

Minutes of Meeting

Research Support Panel (RSP) of the UK Children's Neurological Research Campaign
Child Brain Research

16th June 2014, 11.30 – 14.00
ICH Neurosciences Unit, 4-5 Long Yard, London WC1

Part A – for publication

Present:

- Dr Anna Basu (by teleconference) (AB)
- Dr Richard Chin –Chair (RC)
- Mrs Katie Wilkinson (KW)
- Dr John Coleman (JW)
- Prof Helen Cross (HC)
- Dr Vijeya Ganesan (VG)
- Dr Rachel Kneen (RK)
- Dr John Livingston (JL)
- Dr Finbar O'Callaghan (FO)
- Dr Mario Cortina Borja (MCB)
- Dr Jeremy Parr (JP)

Apologies for absence

- Professor Stefano Seri (SS)

1. Welcome and introductions

RC, panel chair, welcomed all and introduced Katie Wilkinson as the new Research Manager. RC, on behalf of the RSP, thanked John Coleman for his hard work over the past 5 years.

2. Minutes from meeting of 4th December 2013.

These were accepted as a correct record. The panel confirmed that electronic copies of the agenda and minutes were acceptable from this point forward.

3. Matters Arising

a. Merger

RC informed the panel that the proposed merger of the British Paediatric Neurological Association (BPNA) and Child Brain Research (CBR) will be discussed by the Board of Trustees for CBR at their meeting later that day. A successful application for funding had been made to the BPNA council.

b. James Lind Alliance

RC and HC proposed to BPNA Council working with the James Lind Alliance (JLA) to set the research priorities in paediatric neurology. Council was broadly in support of this but suggested that any cost towards this be deferred to the next financial year.

JP detailed the work the British Academy of Childhood Disability (BACD) has done to date with the JLA. A representative of the JLA had presented to their members regarding priority setting of research proposals.

- The process costs between £15k and £20k and can take up to two years,

- A steering group was set up that included parents and service users.
- The clinicians may prioritise differently from the service users
- The ranking is done by a selected number of people.
- The process has been led by Chris Morris from Peninsula Cerebra Research Unit and Doug Simkiss from the University of Warwick, Medical School.

HC provided the costs she had been previously given and informed the panel that the NIHR is looking for priorities to be put forward. It was thought that some of these costs could be reduced by using internal resources and spread over three financial years.

AB suggested that some of the research priorities of BPNA would overlap with those of BACD.

HC stated that a representative of the JLS should be invited to speak to the RSP. It was decided that additional members of the BPNA council and the Clinical Research Network: Children (CRNC) should also be present.

JP recommended that a lead person was needed to undertake the process.

It was decided that this should come from the general BPNA membership rather than from the RSP but that the RSP would be determine selection which would need to be ratified by the BPNA executive committee.

JL informed the panel that the he would discuss this at next BPNA council meeting.

Action:

HC will ask for a more detailed breakdown of costs and establish also if there are recurring costs.

HC & RC will draft a proposal for 'expressions of interest' for the lead role to be submitted to the next BPNA executive committee meeting on the 29th October 2014.

KW will find out the deadline for items for the BPNA newsletter.

c. UK Rare Diseases

RC and KW attended the 'Rare Diseases Day Networking event at the RCPCH on the 20th March 2014. The event detailed the national strategies for Rare Diseases.

HC informed the panel that there were discussions at the meeting of the CRNC regarding the funding call for registries and collaborative working and that there will be recurrent calls.

JL thought that these may only be open to Biomedical Research Centres.

d. Researcher Training

RC felt that there was a need to increase the scope of the Research Fair, and that the addition of information about ethics, funding streams and the R&D process would be useful. It was suggested that funding bodies such as the Wellcome Trust and the MRC be invited and a representative from a R&D department. VG suggested that CPD points be offered.

Action

RC, VG and KW

4. Seed Funding

RK was asked at this point to leave the meeting as a co-applicant on one of the applications.

The purpose of scheme is to provide funds for early stage/pilot studies broadly in the field of paediatric neurology. Funded studies should be expected to yield results that promise to provide the foundation for full scale funding applications (from other sources) for larger scale definitive studies. Two applications were received and comments received from lead reviewers.

- a) Non-invasive measurement of intracranial pressure and cerebral oxygenation in paediatric brain injury.
- b) A study to validate the 'Cambridge London Quality of Life Questionnaire' in children with epilepsy and severe intellectual disability.

At this point in the meeting HC left.

5. Other funding

Early onset Epilepsy

The panel decided to award £1000 of seed funding to assist in the early stages of the study. This study was peer reviewed by the panel in June 2014.

6. Study updates

To be discussed at next meeting

7. Any Other Business

8. Next meeting date

To be determined by email poll but provisionally within the first 2 weeks of December 2014.

Approved