Assessment and satisfaction of services for Juvenile Huntington’s Disease and modelling alternative methods of service organisation

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Country

United Kingdom

Title of project or programme

Assessment and satisfaction of services for Juvenile Huntington's Disease and modelling alternative methods of service organisation

Source of funding information

NIHR (RfPB Competition 20 - Yorkshire and The Humber)

Total sum awarded (Euro)

€ 372,502

Start date of award

01/11/2014

Total duration of award in years

3.0

The project/programme is most relevant to:

Huntington's disease

Keywords
Research Abstract
Juvenile Huntington’s disease (JHD) is a rare slowly progressive neurodegenerative disorder with onset ? 20 years. The clinical picture often differs from that of the more usual adult form in

that bradykinesia and dystonia are prominent earlier in course of the illness with myoclonus and epilepsy being more common. The condition is rare with the patients widely dispersed. There are no evidenced based guidelines for management but there are recommendations that there should be a multi-disciplinary approach. The problem with this suggestion is that most professionals are caring and supporting a family with JHD for the first time. We will use multi-phase qualitative and quantitative methods to evaluate the current economic costs of providing the current *ad hoc* service and model the costs of organising care by concentrating expertise in either multidisciplinary clinic(s) or alternatively, delivering this using tele-health technology. In phase 1 we will interview 12 carers and 6 patients and administer the HD quality of life questionnaire. Information from the Framework analysis and HD quality of life instrument will be used to develop a questionnaire which can be sent to patients. In addition carers will be sent the EQ-5D to estimate quality adjusted life years and the EQ-5D proxy version for them to complete on behalf of their child/young adult. This will enable us to evaluate the current care and identify the professionals involved with the family. A web based survey will be developed for all professionals and a subset of different professionals will be asked to participate in a telephone interview. We will enquire about cares and professionals' perception of improvements which could be made and their views on concentrating expertise in either a traditional multi-disciplinary clinic(s) or; alternatively, delivering concentration of expertise via tele-health technology. Data merging from qualitative and quantitative data will be achieved through the development of matrices to array and merge the qualitative themes with key quantitative items.

Where possible, information will be gathered from routine data collections such as sessions with health professionals. We will gather information on treatments (both pharmacological and non-pharmacological), care home stay, school attendance and carer time away from usual activities. Information obtained from primary carers will be based on questions on the Database Instruments for Resource Use Measurement. Unit cost information will be obtained from standard sources and the EQ-5D proxy version 2 will be used to measure quality of life in order to estimate quality adjusted life years. We will present a cost per quality adjusted life years from an NHS and social care perspective. Decision modelling, using probabilistic sensitivity analysis, will be used to estimate the costs of organising new models of care based on either traditional multidisciplinary clinic(s) or use of tele-health technology to concentrate expertise.

At the end of the study we will make firm recommendations for the organisation of care and modelled alternatives. Based on the views of parents/carers as well as the cost benefit analysis, an alternative model can be evaluated in a further study.

Lay Summary
Further information available at:

Types:
Investments > €500k

Member States:
United Kingdom

Diseases:
Huntington's disease

Years:
2016

Database Categories:
N/A

Database Tags:
N/A