# Picture3.jpgMinutes of the meeting of the RCOG Stillbirth Clinical Studies Group,**2pm,** 1 May 2014, RCOG London

**Present:** Gordon Smith (GS; Chair), Charlotte Bevan (CB), Jane Sandall (JS), Baskaran Thilaganathan, Peter Brocklehurst (PB), David Cromwell (DC), Steve Charnock-Jones (SCJ), Neil Sebire (NS)

**Attending via conf. call:** Alex Heazell (AH), Alyson Hunter (Aly H), Tracey Mills (TM)

**Apologies:** Jim Thornton, Catherine Calderwood (CC), Dimitrios Siassakos (DS), Shantini Paranjothy (SP), Janet Scott

1. Welcome and apologies. Amendments to minutes of the last meeting and completion of CSG documentation from several members.

1. **James Lind Alliance Stillbirth Priority Setting Partnership (PSP)**(AH) The PSP is inviting stakeholders to complete a survey stating what they believe are the unanswered questions in stillbirth research, whether related to prevention, management or bereavement care (survey opens 12 May for 8–10 weeks). A final set of priorities will be established through a stakeholder workshop in early 2015, and published by the NIHR. Whilst the NIHR recommendations have influence with funding bodies. The Steering Group includes Sands, and representatives from other parent charities, the Royal Colleges and professional bodies.

***ACTION: Each CSG member to propose 2-3 long-sentence research questions by end of May, to be considered by CSG, which will formally submit. Members to contribute individually if desired at*** [***www.stillbirthpsp.org.uk***](http://www.stillbirthpsp.org.uk)***).***

1. **Life Study Birth Cohort** (PB) Launching in May 2014 recruiting at 20 weeks, for assessment (biological samples and measurements) at 28 weeks; samples taken at birth (including cord, cord blood and placenta) and follow up at 6 and 12 months on 60,000 women and their babies. Psychosocial data will also be collected. Seeking additional funding for pilot of data collection during labour for 6,000 women, focusing mainly on infection. By end 2016, funded researchers can apply for data access, but data analyses have to be published via the Life Study. NS currently piloting study on effect of delay on placental deterioration as placental samples will not be frozen in units but transported to special centres.
2. **AFFIRM** (AH) Launched 1 May. Second-round units now randomised. There will be eight clusters of 3–5 units resulting in involvement of 40 units, equivalent to ~ 140,000 births in Scotland, Ireland, Wales, parts of the north of England and London.
3. **Perinatal Post Mortem** (NS) Data entry is near completion for 1,150 unselected cases of intrauterine death after 20 weeks, from St Georges and GOSH.
4. **POPS** (GS) The first paper from the cohort (on routine ultrasonic fetal biometry to screen for small babies) has been submitted for publication. Further analyses will be forthcoming which will address use of ultrasound to screen low risk nulliparous women for fetal growth restriction using the combination of serial fetal biometry, utero-placental Doppler and placental biomarkers. Moreover, two MRC- funded studies are using next-generation sequencing to analyse stored placental samples from the cohort with the aim of identifying novel pathways involved in fetal growth restriction.
5. **MiNESS** (AH) Funding confirmed from Action Medical Research and Sands. The study follows on from NZ study on 'modifiable risk factors associated with stillbirth' (left-side sleeping). Will improve on cohort (300 stillbirths and 800 controls – gestationally matched – vs 100 stillbirths and 200 controls in previous NZ study), with 35 sites participating.
6. **InSight** (CB) Study on schedule and work to disseminate results ongoing. In addition to InSight, a systematic review of all qualitative, mixed method studies and surveys of bereavement care in Western high-income settings has been completed. Abstract submitted to ISA and paper considered for *Lancet* follow-up series. Group has funding from Wellcome Trust for INSPIRE study to look at religious and cultural attitudes to bereavement by conducting interviews with representatives from Jewish, Christian, Sikh, Hindu, Buddhist and Islamic faiths.
7. **35/39 Study** (GS) Updated from Jim Thornton that the study is on schedule.
8. **REACH (**JS) Now has funding for full-time studentship for qualitative research in response to results of a CQC survey, which found a large proportion of women felt they were not listened to. This research will also investigate the difficulty of responding to parents' concerns.
9. **Listening to Parents** (CB) Launch on 9 April went well, with focus on variability of bereavement care, problems of communication and important gaps in post natal care. DH will in time make recommendations for improvements to care. Sands and other charities discussing co-ordinated response to the survey.
10. **Care in Subsequent Pregnancy** (TM) Preliminary data obtained on care for women in subsequent pregnancy. Qualitative data suggest lack of equity and good care, and highlights failure of communication; network of bereavement midwives to share good practice is not effective. TM will be taking forward a mixed-method study to look at women's experiences, with the view to generating small low-level interventions to improve care.
11. **Prospective IUGR audit** (AlyH) Conducted in Belfast; highlighted failure to manage identified SGA in high-risk groups well or to identify SGA at all in low-risk group. CSG felt model AlyH has developed is extremely worthwhile and fits in well with current drive in England's Strategic Clinical Networks who are looking for tools to reduce avoidable stillbirths. AlyH to draw up a proposal for prospective IUGR audit, to be supported by the CSG, and presented to CC in her role as Clinical Director for Maternity. This can be promoted to Strategic Clinical Network leads for maternity (CB to provide list of contacts Sands has developed) as an initiative to understand variations in care.

***ACTION: AlyH to draw up 2-page proposal, to be circulated round CSG, to liaise with CC for dissemination to Strategic Clinical Networks as a CSG-recommended piece of work.***

1. **DH/Sands Task and Finish Group** (CB) Standardised Perinatal Mortality Review group has settled on full data set which will generates taxonomy and lesson learning. Currently needs funding to create a web-based tool. CC has taken this to NHS England. DH currently working on a cost-benefit analysis.
2. **National Maternity Audit** (CB) No update. CB to follow up.
3. **International Stillbirth Alliance** to be held from 19 to 21 September in Amsterdam. Sands sponsoring the event. Several CSG members attending including GS, CC, DS, Sands team and NS who will attend meeting on 18 Sept (classification of placental IUGR).
4. ***Lancet*** (GS) *Lancet Stillbirth Series* (2011) reportedly most popular series. Follow up series in 2015 about subsequent developments. One paper will address stillbirth in high-income countries.
5. GS reported that there is now a demand for academic clinical fellows and lecturers to have experience of CSG work. Group agreed individuals could attend occasional meetings, but highlighted need for signed confidentiality agreements.
6. **PPI for research** (GS) Research funders require increased PPI in projects and parents want to be involved, but there are challenges: scientific nature of the work makes it challenging for non-scientists, groups of academics can be potentially intimidating, also objective, scientific nature of these meetings may be upsetting to bereaved parents. CSG to support access to PPI. In short term, Sands will provide a ‘buddy’ system for parents invited to provide PPI.

***ACTION: CB and JS to work on developing PPI ensuring parents get the right support.***

**AOB:** AlyH - suggested CSG has representation from Southern Ireland. PB raised the process for adopting new members of the group. To check whether allowable to have members from outside UK.

***ACTION: GS to raise at next RCOG Research Committee.***

**DATE OF NEXT MEETING: 6 November 2014, 2–5pm, RCOG**