

BAPS Clinical Outcomes Committee Meeting Minutes

28th March 2017

Attendees:

Simon Kenny (Chair), Richard Stewart (webex), Paul Johnson (webex), Hany Gabra (webex), Stefano Giuliani, Shan Teo (webex), Peter Badger (webex)

Apologies:

Liam McCarthy, Carl Davis (flight delay - fog), Nick Lansdale, Marian Knight

Minutes of previous meeting minutes were accepted without further amendments. RS commented that he has paper copy of outcome / activity data collected by Ray Buick 1997-1998 and will endeavour to obtain electronic copy that could be used for comparison / made available on website.

Oncology update (Hany Gabra) number of databases / tumour study groups that will BAPS able to publish outcome data:

Wilms tumour database (IMPORT study)

SIPOEN & NCRI groups (neuroblastoma)

Soft tissue sarcoma (Tim Rogers/Ross Craigie)

Ovarian tumours (Ross Craigie / Paul Losty)

SG commented the European Research Network may be a source of funding

Action: HG to coordinate reporting structure and give progress report on timings / structure for next meeting. BAPS COC will need this and costings to agree support.

Dendrite update Over 1000 hypospadias cases now registered. SK demonstrated PROMS resulting from smartphone feedback (40% response rate). Parental decisional regret score and freetext comments. SG suggested adopting 'Picker' survey to suit paediatric surgery

Action: SG to develop proposal and present at next meeting

Badger demonstration Peter Badger demonstrated the 'gastroschisis' operation record. This is allows rapid data entry as part of operation record thus allowing single data entry by surgeons to be linked to outcome databases. Alder Hey have 15 procedure specific records under development.RS asked about costs. PB responded that Badger full EPR is not widely used at present and that Alder Hey was the first neonatal surgical unit to adopt it. However, all NNUs use some form of Badger and the Badgernet perinatal spine

provides an interface to 3rd party systems to write data to spine allowing centralization of data collection. This is used by several groups including NPEU and NNRD. PB suggested that it would not be possible to mandate Badger but the most expedient solution is to develop a 'BAPS dataset' for each index condition. This could then be adapted for use across different EPRs. Such datasets have been developed for neonatology and are mandated by the Clinical Reference Group commissioning documents (attached). If a similar model could be developed in paediatric surgery then the costs of electronic data collection could be met by the providers of specialised services rather than BAPS. This would also have the advantage of avoiding the problems of multiple data entry that surgeons complain about. All agreed that there was considerable merit in this suggestion. This could also be adopted internationally. NL has rightly suggested that we could apply to NIHR etc to host the data repository permitting outcomes analysis outputs to individual surgeons / units. Underlying this would need to be a commitment by surgeons to the publication of centre-level data in the public domain. The forthcoming congenital diaphragmatic hernia outcome registry would be a good test platform for national dataset testing. Process summarized in diagram form:



Actions

RS to contact Olly Gee (as Chaird of CRG) to inform him that BAPS likely to be developing datasets for each clinical condition

Input / thoughts from MK gratefully received

CD to produce / circulate CDH dataset in spreadsheet format (please contact SK to discuss format)

BAPS website / SWORD

Clinical Outcomes element of BAPS website needs development. At moment links to Dendrite are difficult to find. In addition will need development to facilitate links to SWORD HES data portal for each surgeon to see their outcomes / centre outcomes. GMC numbers will be required for this. RS hoped that we will be able to launch SWORD at the BAPS summer meeting although timescale tight. Also discussed that ideally 'single sign on' to BAPS website would permit login to databases.

Actions:

RS to confirm delivery timescale with SWORD

ST to explore single sign on with BAPS website providers

ST / SK to discuss webpage development

AOB

SK apologised for ineptitude over file attachments and also the short notice for the agenda being issued. All agreed that Webex had worked well and that most future meetings would be via this forum thus saving cost, time and the planet. A win-win.

SK would however explore potential for having a meeting during BAPS London congress.

SK to circulate meeting dates in May via Doodle Poll to optimize availability