



Minutes of the SWCAR Steering Committee Meeting

held on
Tuesday 4th February at 1 pm
in
The Obstetric & Gynaecology Meeting Room,
St. Michael's Hospital, Bristol

Present:

Dr Jonathan Davis (Chair), Consultant Neonatologist, SWCAR
Julie Chamberlain, Information Administrator, SWCAR
Cath King, Genetic Nurse Counsellor, Royal United Hospital, Bath
Beverley Lovering, Midwife Sonographer, Southmead Hospital
Dr Karen Luyt, Consultant Neonatologist, SWCAR
Rosalie Morgan, Information Administrator, SWCAR
Alison Phillips, Ultrasonographer Advanced Practitioner, Torbay Hospital
Dr Shavanthi Rajatileka, Information Assistant, SWCAR
Ben Wreyford, Data Manager, SWCAR

1.0 Apologies

Apologies were received from Maggie Brooks, Dr Emma Kivuva, Dr Jo Williams, Dr Julie Mytton, Dr Germaine Pierre and Dr Sarah Smithson.

Dr Jonathan Davis introduced himself as the new Chair of the SWCAR Steering Committee taking over the role from Dr Peter Fleming. He explained that Peter's role had been split into two with himself having responsibility as the Clinical Lead and Dr Karen Luyt as the Academic Lead for the project.

2.0 Minutes of last meeting

The minutes of the last meeting were agreed.

3.0 Public Health England and congenital anomalies registers update

BW gave a progress report on the negotiation of the Service Level Agreement between SWCAR and Public Health England (PHE), following the move by PHE to fund all English congenital anomaly registers from 1 April 2013. The member registers of the British Isles Network of Congenital Anomaly Registers (BINOCAR) are collectively following the lead of CAROBB (based at National Perinatal Epidemiology Unit of Oxford University), where staff are in the final stages of negotiation. An SLA consistent across registers will be ready shortly.

BW recently attended a meeting in Cambridge between cancer registry staff, already part of PHE, and anomaly register staff, where PHE's plans were outlined for a national anomaly register, based on the national cancer registries model. Over the last 10 years the cancer registries have successfully moved from a paper-based to a mainly electronic notification system using a national database. The functionality of the cancer database was demonstrated and some interesting points were raised which highlighted that both types of register have faced some similar issues. However, there were also some significant differences (see next para), and these were to be discussed in the coming weeks. Also, greater and centralised funding and a higher profile for cancer had enabled the cancer registries to achieve most of their aims. BINOCAR have already achieved standardisation of datasets and definitions, a national Hub to collate data from regional registers and some standard operating procedures. PHE felt it would be able to assist in modernising notification systems, arranging data sharing agreements and dealing with Information Governance issues.

PHE were keen to map the cancer registry process to a national congenital anomaly system. Register staff at the meeting raised concerns over the appropriateness of this mapping, as it was felt the two systems were not directly comparable. For example, anomaly registers record details of two patients, a mother and baby, rather than individual patients diagnosed with a cancer. Cancer registries focused on using patient NHS number but anomaly registers collect data on terminations and fetal losses which are not assigned NHS numbers. KL explained that cancer diagnoses were time driven and PHE had achieved 100% ascertainment by linking with the single care pathway for cancers involving Multi-Disciplinary Teams, whereas anomaly register work involves multiple notifications and information sources and a comparable single pathway does not exist.

Jem Rashbass, National Director for Disease Registration, PHE, was present at the Cambridge meeting. He explained that in a previous role he had been brought in to modernise and update one of the regional cancer registries. The changes were successful and the model was adopted by all cancer registries across the country. He was keen to bring the benefits of his experience to congenital anomaly registration.

PHE have a tight timescale and aim to implement the national database and achieve national geographical coverage by anomaly registers for mid-2015. At present existing registers cover about half the population of England.

BINOCAR register leads were not invited to the Cambridge meeting but were due to meet separately with PHE on 20th Feb 2014, where PHE would outline their vision for national congenital anomaly registration processes and database functionality. KL was confident that the BINOCAR Chair, Liz Draper, would represent regional register interests and viewpoints well, and that PHE would come to recognise the need to incorporate the valuable experience and knowledge of all register staff for the new system to be effective.

BW explained that denominator data had now been requested from PHE following Julie Mytton's information at the previous SWCAR meeting that it was no longer available from Bristol PCT.

4.0 EUROCAT funding and support

EUROCAT is an established European network of population-based congenital anomaly registers, and is important to SWCAR and other BINOCAR registers. SWCAR supplies anonymised data to EUROCAT at regular intervals and BINOCAR's operating procedures are intentionally consistent with EUROCAT's. The EUROCAT database performs a surveillance function.

EUROCAT has a shortfall of funding for 2014 and BINOCAR had asked PHE to contribute funding. This proved unavailable so BINOCAR had asked each register to contribute £3000 each towards keeping EUROCAT operational during this time. As this was a one-off payment, KL felt this was not an issue worth opposing as funding for EUROCAT had been re-established from 2015 onwards.

5.0 SWCAR developments and priorities

Two new members of staff were introduced to the committee; Dr Shavanthi Rajatileka, who was temporarily helping out with data entry and validation work for a three month period, and Rosalie Morgan who was covering for BW's post for 10 months whilst he was acting Project Manager during Sylvia's absence.

The EUROCAT/BINOCAR mid-Oct data submission deadline had been met.

A new information leaflet/flyer had been produced and circulated to current and potential notifiers. Following previous suggestions from Emma Kivuva, it now contained information on the legal framework supporting SWCAR's collection of data without explicit consent. It was hoped this would encourage individuals to be more willing to notify and to raise the profile of the register. BW planned to give a presentation in early May to the Clinical Genetics Team in Exeter to raise SWCAR's profile with them, and outline SWCAR's approach to Information Governance and consent issues.

Action: BW

JD asked if the paediatric trainees in the United Bristol Healthcare Trust got any training about SWCAR. He wondered if the register profile could be raised at the SW Neonatal Forum or the Bristol Children's Hospital Grand Round. AP suggested it may be useful to present to the Fetal Medicine Regional Network meeting in Royal Devon and Exeter Hospital and KL thought that would be opportunity for Tim Overton to present the new leaflets to keep the profile raised. JD thought it useful to look at every potential educational meeting available in all SW hospitals.

Action: BW

KL felt it would be beneficial to send the BINOCAR annual report out to all contacts, especially Heads of Midwifery and Paediatrics.

Action: BW

JD thought it would be good to have a specific day and ask people to present. BW explained that BINOCAR have an AGM and Scientific Meeting every two years, hosted by individual registers. It was agreed that conference information should be forwarded to someone in each Trust.

Action: BW

The new SWCAR notification form was now available as a PDF document on the SWCAR website. This could be completed electronically, saved and securely sent by NHSmail or printed and sent by regular post. The longer term aim was to provide a secure web-based form where notifiers could submit case information to SWCAR directly.

As one of our notifiers, BL pointed out the tick boxes in the risk factor sections were a little close together making it difficult to determine which box referred to which option. KL was keen to ensure that notifiers realised the PDF form could be completed electronically as not all PDF forms have that facility.

The SWCAR team was currently working hard to meet the next data submission deadline for EUROCAT/BINOCAR on 15th February 2014. Shortly afterwards work would begin on updating the website data.

An IT contractor was currently redesigning the database to make it more efficient to input and extract data, change the functionality and allow the team to make modifications themselves. This has taken longer than anticipated but it was hoped to be finished by the end of February 2014.

Data had been requested by KL on cases of spina bifida and birth outcome. Anecdotally KL felt she was seeing more live born babies with spina bifida in the neonatal unit and wanted to find out if there was a real increase in numbers. If this proved to be the case, it was important to know to enable planning of neonatal cots. CK agreed that, anecdotally, she felt more mothers were considering continuing with pregnancies when given an antenatal diagnosis.

Two further data requests had been received. A PhD student had requested data on neural tube defects, ethnicity and folic acid, via BINOCAR. Judith Rankin from NorCAS, the northern congenital anomaly register, had requested data from BINOCAR registers on arthrogyriposis to investigate a possible link with the Schmallenberg virus. JD was interested to know if any cases of congenital infection were recorded on the SWCAR database and BW confirmed that congenital toxoplasmosis, congenital cytomegalovirus and congenital rubella were collected.

Staff time would be allocated to improving the quality, completeness and consistency of data, especially the EUROCAT and BINOCAR core variables, over a two week period. Between 2008 and 2011 a full dataset was not collected and there were gaps in data fields which now need to be filled. This time would also provide an opportunity to create more validation queries and look more closely at the EUROCAT and BINOCAR Data Quality Indicators against which performance is measured. Also, time allowing, to move towards providing some of the non-core variables to BINOCAR/EUROCAT.

Completion of the IG Toolkit was due by the end of March 2014. All documents, policies, permissions and agreements were currently being collated in one place by BW together with records of training, data transfers, secure physical storage needs and IT security policies. The current SWCAR Code of Practice would also be updated as part of this exercise, and signed off by JD and KL. KL explained that if SWCAR had been embedded within an NHS Trust this would be taken care of directly by the NHS.

However as SWCAR is a university project based within an NHS hospital it was responsible for providing all the documentation itself. Although this was a self-assessment exercise, it was hoped the register could attain Level 2 (out of a possible 3) on this first attempt. Guidance was provided on how to make improvements in the future to attain a Level 3 rating.

Action: BW

BW explained he was attending a BINOCAR Training Day with his team on 5th February 2014 to agree on further standard operating policies across the registers. He had hoped to get a better indication of the new early screening variables which all registers had agreed to collect before deciding how best to acquire this biochemistry data from the SW hospitals.

6.0 Any Other Business

KL was very keen that the University of Bristol were kept updated with any research papers published using data from SWCAR, whether as direct authors or as co-authors. The University was particularly keen to highlight news issues on their website showing causative links and this could raise the profile of the register.

Action: BW

KL wondered whether it was worth exploring the possibility of using video or teleconferencing facilities to see if this would benefit committee members who have to travel some distance to attend the meeting in Bristol. St Michael's Hospital had a room with such facilities and the University of Bristol had a conference room at 69, St Michael's Hill which may prove useful.

Action: JC

7.0 Date of Next Meeting

The next meeting would be held in mid-September. As previously, a doodle poll will be sent out to members with a number of possible dates.

Action: JC