

Guidelines for the *modus operandi* of the Research Support Panel* (RSP) of the UK Children's Neurological Research Campaign (UKCNRC)

*Currently operating as the The Roald Dahl Child Brain Research Development Service

UKCNRC Board and RSP approved in December 2011

Composition of the RSP

The Chair of the RSP is appointed by the Board of UKCNRC for a three year term. Membership of the RSP is by invitation of the Chair, usually for a term of three years, and will not exceed two consecutive terms. The term of office of founding members will be staggered to provide continuity. RSP members will not exceed 14 in number. The Chair of the MCRN Neurosciences Clinical Study Group, and the BPNSU Lead will be invited to serve as *ex officio* appointments. The Chair may invite "corresponding members" to join the RSP to provide expertise as called upon.

The duties of the RSP

The duties of the RSP are to follow the stated objectives of the UKCNRC in general and in particular as follows:

In general:

'The objects for which the Company is formed shall be to preserve and protect public health and advance public education by promoting and advancing national collaborative medical research into childhood neurological and neuromuscular disease and disseminating the useful results of such research.'

In particular, to:

- Maintain liaison, as appropriate, with the UKCNRC Board, British Paediatric Neurology Surveillance Unit (BPNSU) and the Medicines for Children Research Network (MCRN).
- Canvass opinion from the BPNA membership (and where necessary overseas) maintaining balanced support for and dialogue with all departments of Paediatric Neurology across the UK.
- Develop a process of feedback from Regional centres on prospective and adopted studies
- Support research through a selection and evaluation process and to prioritise support for research. Research to be high quality and achievable.
- Facilitate, where appropriate, the development of adopted proposals by the involvement of the RSP, the Research Coordinator (RC) and an identified statistical department.
- Support research wherever possible by advising on potential funding sources. On occasion, to promote a project for funding. Advising the Research Coordinator and Project Lead on sources of funding.
- Research to include but not be limited to:
 1. Cohort studies,
 2. Case control studies,
 3. Epidemiological studies
 4. Clinical trials.
- Provide professional and academic advice to improve applications.

- Provide guidance for researchers on the regulatory approvals process. Note that the UKCNRC will aim to provide help in the same for adopted studies, especially but not exclusively where funding has been identified.
- Be responsible for the person specification and job description for the Research Coordinator. Evaluate the likely development of staff and resources needed to support adopted or planned research and to review the same regularly. *To advise the Research Coordinator on priorities and management of his/her time.*
- Develop and maintain a working relationship with one or more established statistical departments.
- Focus on collaborative research.
- Consider the development of an “outcomes” unit that can advise on the assessment of outcomes and undertake this, with appropriate funding and where able and requested to do so. *To consider a working relationship with an established department(s) or person(s) working in this area.* This would lead to economic benefits, to better quality control and would develop skills in this area faster than if left to each study coordinator.
- Consider the development of a relationship *with an established department (or person within a dept)* of Health Economics.
- Consider the need for and cost of research support at each regional centre (personnel such as research assistants or nurses).
- Advise on the development of the website for the UKCNRC.
- Develop a lay advisory service.

Conflicts of Interest

- In order to protect the integrity of the RSP and the UKCNRC, members of the RSP will maintain an up to date register of their active research interests (outline plans through to funded research). This will be updated at least annually and will be held as a written record by the Research Coordinator.
- When projects are submitted that are not already declared on the register, no member of the RSP will develop a competing project, at least until the submitted project is funded or no longer being actively pursued.
- In the event of any RSP member developing a competing proposal without having registered a prior interest, that they will be required to resign from the RSP and will be barred from submitting projects to the UKCNRC in the future.
- Where two or more proposers independently declare a significant interest in the same subject area, the RSP will first consider the proposals submitted to them but will consider brokering collaboration if possible and appropriate.
- The verbal statement of an interest in the subject area without any written accompanying documentation will not be accepted as a significant interest.
- Any RSP member who is associated with a proposal or is a member of the same department as the proposer will absent themselves from all discussion of that proposal at RSP meetings. Being within the same institution but a different department as a proposer does not necessarily constitute a conflict of interest. Any RSP member uncertain as to whether they have a conflict of interest will raise the matter prior to discussion of the proposal.

- Disagreements as to conflict of interest will be referred to the UKCNRC Board.

Confidentiality

- RSP decisions about proposals will remain confidential until the public minutes are agreed and published.
- RSP discussions that lead to decisions will remain confidential indefinitely.
- Formal feedback to proposers arising from RSP discussions will be recorded as an Appendix to the minutes, will not be made public or posted on the website, and will remain confidential to RSP members. Such feedback will not be attributed to individual members of the RSP.

Adoption/Sanction

- On those rare occasions where there is not satisfactory progress with a UKCNRC-adopted study, to agree a process, where appropriate, for making alternative arrangements to ensure completion of a study. To establish a protocol whereby investigators are aware of this and other aspects of their relationship to the UKCNRC when studies are adopted.
- Any disagreement between the RSP and the Chief Investigator of a study adopted by the UKCNRC may be referred to the Board for resolution, if necessary.

To be completed on acceptance of membership of the RSP.

Name of appointee:

Term of appointment:

I agree to the above terms of appointment to the RSP of UKCNRC

My planned and active research interests are in the following areas:

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Signature:

Date: