



## **Minutes of the SWCAR Steering Committee Meeting**

held on

Wednesday 1<sup>st</sup> March 2006

between 2.30 – 4.30 pm in

Tutorial Room 5, Level 4, UBHT Education Centre, Bristol.

### **Present:**

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

Ms Julie Chamberlain, Information Administrator, SWCAR

Ms Aileen McLoughlin, Co-ordinator, SWCAR

Ms Julie Mytton, Specialist Registrar in Public Health, Bristol South & West PCT

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 Mr D Bryne, Ms J Drury, Ms J Ford, Ms C Hammonds, Ms C King, Dr R Martin, Ms A Philips, Ms M Robson, Dr P Turnpenny and Ms J Verne.

### **2.0 Notifications**

#### **2.1 Levels of notification**

A spreadsheet (*SWCAR case status summary*) was tabled by AM showing the number of confirmed, probable and suspected cases from 2002 – 2005 together with the “usable” cases for each year. Data for 2005 was not yet complete as electronic downloads from Exeter and Swindon still had to arrive, hence the dip in numbers. However it was felt that overall 2005 figures would be lower than 2004 but reasons for that were not yet clear. Members were reassured that figures for the first three years were remarkably stable.

A second spreadsheet (*Notifications 2002 to 2005*) showed the number of notification types by booking hospital.

RT mentioned that post mortem notifications had dropped significantly since the closure of paediatric pathology at St Michael's Hospital and the subsequent transfer of post mortem examinations for the south west to Birmingham. TO confirmed that post mortems were not being encouraged at the present time as the turnaround time was too great and posed difficulties for parents wishing to bury their children. However, paediatric pathologists from Cardiff (Dr Gordan Vujanoc) and Birmingham (Dr Nikola Ostojic /Dr Tamas Marton, Consultant Perinatal Pathologist, Birmingham Womens Hospital) are now carrying out examinations each Saturday in the Bristol Royal Infirmary and it was possible these reports were written up in UBHT. RT agreed to try and pursue this further to try and obtain copies of these reports for the Register. Alison Headford, Senior Lab Technician at St Michaels (ext 2363) may be able to assist.

It would appear that there was a drop in electronic notifications between 2004 and 2005. AM clarified that this was not actually the case but following the first year of downloads, experience had suggested that not all cases should be uploaded and now staff had a clearer understanding of what should be used and what discounted.

AM explained that the SD56 notification forms, formerly sent direct to ONS, were now sent to SWCAR instead. The majority of these notifications were received from Child Health Departments linked to Royal Devon and Exeter and Royal Cornwall Hospitals. Very small numbers had been received from other areas. This highlighted the level of prior under-reporting to ONS.

JM noted that there had been a drop in paediatric notifications and AM explained that it was sometimes difficult and time consuming to motivate staff in neonatal areas as they changed on a regular basis.

## **2.2 New notifications**

The Lewis laboratory at Southmead Hospital had agreed to provide electronic downloads from the 1<sup>st</sup> March 2006 on all cases of inborn errors of metabolism and single gene disorders. It had been agreed that this would extend to include backdated cases when time allowed. Clinical genetics had also agreed to start reporting to SWCAR and to provide follow-up diagnoses when available.

## **3.0 Public Health/SWCAR Folic Acid Audit**

JM tabled a report (*Regional audit of folic acid data held on SWCAR*) on her preliminary Folic Acid Audit findings. The audit's aims were to examine the completeness and accuracy of the recording of folic acid use (pre-pregnancy and during early pregnancy) in recent registered cases of neural tube defects in the southwest region.

Bath cases could not be included as Bath approval has been gained from August 2005 only. All other audit forms were returned except 12 cases outstanding from Cornwall. AM plans to chase the remaining audit forms so that JM can finalise the audit data. AM will further investigate the remaining suspected NTDs to gain confirmation of diagnosis. Parity needed to be incorporated to make sense of the data on past history of NTDs.

JM noted that the recording of details such as dosage and gestation at commencement of Folic Acid use was poor in the audit cases. PF felt the audit findings would be enhanced by the incorporation of controls. If two control cases for each NTD case were checked this would allow verification or otherwise of the recording of Folic Acid use in the general pregnant population. AM was unsure that the unit contacts used for the audit would have the time/inclination for this additional work. RT suggested we considered the possibility of employing someone for this task. Another possibility would be to focus only on STORK records for control cases or including controls only for local units so that AM could do the work more easily herself. JM, AM and RT agreed to consider this more closely and decide on a way forward.

JM felt the data may not be robust enough to draw strong conclusions but needs to look more closely at the data. JM and AM to liaise over the next steps for the audit data.

RT suggested that the audit could be published as an abstract for the BINOCAR Scientific Meeting in September.

TO enquired whether future collaboration between Public Health and SWCAR would be likely. He stressed how valuable this would be for SWCAR and the use of SWCAR data. JM explained that, although there are a steady stream of Public Health trainees, their training needs are very closely defined. SWCAR projects may not exactly fit the training criteria and priorities thus presenting a possible obstacle to collaboration. JM stressed that an interest in the register and potential for small scale projects existed. SWCAR should feel able to suggest areas of collaboration in the future but she could not guarantee the department would be able to respond. AM enquired whether the area of congenital anomaly surveillance might be an overlap of interest/focus. JM stressed that Public Health priorities were heavily influenced by government White Paper and if work did not fall in these areas funding was very unlikely to follow. She felt funding unlikely for such surveillance work.

JM was thanked for her work to date and then left the meeting.

## **4.0 Connecting for Health**

### **4.1 IT Developments in south west: implications for SWCAR**

NHS Southern Cluster and Fujitsu have signed a contract for the new maternity module as part of the new NHS IT implementation around the southwest. The new software, Cerner Millennium, was developed from an old existing London hospitals package and would replace the current Stork maternity package. The first release is an "off the shelf" software package that cannot be adapted for additional requirements.

SWCAR staff currently have remote access to Stork and are able to retrieve dataforms for the majority of the hospitals in the south west. However, AM explained, that despite tremendous efforts on her part, the first release of the new Cerner system would not cater for SWCAR's needs and as a result this could seriously affect the quantity and quality of data which could be obtained by the Register.

On a brighter note, the first response from Taunton and South Devon hospitals, initially due to swap packages in May 2006, was that they were very unsatisfied with the new maternity package as it stood. They had decided to extend their Stork contracts with EDS until the next Cerner release (April 2007/8) was able to make changes to meet their current needs. Best Practice Groups will make recommendations for necessary changes.

In response to a letter from PF and TO, Fujitsu have sent SWCAR a Requirement Request Form. AM has returned this to Southern Cluster with very specific details of SWCAR requirements. AM used this opportunity to stress the advantage of electronic reporting with the facility for the clinician to complete a short paper-based form providing more detail on the nature of the anomaly.

AM will keep in close contact with Glyn Brace, Royal Devon & Exeter who is on the Best Practice Group. Glyn has requested that all the register covering the Southern Cluster agree on a common set of requests. TO suggested it may be useful to find out how CAROBB and WESSEX registers were planning to deal with this. AM agreed to investigate further.

## **5.0 Responding to Data Request**

### **5.1 Senior Dental Officer, Somerset**

A request had been received from a senior dental officer in Somerset for access to register data. AM had consulted PIAG who clearly stated that SWCAR would be unable to provide this data even if ethical approval were granted as Section 60 only allows for data to be feed back to those clinicians who already have a relationship with the client. It was pointed out that this data may still be provided via an alternative route, eg, via local paediatricians. The dental officer could then seek approval from their local Caldicott guardians for use of this internal data. AM to feed back these findings to the Senior Dental Officer.

## **6.0 Reporting**

### **6.1 Future Reporting of SWCAR data**

AM asked for more guidance on what type of statistics would be of use and of interest to clinicians. She tabled three separate documents focusing on gastroschisis, renal agenesis (all), and Down's syndrome (see attached). Figures were provided on when first suspected, outcome, maternal age and association with other anomalies.

PF & TO were impressed with how the data was presented and felt that with the addition of information on specific rates the figures would prove very useful. It was again reassuring to see that figures were consistent over the years. AM asked what top five conditions she should focus her attention on. TO confirmed that there still was a high level of interest in Down's figures particularly at the present time with PCT's refusing to pay for dating scans. Abdominal wall defects were topical and of the moment.

PF suggested it was important to identify clinicians with particular interests and provide data to them. TO agreed to meet with AM and work out who to send the data to.

## **7.0 Patient Information Advisory Group (PIAG) Support**

AM highlighted that Section 60 approval for the Register was due to expire in June 2006. However, this was not of immediate concern as an extension was currently being sought via BINOCAR (The British Isles Network of Congenital Anomaly Registers) for all registers via the Chair Person, Liz Draper.

## 8.0 Register priorities

### 8.1 Surveillance

AM stressed that surveillance should be a key aim of the Register and that current surveillance through ONS was quite a slow process.

General discussion took place about the importance of feeding back data to those paediatricians with an interest in particular anomalies. It was felt this data would be well received by paediatricians if presented in an attractive, simplified format and that it must be relevant to each of them. They would then be able to spot if a rare condition was occurring more frequently than expected. For example, surgeons would be interested in receiving data on abdominal wall defects.

RT suggested that AM could consider GIS Training as a start towards achieving the above aims.

### 8.2 Use of SWCAR data

RT was pleased to report that on a national level several requests for use of SWCAR data had been received. These requests were from:-

**FOCAL** (Follow-up Of Congenital Abnormalities Longterm), a body funded by the Birth Defects Foundation, who are currently seeking ethics approval for a study following up on babies at 2 years of age born in 2004 with diaphragmatic hernias.

**EUROSERCAN** Claude Stoll, Service de Genetique Medicale, Faculty of Medicine, Strasbourg (EUROCAT Member) hopes to gain funding to look at the effectiveness of prenatal screening in cases of Trisomy 13, 18 and 21. If successful they will be requesting anonymised trisomy data from local registers.

**NATIONAL SCREENING COMMITTEE** who had requested data for two separate studies on ultrasound soft markers and neural tube defects.

**CARIS-ANOMALY REGISTER FOR WALES** had Welsh MREC approval to interview 20 mothers with babies born with gastroschisis. It was hoped this study would also be expanded to incorporate England as well.

### 8.3 EUROCAT

AM raised the issue of whether it was worthwhile for SWCAR to make an application for membership of EUROCAT (EU epidemiologic surveillance of congenital anomalies). The basis of EUROCAT was to provide essential epidemiologic information on congenital anomalies in Europe. However, AM stressed that in order for the Register to report its data effectively it would involve considerable time and resources to be made available, particularly with regard to IT input.

Members were initially enthusiastic at sharing data with EUROCAT. PF felt detailed costings should be obtained and that it was essential to know at the outset what the Register would gain from membership. AM agreed to look at this matter in more detail and to contact other anomaly registers who currently submit data to EUROCAT.

## **9.0 BINOCAR Scientific Meeting and AGM - 28<sup>th</sup> - 29<sup>th</sup> September 2006**

RT explained that she was hosting the next BINOCAR scientific meeting in Bristol at the Clifton Pavilion, Bristol Zoo on 28<sup>th</sup> and 29<sup>th</sup> September. A meeting of BINOCAR members would be held on the afternoon of the first day followed by a formal dinner in the early evening.

Professor Kypros Nicolaides, Fetal Medicine, King's College Hospital and Professor Martin Whittle, Fetal Medicine, Birmingham Women's Hospital, would be the main speakers on the second day. Our Chairman, Professor Peter Fleming, Infant Health & Developmental Physiology would also be speaking on "Sudden Death and the Undiagnosed Anomaly". RT had planned to invite other speakers to talk on cardiac anomalies and/or inborn errors of metabolism. Professor Jean Golding, Paediatric and Perinatal Epidemiology, Bristol University would give the closing speech to round off the day.

The full programme would be finalised over the next couple of weeks.

## **10.0 Any Other Business**

PF informed the meeting of the SIDS International Conference to be held in Bath from 24<sup>th</sup> to 27<sup>th</sup> June 2008

## **11.0 Date of Next Meeting**

The next meeting will be held at 2.00 pm on Wednesday 6<sup>th</sup> September 2006 in the UBHT Education Centre, Upper Maudlin Street, Bristol.