



Minutes of the SWCAR Steering Committee Meeting
held on
Thursday 18th July
between 12.00 – 2.00 pm in
The Geoffrey Dixon Seminar Room, St. Michael's Hospital, Bristol

Present:

Prof Peter Fleming (Chair), Infant Health & Developmental Physiology, SWCAR
Julie Chamberlain, Information Administrator, SWCAR
Dr Jonathan Davis, Consultant Neonatologist, St Michael's Hospital
Jenny Ford, Midwifery Matron, St Michael's Hospital
Jaspal Kang, Information Assistant, SWCAR
Dr Emma Kivuva, Consultant Clinical Geneticist, Royal Devon & Exeter Hospital
Beverley Lovering, Midwife Sonographer, Southmead Hospital
Dr Julie Mytton, Associate Prof in Child Health, UWE
Mr Tim Overton, Consultant in Fetal Medicine, St Michael's Hospital
Alison Phillips, Ultrasonographer Advanced Practitioner, Torbay Hospital
Dr Germaine Pierre, Paediatric Metabolic Consultant, St. Michael's Hospital
Sylvia Stoianova, Project Manager, SWCAR
Ben Wreyford, Information Administrator, SWCAR

1.0 Apologies

Apologies were received from Maggie Brooks, Dr Rob Martin, Steve Savage and Dr Sarah Smithson.

2.0 Overview of SWCAR work and introduction of new members of the team

For the benefit of new members present, PF provided an overview of the work of the Register, originally set up in 2002. He explained the reasons for the collection of data to record information on incidence and clusters of congenital anomalies, patterns of change and the implications for NHS service provision. He described the area of overlap of our region with the Wessex congenital anomaly register and how that had created ongoing difficulties obtaining notifications.

SWCAR was different from other registers in that it remained permanently open to receive information on anomalies diagnosed up to a child's 18th birthday. PF felt it may even be worth considering removing this cut off point in the future and leaving the Register open for life.

3.0 Public Health England and congenital anomalies registers update

PF advised members that Public Health England (PHE) had taken over responsibility for funding all English congenital anomaly registers from 1 April 2013. In the year prior to the changeover, SWCAR had received a much needed increase in funding from Specialist Commissioning and PHE had agreed to match this level of funding for the financial year 2013/2014.

PHE planned to expand the number of congenital anomaly registers into areas of the country not currently covered and were considering the best way to do this. All registers have very different systems of operation and it has been suggested to them they should not impose a uniform nationalised system of reporting but continue with the systems currently in place which were working well. Any changes made to these systems could have disastrous consequences as the success of these registers relied on the local nature of reporting.

JM asked if a standard dataset was collected across all registers and PF explained that every register had agreed to provide a minimum dataset for each case to the British Isles Network of Congenital Anomaly Registers (BINOCAR).

PF explained that PHE wished to take over direct responsibility for running the Register from the University but he was unclear whether this would happen in the next financial year or not. He felt this was unlikely as physically resiting the register and its equipment would have financial implications for PHE at a time when resources were tight. PF said he would strongly resist any such change and had previously been in contact with Prof John Newton, Chief Knowledge Officer, PHE, concerning the matter. One issue of concern was the ability for PHE to access data from the NHS and to hold identifiable data within its new structure.

BW was asked to describe to the new members present how the notification system worked within the Register. He explained how and where notifications were sent from, how this information was interpreted and input to the database and the process of follow-up which occurred to ensure the accuracy of the diagnoses provided.

PF and SS were due to meet with Christine Harvey, Interim National Congenital Anomaly Registry Programme Manager, PHE, on 6st August 2013 where it was hoped more information would be forthcoming.

Action: PF and SS

JM asked if SWCAR had made contact with the local PHE teams and offered to provide SS with further details. SS explained her current contact was Magda Szapiel, Public Health Intelligence Specialist, PHE, who provided ONS Vital Statistics Data for calculation of denominator data. JM suggested it may be beneficial to go directly to the Primary Care Support Agency for this data.

Action: JM

GP asked if the Register still wished to receive notifications of non-dysmorphic metabolic conditions and agreed to notify cases to the Register.

Action: GP

PF drew the attention of members to the SWCAR website where anonymised data was available to the public for the SW region and password protected hospital data was available to health professionals. Numbers of cases less than 5 had been suppressed.

JM asked if SWCAR had linked in with other systems and PF said this had not yet been done as it had proved quite tricky to get the relevant permissions to interact together. However, with 10 years worth of data and the appointment of SS to her new role, this was something which was being considered for the future. JM hoped that the new NHS structure would be more transparent about data sharing.

PF explained he was leaving his role as Chair of SWCAR from 1 August 2013 and handing over the reins to JD who would take over as Clinical Lead. Dr Karen Luyt, Consultant Neonatologist, St. Michael's Hospital, would be taking over PF university commitments for the Register. PF felt it was an exciting time of change for JD to be joining.

4.0 EUROCAT funding and support

SS explained the Register had strong links with EUROCAT (European Surveillance of Congenital Anomalies) and the team often flags up coding issues which triggers discussion and subsequent decision making on a European level. SS attended the annual conference in Zagreb.

EUROCAT is in the process of compiling a questionnaire which will be sent out in October. SS may ask clinical members of the committee if they would like to participate.

Action: SS

SS complimented her team on their hard work.

5.0 Future SWCAR plans and priorities

SS explained that the main priority for the team at the moment was to meet the mid-October deadline to provide data on anomalies for all pregnancies ending in 2012 to EUROCAT, for European surveillance purposes as well as to BINOCAR.

To raise the profile of the Register and improve communications between health professionals, SS had compiled a list of current notifiers with a view to expanding this list to include other specialties, such as dermatology. An updated information leaflet was being produced and SS asked the committee if they would look over the text prior to distribution. EK asked if it would be possible to add a section about the legislation in place to collect confidential data as she had found this an issue when asking professionals to notify the Register, in particular asking clinical geneticists to report.

SS explained that it was likely any previous issues about the North Wiltshire overlap with the Wessex Register has now been resolved as North Wiltshire is part of the Wiltshire CCG.

6.0 Any Other Business

TO felt that he had not been able to give as much time to the Register as he would have liked and wondered if it would be helpful if someone else took on the role of Clinical Lead. PF felt it was really important to have active obstetric input but with JD taking on the role as Clinical Lead it would not be necessary to be as involved as much. TO felt happy to continue helping with obstetric and fetal medicine queries and will continue to be involved with the Steering Committee.

JM informed the committee of the potential for disruption to data flows across the city (e.g. following the NHS Reforms and major service changes such as the centralisation of specialist paediatric services).

Local authority Joint Strategic Needs Assessment (JSNA). Every Clinical Commissioning Group (CCG) will have a Health and Well Being Board. It is useful for these boards to include localized data for the Bristol area on congenital anomalies to increase the profile of children. JM would provide contact details for the boards. JM did note that this data was outside the interest of PHE and could be compiled into five year rolling averages to overcome the issues with small numbers and it would be interesting to look at changes in demography and the numbers of congenital anomalies.

Having now changed her role, JM asked if the Register would like a local public health representative to sit on the committee instead of her. She suggested Dr Jo Williams, Consultant in Child Public Health, may be a good person to approach. JM and SS would liaise over this.

Action: SS and JM

EK explained that she recently attended a SW Maternity Strategic Clinical Network meeting on Maternity and Children's care and wondered whether a representative from SWCAR should attend the meetings. After some discussion it was felt that this may not be particularly useful to SWCAR as the main purpose of the network was to look at clinical pathways.

AP asked if it was possible to complete notifications electronically and send them via nhs.net as more people had access to this secure form of email. SS agreed that this was a good idea for those who were not keen on notifying via the post and would develop a form which was easy to complete.

Action: SS

7.0 Date of Next Meeting

PF suggested a Doodle poll to determine the most popular dates for the next meeting, possibly sometime towards the end of November, beginning of December 2013. JC will contact JD for a selection of dates before contacting members.

Action: JC