Information leaflet for parents/carers
Focus Groups

What outcomes of NHS care should be measured for children with neurodisability?

Study Researcher: Dr Chris Morris, Peninsula Cerebra Research Unit
What are NHS outcomes?
NHS outcomes are things that we measure to give us a clear picture of the effect that NHS health care has on patients.

These are a few examples of the types of things (or outcomes) that we might measure:

- Daily activities (e.g. getting dressed, eating, washing)
- Well being
- Quality of life

Questionnaires are often used to measure these outcomes.

What is this study about?
There is widespread recognition that too often the current health system fails to meet the needs of disabled children and their families. The key government tool for improving services is setting and measuring outcomes. The Department of Health are developing a new ‘NHS Outcomes Framework’. The aim of the Outcomes Framework is to measure the outcomes for NHS patients. We want to make sure that it includes a measure from disabled children (and or their families) themselves.

As mentioned above, outcomes are often measured by using questionnaires. The aim of this study is to find out which of the questionnaires being used at the moment are the most suitable to measure NHS care in children with neurodisability.

For this study we are using the following definition of neurodisability: An impairment of functioning relating to any condition that affects the brain and nervous system. This may, for example:

What will happen to the results of the study?
We will publish reports for different audiences; for families, healthcare practitioners and scientific journals. Anyone who has taken part in a focus group will be sent a link to the final published report. None of the people who took part in the study will be identified in any report.

Complaints
If you wish to complain, or if you have any concerns about any aspect of this study, you should first speak to Amanda who will do her best to answer your questions (see contact details below).

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Thank you for taking the time to consider this study.
What are the possible risks of taking part?
During the focus group, it is possible that you might find it upsetting to talk about issues relating to your child’s health. If this happens, the researcher can pause the discussions and give you the opportunity to decide whether or not you feel able to continue. If you are unable to continue, the group co-ordinator (the person who invited you today) will accompany you out of the focus group setting. You can then take some quiet time and decide whether or not you would like to rejoin the session or if you feel you’d like to call it a day.

Will my details be kept confidential?
Yes. All focus group recordings will be identified only by a code, and any mention of any names or personal details made during the focus group will not be transcribed, to ensure the recordings remain completely anonymous. Only members of the research team and the person typing up the recordings (transcriber) will have access to them. The recordings will be kept securely on password protected computers and all manuscripts of the interviews kept securely in accordance with the relevant research guidelines. We will keep the recordings and manuscripts for ten years, and after this time they will be destroyed. All information that we collect about each participant will be kept confidential, unless doing so would put anyone at risk of serious harm. All information will be held and processed in accord with the Data Protection Act (1998) and that confidentiality will be breached and appropriate actions taken if any abusive, illegal or unprofessional behaviours or actions are suspected, disclosed or discovered in the course of the study.

What will we do in this study?
The National Institute for Health Research (NIHR) have funded this study. In this study we will:

- look at scientific journals to find questionnaires that have been used with children affected by neurodisability,
- conduct focus groups and interviews with children, affected by neurological conditions, and their families,
- ask health professionals working with children, affected by neurodisability, about their views on what should be measured.

This is a collaborative project involving the Peninsula Cerebra Research Unit (PenCRU), Council for Disabled Children (CDC), British Academy of Disabled Children (BACD) and a number of universities.

The University of Exeter will Sponsor this study and provide the appropriate insurance and indemnity cover.
Who are the Peninsula Cerebra Research Unit (PenCRU)?
The Peninsula Cerebra Research Unit (PenCRU) is a childhood disability research unit at the Peninsula Medical School, University of Exeter. The Unit receives funding from Cerebra, a national charity for children and young people with neurological conditions. The research that PenCRU undertake evaluates services and treatments for disabled children. Find out more by visiting: www.pencru.org

Who are the Council for Disabled Children (CDC)?
The Council for Disabled Children (CDC) is the umbrella body for the disabled children’s sector. CDC works to influence national policy that impacts upon disabled children, and children with special educational needs (SEN) and their families. CDC aim to promote the active participation of disabled children and young people, making sure their voices and success stories are heard. The CDC is made up of a wide range of professional, voluntary and statutory organisations, including parent representatives, disabled young people and representatives of disabled people. Find out more by visiting: www.councilfordisabledchildren.org.uk

Who has reviewed the study?
All research in the NHS is looked at by an independent group of people, to protect the interests of the individuals who take part in studies. This study has been reviewed by the County Durham & Tees Valley Research Ethics Proportionate Review Sub-Committee.

Do I have to take part?
No. It is entirely up to you to decide if you would like to take part in the study. If you would like to take part please contact Amanda Allard (see contact details at the end of this leaflet).

We will do our best to make sure that the focus group you attend will be at time and date that is convenient for you. When you come to the focus group, we will ask you to sign a consent form agreeing that you are happy to take part. We will copy these forms and give you a copy to keep for your own records and we will keep a copy for our records.

What will I have to do?
Taking part in this study will involve joining a focus group. The focus group should take about an hour.

What will I have to talk about?
We will be asking you what sort of health outcomes you think are important for children affected by neurological conditions. To help with our discussions, we will bring examples of questionnaires that have already been used with patients. We can look at and discuss these together. We would like to gather your views on whether you think they are appropriate for measuring the health care of children affected by neurological conditions.

What information will be collected?
With your permission, we will record the focus group on an audio recorder, so the researcher can concentrate completely on what you are saying. The recordings will be typed up (transcribed), so we can study them in detail.

Acknowledgement
To thank you for taking the time to take part in the focus group each participant will receive a one off payment which will come directly from the research funding.