultant Perinatal Pathologist, St Michael's Hospital would be available to comment.

RT raised a general point about the possible 'over coding' of both syndromes and their associated symptoms from post mortem reports. TO felt at this stage that both should be coded and excluded at a later date, if necessary. AM and SS offered to produce a list of conditions for the Executive Group to consider **Action: SS & AM**

2.7 Regional Specialist Commissioning

RT was very pleased to inform the committee that future funding for the Register had been included within the service level agreements with the PCT's and therefore funding would now be ongoing.

2.8 Annual General Meeting

General discussion took place about holding an Annual General Meeting, possibly in one year's time, to sell the first annual report to the Region.

It was decided to organise a planning group of committee members to consider matters such as date, time, location, cost implications, sponsorship (if appropriate) and a possible keynote speaker. An email will be sent to all members asking if they would like to participate in this group. **Action: RT**

2.9 Atrial Septal Defects Inclusion Criteria (ASD's)

AM raised the issue about removal of ASD's from the database. It was reiterated that all data should be included on the database and removed later, if necessary.

2.10 Study Session for next meeting

Dr John Madar, Derriford Hospital, had offered to present a study session at the next Steering Committee meeting in September. RT would check with him to see if that was still possible. **Action: RT**

3.0 Any Other Business

There was no other business.

4.0 Date Of Next Meeting

The next meeting will be held at Derriford Hospital, Plymouth on 24 September 2004 between 11 am – 1 pm with lunch provided. Further details of the meeting room location will be sent out nearer the time. A date for the following meeting would be sought from members by email. **Action: JC**