

Regulations for the working of the Steering Group (SG) of the UK Children's  
Neurological Research Campaign (UKCNRC).  
June 26<sup>th</sup> 2008

Steering Group Members:

1. John Osborne, Convenor
2. Paul Eunson
3. Colin Kennedy (ex-officio nominated by the UKCNRC Working Group)
4. Finbar O'Callaghan
5. William Whitehouse – (ex officio Lead of the MCRN Neurology CSG)

The duties of the SG 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:

- Maintain liaison, as appropriate, with the UKCNRC Board, British Paediatric Neurology Surveillance Unit (BPNSU) and the Medicines for Children Research Network (MCRN).
- To 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 SG, 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.

(Note: The BPNSU and MCRN do not fund studies. The MCRN Neurosciences clinical study group has a remit for a wider clinical area

including child psychiatry. It has a lack of power to adopt studies and can only recommend adoption)

- To provide professional and academic advice to improve applications.
- To 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.
- Consider the skills needed of the Research Coordinator and write a Person Specification and Job Description for approval by the UKCNRC WG. 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 to managing this post.*
- 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.
- To 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).
- To advise on the development of the website for the UKCNRC.
- Develop a lay advisory service.
- Agree terms of office within the framework of 3 year terms for substantive members but staggered for current SG members so that all the initial substantive members do not leave at once. Inform the UKCNRC WG of proposal.

#### Conflicts of Interest

- In order to protect the integrity of the SG and the UKCNRC, members of the SG will maintain an up to date register that will be updated at the start of each meeting of the SG, of the active research interests of members of the SG (outline plans through to funded research).
- To agree that when projects are submitted that are not already declared on the register, that no member of the SG will develop a competing project, at least until the submitted project is funded or no longer being actively pursued.
- In the event of any SG member developing a competing proposal without having registered a prior interest, that they will be required to resign from the SG and will be barred from submitting projects to the UKCNRC in the future.
- Where others declare a significant interest in the subject area after the submission of a reasonable protocol by someone else, that the SG will continue with the

protocol submitted to them first – but will consider brokering a collaboration if appropriate and possible.

- The verbal statement of an interest in the subject area without any written accompanying documentation will not be accepted as a significant interest.
- Disagreements as to conflict of interest will be referred to the UKCNRC Board.

#### 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 SG and the Chief Investigator of a study adopted by the UKCNRC may be referred to the Board for resolution, if necessary.