MINUTES

CARDRISS Expert Advisory Group

Date: Thursday 26th March

Venue: via Teams

Time: 2pm-4pm

Attendees: Judith Rankin (JR) – Chair, Rachael Wood (RW), Jonathan Berg (JB), Stephen Bush (SB), Isobel Clegg (IC), Eddie Doyle (ED), Natalie Frankish (NF), Lyndsey Hunter (LHr) Lyn Hutchison (LHn), Vivien Jayne (VJ), Margaret Macleod (MM), Karen McIntosh (KM), Zosia Miedzybrodska (ZM), Carol Anne Redpath (CR), Bruce Rennie (BR), Martina Rodie (MR), Sarah Stevens (SS), David Tucker (DT) and Gregor Walker (GW)

Apologies: Jenny Kurinczuk, John Fegan, Janet Brennand and Lorna Watson

Item

1. Welcome and introductions

JR welcomed everyone to the first meeting of the EAG and invited all attendees to introduce themselves. Due to the COVID-19 situation the meeting was changed from an in person meeting (as initially planned) to teleconference-only.

2. Establishing a Congenital Anomalies Register for Scotland

RW gave a presentation to outline the history of CARDRISS, the proposed initial set up, progress to date and the future plans.

Following the presentation, JR congratulated the team on the progress to date and opened the meeting up for discussion.

GW advised that he had compared the published figures for 2012-2017 with figures held by SCAN on the number of babies affected by 5 surgical anomalies and that they matched very closely for four of the five conditions. However, only around 80% of the cases of duodenal atresia had been picked up by CARDRISS and he was unsure of the reason for this. RW advised that CARDRISS may only be picking up the headline diagnosis in the data that is available nationally so may be missing cases where they are listed as another diagnosis. This may particularly affect duodenal atresia as this condition commonly co-occurs with Down’s syndrome.
GW also asked if there was a similar issue with termination of pregnancy for fetal anomaly. RW advised that work done to date by CARDRISS to produce national estimates of anomaly prevalence based on existing routine records has identified some under-reporting of statutory termination of pregnancy records relating to later TOPFAs conducted in some maternity units. In these cases, CARDRISS can identify that the TOPFA took place (as that is recorded on the woman’s maternity discharge record) but not the underlying anomalies that led to the TOPFA (as that is only recorded on the statutory TOP record). This means that CARDRISS can currently accurately report the total number of TOPFAs, but may undercount the number of TOPFAs carried out on babies with specific anomalies. Work is ongoing with the CMO aimed at improving the reporting of terminations and that is already showing some improvements. RW also noted that both these issues will be addressed when the formal CARDRISS register is established, as registration staff will have access to local records to ensure that all anomalies in registered cases are accurately recorded on the register.

It was also noted that babies with certain anomalies are generally referred to England for specialist surgery. Examples given were:

- Hypoplastic left heart syndrome (GOSH)
- Bladder extrophy (Manchester)
- Biliary atresia (Birmingham)

RW advised that CARDRISS will seek to set up a data sharing agreement with NCARDRS to facilitate data sharing between England and Scotland to ensure that registers in both countries can register babies usually resident in their areas. It was confirmed that such an agreement already exists between England and Wales. The general point was made that it will be better for CARDRISS to be notified of cases meeting registration eligibility criteria from multiple sources than to miss cases.

3. EAG Terms of Reference

The draft Terms of Reference (ToR) document was presented to the Group. The document outlines the objectives of the EAG, the duties of members, practical details of the meetings and the list of members. There were no comments raised on the document. JR advised that if anybody had any comments to make after the meeting then these could be shared by contacting the CARDRISS team. If no further comments were received the document will be signed off.
**ACTION:** To feed back any comments on the content of the ToR to the CARDRISS team by April 30th.

Comments were invited on the membership of the EAG. Suggestions were made to look into also inviting representatives from:

- SOFT UK – Support Organisation for Trisomy 13/18
- CDH UK – Congenital Diaphragmatic Hernia
- a sonography/obstetric radiology background and,
- an inherited metabolic disorders (IMDs) background.

RW thanked the Group for the suggestions but advised that the latter suggestion would not be appropriate at this stage as IMDs would not be covered by CARDRISS in the initial phase.

### 4. Specific questions for this meeting

- Access to data on trisomy screening and genetic diagnostic testing

RW noted that, to strengthen registration processes, CARDRISS is interested in getting access to data not currently available to Public Health Scotland (e.g. data held by local NHS Boards) to improve case ascertainment and/or efficiently provide information required on cases to complete the registration data set. It was noted that the team are initially pursuing getting access to data on the results of trisomy screening and genetic diagnostic testing from relevant biochemistry and clinical genetics labs. A query was raised about the level of data that would be requested. RW outlined that it would include data items such as test(s) carried out, results in the standard nomenclature and the free ‘interpretive’ text. A specification will be pulled together by ISD and sent out to laboratory colleagues to see if the data can be obtained in the format required. It was noted that there are clearly some challenges with this but all agreed that it is still worth exploring.

An example suggested could be where the data may contain duplicates in cases where multiple samples are taken from a child and there is a potential scattering of results – positive, negative and/or inconclusive. RW acknowledged that this may happen but advised that the data could probably be ‘de-duplicated’ by ISD once it has been received.
A separate challenge noted was that, unlike in Wales, Scotland currently has no national system for radiology hence it is currently not feasible for CARDRISS to instigate a national feed of data on the results of antenatal scanning. Such a data source would be useful in ascertaining cases and/or adding supplementary information to an existing record.

The plan is that CARDRISS will only record data for confirmed cases. This is a different approach to that taken with registers in England and Wales where data on suspected cases is also recorded. DT advised that such cases were recorded as it was not clear whether it would be a confirmed or rejected case until definitive information was obtained at a later examination. GW suggested that there is a danger that if the proposed approach for CARDRISS was changed to include suspected cases then there was a danger that it could be overwhelmed. RW agreed that was indeed a concern and that the focus was likely to remain on recording confirmed cases only. MM also pointed out that the registration staff that are posted out in the Boards would either confirm, reject or leave cases. If they are confirmed, then they will be added to CARDRISS. If they are left (due to incomplete information) the records would stay as provisional until there was enough information to either confirm or reject the case.

The discussion moved on to talking about other good sources of data that the CARDRISS team could potentially explore. Examples suggested were:

- Cleft lip and palate
- Paediatric neurology / orthopaedics
- Badgernet

RW advised that any local data would need to include patient identifiers (preferably CHI) to be considered for linkage with CARDRISS data. Any non-identifiable data could only be used for aggregate numbers.

MR suggested that the CARDRISS team could follow the example of the European Reference Network for Rare Endocrine Conditions (Endo-ERN) which had successfully sent a questionnaire to all of their members asking for information on any local rare endocrine registries/databases. Sending a questionnaire to all EAG members and asking them to circulate it to their contacts could be a good way to gather information on local disease registries in Scotland.

**ACTION:** CARDRISS team to produce an email that EAG members can send on to their colleagues to enquire about good quality data sources.
**ACTION:** To send any suggestions of good quality data sources to the CARDRISS team.

- Strengthening engagement and communications e.g. developing a local CARDRISS network

RW advised that families will not be asked for explicit consent for adding details of their children to CARDRISS. Therefore, there is a need to be completely transparent about the approach being taken for CARDRISS and development of clear, accurate and meaningful materials for communication. VJ noted that we need to be cautious about the language used in any materials that we produce so that they are empowering and helpful and not in any way offensive. RW agreed that there would be a need for careful use of language.

LHn suggested engaging with our Health Scotland colleagues – who, along with ISD, will form part of Public Health Scotland which launches on 1st April 2020 – as they have expertise in the creation of public information materials. DT enquired about the number of languages covered when materials are produced by Health Scotland. LHn advised that they focus on the current ‘Top 5’, include braille editions and any other languages are done on demand.

**ACTION:** To contact the CARDRISS team if they are able to help with the development/review of the public information materials.

The discussion moved on to cover how the CARDRISS team could enhance their engagement with interested parties, particularly in relation to frontline health services. One suggestion was to engage with the Neonatal MCN (and the Maternity MCN once it starts up) as those groups will effectively include a representative from most Boards. KM suggested the Fetal Medicine Group as the best forum to discuss development of – and access to – structured data from the 20-week anomaly scan. DT outlined that in Wales there was a network of local CARIS coordinators in each hospital who were generally screening midwives. RW advised that there may not be a need to mirror that approach in Scotland as the local registration staff would mostly perform that role. ZM suggested an approach where we could look at the data, identify where the biggest gaps are and then nominate people on that basis to help fill those gaps.

RW thanked everyone for their suggestions and noted that, as CARDRISS is still in the developmental stage, there was no immediate need to establish a
network of local ‘CARDRISS champions’. However, it may be useful to establish this network at a later stage.

**ACTION:** To send any other comments/suggestions on enhancing engagement to the CARDRISS team, particularly in relation to the aim of establishing clear frontline engagement.

5. **Date and format of next meeting**

It was agreed that the next EAG meeting should be arranged for early November which would follow the second annual CARDRISS statistical publication which is scheduled for 6th October.

RW talked through the idea of hosting an ‘all day’ joint event – the EAG meeting in the morning and an educational event in the afternoon which would focus on a specific topic area such as neural tube defects. Members agreed that this would be a good idea and could also offer a good opportunity to demonstrate how CARDRISS data could be used. ZM asked if we could consider a start time for the morning meeting of no earlier than 10am. This would assist those that would be travelling from outwith Edinburgh to arrive in time for the meeting. Times suggested were 10am – 12pm for the EAG meeting and then 1pm – 4:30pm for the educational event.

RW suggested Professor Nick Wald as a guest speaker for the event. Another suggestion was Margot Whiteford, the ex-president of the Spina Bifida Association and a doctor who has spina bifida herself.

DT advised that they run similar events in Wales. He went on to suggest that the CARDRISS team should consider running follow up ‘satellite’ events in other parts of the country to cater for other interested staff who are unable to travel to an event in the central belt and that this would also be a good way of promoting engagement across Scotland.

**ACTION:** To identify a venue and suggested dates for the second EAG meeting and educational event in early November.  
**ACTION:** To consider the idea of follow up satellite events for interested staff in other parts of Scotland.

6. **AOB**

BR enquired about whether any oversight was required from the project team if he was to write an article about CARDRISS for the TOFS magazine. RW
advised that such oversight would not be imposed however the team would be
happy to review and comment on any drafts prior to publication to help ensure
that any details were being captured accurately.

7. Date of next meeting

Early November 2020. Exact date and venue TBC

8. Summary of meeting actions

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