

# Response from the Nuffield Council on Bioethics to the Health Research Authority consultation on UK policy framework for health and social care research



*March 2016*

## Introduction

This response draws on the conclusions of the Nuffield Council on Bioethics' report *Children and clinical research: ethical issues*, which was published in May 2015. The full report is available at <http://nuffieldbioethics.org/project/children-research/>.

## Responses to consultation questions

In responding to this consultation we have answered the questions on the parts of the framework to which the approach and recommendations set out in the Council's report are most relevant.

**Does the policy framework address all the key issues (e.g. obstacles to good practice in the conduct and management of research)? If not, what are they and how could they be addressed?**

- We welcome the approach in this framework that research should be 'core business' – an everyday part of the health service provision. Our report concludes that in order to establish research a genuine part of everyday life, commitment to evidence-based care will be required from all those able to influence how care is delivered, including health professionals, managers, and policy makers. It also identifies a need to increase general public awareness of clinical research in general.
- We suggest that the 'core business' approach could be strengthened by employers viewing research activity (including membership of research ethics committees) as part of their employee's 'core business' and hence legitimate use of contracted NHS time. Our report recommends that the UK Departments of Health, NHS and Universities UK should protect the time needed for expert's in children's healthcare to contribute to RECs.
- We support the principle of making the outcomes of research available in a meaningful form to participants in research, and would urge researchers to think about formats that are appropriate for children and young people.

**Do you agree with the responsibilities stated for professional bodies?**

- In line with the 'core business' approach, we recommend that Royal Colleges and other professional bodies concerned with children's and young people's health should make their commitment to evidence-based care clear by reinforcing the professional responsibilities of their members to contribute to

the ethical review of research over their professional lifetime. For example, involvement of some form in a research ethics committee (including in an *ad hoc* advisory role) could be encouraged as part of continuing professional development schemes. A number of rotational posts for trainees working in different areas of children's and young people's healthcare could be linked with their local research ethics committees.

### **Do you agree with the responsibilities stated for regulators?**

- We welcome the statement that patients, service users and the public are involved, where appropriate, in the design, management and conduct of research. Our report recommends that research ethics committees should require researchers to involve children and parents in the development of their studies, unless there are good reasons not to.

### **Do you agree with the responsibilities stated for employers?**

- In our report we recommend that, whenever research ethics committees consider protocols relating to research with children, they should always ensure that they have timely access to expert advice from the relevant area of children's and young people's healthcare.
- However, we understand from health professionals and others engaged in research that difficulties are often encountered in convincing their employers that the time required to serve as a research ethics committee member is worth committing.
- Our report therefore recommends that that the UK Departments of Health, NHS Employers, Universities UK and the Health Research Authority should jointly consider what steps they can take to protect the professional time needed for research ethics committees to work effectively.