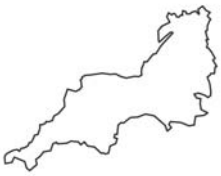
South West



Congenital Anomaly Register

# Minutes of the SWCAR Steering Committee Meeting

held on
Wednesday 29th June 2005
between 2 – 4 pm in
Tutorial Room 3, Level 4, UBHT Education Centre, Bristol.

**Present:**

Prof Peter Fleming (Chair), Infant Health & Developmental Physiology, Bristol University
Ms Lynne Appleby, Antenatal Co-ordinator, Government Office, South West
Ms Julie Chamberlain, Information Administrator, SWCAR
Mr Ed Cross, Information Assistant, SWCAR
Ms Cath King, Genetics Counsellor, Royal United Hospital, Bath
Ms Aileen McLoughlin, Co-ordinator, SWCAR
Mr Tim Overton, Consultant in Fetal Medicine, St Michael's Hospital
Ms Alison Philips, Advanced Ultrasound Practitioner, Torbay Hospital
Mrs Rosie Thompson, Project Manager, SWCAR
Dr Peter Turnpenny, Clinical Geneticist, Royal Devon & Exeter Hospital
Dr Julia Verne, Director, South West Public Health Observatory
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, Ms A Knight, Dr J Madar, Dr R Martin, Ms A Philips, Ms M Robson, Mr S Savage

Lynne Appleby informed the meeting that she was the Antenatal Co-ordinator for the South West. She works for the Regional Public Health Group, Government Office, South West who offer advice to strategic health authorities, primary care trusts and trusts on public health issues and aim to quality assure antenatal and child health screening programmes in the region.

## 2.0 SWCAR Website

A flyer had been produced for distribution to advertise the new SWCAR website which was due to go live shortly. TO congratulated AM for her work on the website as a great step forward which would increase credibility and improve enthusiasm to report to the Register.

Data would be published on the website for the whole region, by strategic health authority and by individual hospital. Access to regional and strategic health authority data would be open to anyone but the hospital data would be password protected with the hospitals being identified by letters known only to hospitals themselves. The initial data on the website would be basic with numbers and rates per 10,000 registered births.

The website was a useful tool for providing access to information and data to those who contribute around the region. There were however issues surrounding the use of the website for directly reporting to the register. Identifiable information would need a secure website area to ensure data security. Rapid reporting of minimal data via the website may be worth exploring in the future but is not an option at present.

## 3.0 Reporting of Data

### 3.1 Sample reporting methods from other Registers

AM talked through the printouts that had been distributed. These included a summary of the types of analysis of data published by other registers and samples of publications from the following registers:

CARIS – Congenital Anomaly Register and Information Service, Wales
Northern
Merseyside
Office for National Statistics (ONS)
Michigan Registry
NW Thames
Trent

Typical breakdowns of data included: by year of birth; by birth outcome; by sex; by multiplicity; by gestation; by hospital of birth; by maternal age/race (see attached list).

Some registers had also looked at factors such as mortality at different ages for given anomalies; analysis of when anomaly types were diagnosed and focuses on specific conditions. Different rates were also calculated giving total prevalence, prevalence at birth and livebirth prevalence for example (see list).

Copies of SWCAR regional data and sample data for one SWCAR strategic health authority were provided as printouts for the Committee. All data was now available on the website for viewings.

Some problems had been encountered in the preparation of the data. It had not been straightforward obtaining livebirth/stillbirth rates but satisfactory figures had been arrived at for these. However SWCAR has not been able to gain agreement to obtain rates of termination and spontaneous abortion figures for several trusts. In order to publish various anomaly rates in the future this would need to be resolved.

PT asked whether terminations were not well recorded. AM informed the meeting that the trusts either do not record the data in an easily retrievable form or felt that the information was not accurately entered and would not want to rely on the statistics available. This particularly applied to reason for termination, eg, TOP for fetal abnormality. Some trusts were unable to breakdown termination figures by gestation.

It was agreed that the information was recorded somewhere as all terminations are notified. Further work would need to be undertaken to find a reliable source. ONS figures could be used for the Region but breakdown by hospital would need further investigation.

AM reported that SWCAR had to decide how to deal with the issue of non-reporting hospitals and the effect this had on numbers/rates of anomalies. Inclusion of non-reporting areas resulted in distortion of anomaly rates. It was therefore decided to remove all anomalies/births for Wessex, Salisbury and Bath. This affected regional data and data for Avon, Gloucestershire & Wiltshire and Dorset & Somerset.

SWCAR rates are consistently about two thirds of CARIS rates. Comparison is difficult at this early stage. Possible reasons include a real variation in anomaly rates or under reporting to SWCAR. It is generally agreed that it take 5 years for a register to become established so we would not expect to have full reporting in our first 2 years.

**3.2 Future Reporting of SWCAR data**

PF felt it more useful for committee members to consider the sample publications at their leisure and report back to SWCAR with any ideas they had on presentation of the data.

TO felt it was important that individual hospitals could see how they were performing and that the Register should not be over ambitious but initially should present data in a simple format. He felt that further feedback may be received once the website was up and running.

JV thought it important to display ONS rates in addition and to be aware of public interest from the media once the site goes live.

JV also mentioned that a colleague had been worried by “alerts” received from ONS and RT suggested she contact SWCAR for background advice.

PT enquired about how the anomaly numbers and rates were recorded. AM explained that the anomaly group data counts CASES for each anomaly group, eg, a baby with a kidney defect and a heart defect would appear in each group but only once in the Total Cases. A baby with two heart defects would appear in each subgroup but only once in heart anomalies total.

The Body System data counted ANOMALIES so babies with more than one defect are counted multiple times. This was based on ICD-10 Body Systems. These differed from the EUROCAT based anomaly groups so cannot be directly compared.

Questions were raised about genetic disorders and whether all associated anomalies were recorded or whether they were removed when a syndrome was diagnosed. AM explained that SWCAR follows the current register convention of recording syndromes and all associated anomalies but it was possible to extract the data “according to the question” if specific information was needed.

LA felt that feedback to ultrasonographers would be of great value especially in identifying conditions not diagnosed antenatally.

PF suggested that links from common anomalies to more detailed data would be very useful. This could include what other associated anomalies are found and what proportion are diagnosed antenatally, for example. Paediatricians and geneticists would be interested in the incidence of associated anomalies for a given condition.

## 4.0 Notifications

### 4.1 Levels of notification

A document was distributed to the Committee showing separate spreadsheets on the number of notifications received in 2004 and the number of confirmed and probable anomalies notified to the Register for each year since 2002. These were both allocated by booking hospital.

The large differences noted between suspected and confirmed cases had two main causes; poor follow up on antenatally reported cases and over-reporting of minor anomalies from IT departments. Some downloads had included large numbers of cases of infection, hypotonia and skin anomalies which could not be assumed as accurate. SWCAR had less experience of dealing with IT reporting in 2002/3. We now include fewer of these cases. However further tightening up would be required to avoid problems.

The Register was currently experiencing difficulties obtaining copies of port mortem reports since work at the pathology department in St Michael's hospital had ceased. Letters had been written to pathology departments in Birmingham, Cardiff and Southampton requesting copies of reports but none had been received to date. Further work would need to be done in this area.

JV suggested it would be useful to provide information on notification levels to trusts for internal use/publication and include rates for completeness to show how good the quality of data was. It was agreed that this was something which could be considered for the website in future.

### 4.2 New notifications

SWCAR was continuing to forge links with the Clinical Genetics department and Maggie Williams at Southmead for reporting of in born errors of metabolism and would continue to explore new areas of reporting.

No notifications of cases of inborn errors of metabolisms, sickle cell anaemia, thalassaemia, or haemoglobinopathies were currently being received. LA agreed to take this on as SWCAR should be able to access this data via the National Screening Programmes.

Further consideration may need to be taken by the Steering Committee/Executive Group as to whether traits should be included on the Register.

## 5.0 Use of SWCAR data

In a second meeting with Viv Harrison in the Public Health Department, TO confirmed their interest in a different proposal to use SWCAR data to look at the effect of taking folic acid supplements in pregnancy on the development of neural tube defects. PF asked if this data was entered on the database and AM confirmed it was collected but "when" the supplements were taken was not and more detailed follow up would be needed to retrieve this information from hospital notes.

AM mentioned it would be very useful indeed to have a member of staff with research skills at the Register able to work on such data without the need for ethics approval and JV suggested this could be done with an honorary contract.

PT expressed an interest in data on the maternal use of epilepsy medication. Unfortunately, as SWCAR only collect data on cases resulting in anomalies all other cases are missing so would not be of use for his purposes but JV explained that data on the general use of epilepsy medication may be available from HES data.

Discussion took place about alcohol as a risk factor and it was explained that only "alcohol abuse" was recorded on the database. JV expressed an interest in this data in relation to Fetal Alcohol Syndrome and PT suggested an alternative source.

TO suggested it may be possible to approach COREC and make an application more generic to allow the pursuit of a number of different studies on the SWCAR data and PF felt that this was possible although the application would need to be broad and specific at the same time.

## 6.0 Any Other Business

PT asked how the funding situation was at present and RT emphasised that funding was very tight with the annual allowance from the south west PCT's plus 3% for inflation paid via the UBHT service agreement.

AM explained that SWCAR had recently been reviewing the storage and security of the SWCAR database and back up procedures with the aim of making the database as secure as possible. A meeting was planned for Tuesday 5th July with the University to review the current practice and discussions were also taking place with UBHT to explore the possibility of transferring to the UBHT intranet. The Steering Committee would be kept informed of any developments.

JV suggested it would be worthwhile talking to Tarik Malik and Jill Christmas, Head of IT, Cancer Intelligence Unit who may be able to provide useful advice.

## 7.0 Date of Next Meeting

The next meeting will be held at 2.30 pm on Wednesday 1st March 2006 in Bristol.