

Stillbirth Clinical Studies Group

26 April 2019 10:30-13:00

Meeting minutes

Attending: Chair- Sarah Stock (SS), Tracey Mills (TM), Jane Sandall (JaS), Dimitrios Siassakos (DS), Flora Jessop (FJ), Janet Scott (JSc), Mehali Patel (MP)

By phone: Gordon Smith (GS), Julia Sanders (JuS), Kate Walker (KM), Alex Heazell (AH)

Trainee observers: Emily Vaughan, Claire Austin

Apologies: Steve Charnock Jones, Jim Thornton, Alyson Hunter, Basky Thilaganathan

1. **Welcomed** new CSG member, Dr Flora Jessop, Consultant Paediatric/Perinatal Pathologist, University of Cambridge
Also welcomed two trainee observers, Emily Vaughan and Claire Austin. Two trainees will be invited to every for the first time at the CSG.
2. Minutes of last meeting 16 November 2018, approved.
Actions arising:
 - i. CSG details on website: RCOG site up-dated; BMFMS site redesigned but information still out-of-date. Suggestion that both RCOG and BMFMS link to Sands site where information can be more easily kept up-to-date. Action: SS to take to RCOG/BMFMS.
 - ii. Pro forma for capturing details of ongoing studies circulated. Action: all to complete for relevant studies.
 - iii. Pathologist vacancy on the CSG filled.
3. **Up-dates on on-going projects**
Future minutes will refer to the written up-dates for each study
 - a. TM - Feasibility study for better maternity care pathways in pregnancies after stillbirth or neonatal death: Recruitment for phase 1 (usual care) has completed. Recruitment for intervention phase, phase 2 opened in Sept 2018 - due to complete in Aug 2019.
 - b. TM - Global Health Research Group on Prevention and Management of Stillbirth in Sub Saharan Africa: Exploratory studies to improve outcomes related to stillbirth, in progress. Data collection in the final phase; data analysis underway. Will be moving on to intervention development and feasibility assessment next.
 - c. DP – NMPA: Submitted the clinical report for births in 2016/2017 to HQIP, NHS England, Health Governments of Scotland and Wales. Following approvals, aim to release the report towards the mid-2019.
 - d. DP - DESiGN: Cluster RCT comparing customised and non-customised growth charts for SGA detection. Primary outcome US detection of SGA babies. The trial comparison

period is now over. In the midst of final data down load: aiming to report towards the end of 2019.

- e. GS - Evidence synthesis/health economic analysis of universal late pregnancy ultrasound: project will finish and report end July 2019. First paper published in PLOS Medicine: economic analysis of universal US screening for breech presentation near term <https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1002778> - attracted widespread media coverage and parent interest. Health economics analysis of two further screening models underway: paper on LGA accepted for BJOG.
- f. DS - PARENTS2 portfolio of studies on parental involvement in perinatal mortality reviews: Work completed and published bar final evaluation report. Informing tool for parent engagement in PMRT. Possible further work to be decided.
Action: MP to move to 'completed' section of CSG site
- g. DP - iCHOOSE project to establish Core Outcome Set for research into care after stillbirth: systematic review and interviews with parents almost completed. Looking at extending parent interviews to beyond UK - link-up to Global Health Research Network suggested.
- h. DP - Global Principles on Bereavement Care: arising from ISA. Systematic review of LIC/MIC and global expert survey undertaken. Global set of principles developed and currently being prepared for publication.
- i. WILL trial of IoL for hypertension: about to start recruitment.
- j. AH – REMIT: pilot study of measurement of PIGF to determine birth in women presenting with RFM. 216 women recruited at end 2018. Proof of principle outcomes mid-June. Feasibility-wise, useful lessons about optimum time of day to approach women.
- k. JaS – Study of implementation of open disclosure for parents when there is a serious bad outcomes. Achieved funding from NIHR, and just started.
- l. JaS – Red flags and symptom checkers: Use of digital information in pregnancy when women have concerns. Just started. Sands-funded.
- m. IPD Meta-analysis of stillbirth – no-one available to up-date.

Action: ALL to complete short template for feedback/up-dates on studies for next meeting

4. Funding opportunities

Awaiting outcomes of funding applications:

- i. HTA commissioned calls: Rotational forceps delivery (DS; Denison) Induction of Labour (SS, KW)
- ii. RfPB Maternal Sleep position (AH)

SS outlined up-coming SB-related calls from HTA, RfPB, i4i, MRC PHIND

5. Research Committee up-date

- Annual Academic Meeting in January a success. Academic Engagement report - three priorities: to improve advocacy for discovery scientists, greater engagement with industry and to improve global health research opportunities.
- One-year Genomics Taskforce set up by Dr Brianna Cloke
- Clinical Research Network update. Obs/Gynae accrual slipped. recommend CSGs have CRN reps.
- CSG ToR developed. Advice on PPI involvement though this CSG well covered
- Communication: CSG would like to see Academic Committee newsletters from RCOG.

Action: SS to forward Academic Committee up-dates

6. PICOs

- a. Discussed PICO proposing a case-control study to identify risk factors for early stillbirth (after 20-28 weeks gestation). SB reduction in UK is being driven in 28+ weeks gestation group and in term SB. Sub 28 weeks showing no improvement. Two possible study ideas emerged, one appropriate for a PICO, one appropriate for other funders. AH to consider comments and next steps.

Action: SS to draft a trial PICO about an intervention for sleep position

- b. Stillbirth CSG has submitted no PICOS recently.

Action: all to think of PICO ideas for next meeting

7. Intermittent Auscultation

Variety of packages available to improve IA generally and especially detection of chronically hypoxic babies at onset of labour. No guidance on some emerging technology. Need to understand more about: how to improve variation in practice, training and assessment for competency; the benefits and potential harm of new machines; differentiation between fetal and maternal heartbeat. Agreed initially to combine a meeting with IP CSG to look at what better IA using current knowledge would look like?

Possible idea for PICO around assessing plethora of new IA technology.

Actions:

JuS to approach Debra Bick, chair IPCSG

MP to extend booking of meeting room on 14 November

8. UKNSC call for comments on Screening for Stillbirth

<https://legacyscreening.phe.org.uk/stillbirth> Deadline for comments is 12 May 2019.

Action: SS to collate comments and submit – **ALL** comments to SS by 3 May

9. Membership

David Cromwell, Peter Brocklehurst and Neil Sebire have stood down. Many thanks expressed for their contribution.

New ToR from RCOG for all CSGs. All new positions must be openly advertised. Membership term of three years. Seek equality/diversity of membership.

Need pragmatic approach to ensure continuity. Current members encouraged to remain.

Gaps in expertise identified: statistics, health economics, discovery science, social science, CRN link, neonatology, epidemiology, knowledge of diversity, and a trainee.

KW's trainee status will end in 2019 - she will then become full member of the CSG.

Trainee observers: feedback welcome on the CSG meeting, and on general external perception of CSGs.

Action:

SS/JS/MP will advertise for new members, with RCOG support. Recent requests to join the CSG referred to advert. All CSG members will disseminate adverts

SS will then select from applications

MP/JS to develop package of support for Parent PPI recruitment to CSG

All to sign confidentiality agreements if haven't yet done so

MP to invite observers to feedback, and invite two new observers to next meeting

10. **Sands survey** of bereaved parents' experiences of maternity and neonatal care currently live. 1400 responses so far. Closing on 3 May. Reporting in June/July.

Next meetings:

14th November 2019, 10:30-13:00, RCOG London - extended to 16:00 for joint meeting with IP CSG

26th March 2020, 13:30-15:30, new RCOG building