

To Undertake Prospective Multisource Surveillance for all Cases of Progressive Intellectual and Neurological Deterioration Occurring in Children in the UK

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Principal Investigators

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Contact information of lead PI

Country

United Kingdom

Title of project or programme

To Undertake Prospective Multisource Surveillance for all Cases of Progressive Intellectual and Neurological Deterioration Occurring in Children in the UK

Source of funding information

NIHR (PRP projects (RDD: June 1993-July 2007))

Total sum awarded (Euro)

€ 3,232,238

Start date of award

01/04/1997

Total duration of award in years

20.0

The project/programme is most relevant to:

Prion disease

Keywords

Research Abstract

The proposal will undertake prospective multi-source surveillances through the Surveillance Unit of Paediatrics and Child Health (the 'British Paediatric Surveillance Unit'), liaising with the National Creutzfeldt-Jakob Surveillance Unit (CJDSU), for all cases of progressive intellectual and neurological deterioration (PIND) occurring in children under the age of 16 in the United Kingdom. The incidence of PIND and, as far as possible, its causes will be determined. Further investigation will be encouraged on those cases without a readily identifiable cause to detect children suffering from any form of CJD, should they occur.

The programme will commence through the production of an initial surveillance case definition for PIND by an Expert Neurological Advisory Group. This will be circulated to all paediatricians via the Surveillance Unit of the Royal College of Paediatrics and Child Health (the 'British Paediatric Surveillance Unit'). Paediatricians will make returns of cases and will be sent an "initial contact form". Following this, if a reported case meets the surveillance case definition and does not have a confirmed or likely diagnosis, the case will be followed up by a telephone interview or visit from the research nurse to the clinician. The research paediatric neurologist may need to contact the local clinician to discuss investigations of individual cases of PIND. Any cases identified as possible CJD will be referred to the CJDSU, which will follow them up according to currently agreed CJDSU protocols. The Expert Neurological Advisory Group will agree the case definition and will meet quarterly to discuss all the notified cases of PIND and allocate them to appropriate diagnostic groups.

The surveillance will be overseen by a Steering Committee that includes the participating institutes and representation from the Department of Health. This Committee will also review overall progress and agree release of data.

The contract will run for 5 years but a review after 18 months will be held to give an early warning of a need to extend the surveillance beyond this time. Annual reports will be provided to the Department of Health.

Aims

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Plan of Investigation

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Potential Impact

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Policy Relevance

By observing the epidemiology and causes of Progressive Intellectual and Neurological Deterioration in Childhood (PIND), the proposal addresses three important issues for the Department of Health:

to determine whether CJD (either sporadic, new variant or other forms) exists in children in the UK

to improve diagnosis and management of CJD in children, should it occur, by heightening the awareness of doctors to these diseases and by using common protocols to detect them

to provide a mechanism to monitor CJD numbers in children and to determine risk factors which may lead to CJD

Lay Summary

Further information available at:

Types:

Investments > €500k

Member States:

United Kingdom

Diseases:

Prion disease

Years:

2016

Database Categories:

N/A

Database Tags:

N/A