1HD
N.E.T.S

Next stage in Evidence-based paediatric
surgical Treatment Strategies

January 2016

Newsletter

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Thank you all for registering to take part in the NETS1HD study. We are very grateful for your support

Over the period of the study we will send you four brief newsletters to update you on how the work is progressing and explain what will be happening over the next few months. If you would rather not receive these newsletters, please email *benjamin.allin@npeu.ox.ac.uk*, and we will remove you from the mailing list.

Why are we doing the NETS1HD study?

Hirschsprung's Disease research is mainly aimed at trying to work out whether one type of treatment is better than another. A common way of doing this is to compare children who have had one type of treatment with children who have had a different form of treatment and to then look at what happens to them, for example, how long they stay in hospital, or whether they get complications from the treatment. Each of the things that can be looked at is called an **outcome measure**. There are many different outcome measures that can be looked at, and this causes three problems in research. Firstly, there is a lot of variation in which outcome measures researchers choose to use in their studies. This means that it is **difficult to compare or combine results from different studies**. Secondly, researchers often use a certain outcome measure because it is easy to gather information about, such as how quickly children leave hospital, rather than one that is important to patients, like whether they have long-term pain. This means that the results of the research may not actually be relevant to patients with the condition. Finally, researchers will sometimes investigate many different outcome measures, but only publish the ones that support their argument. This is called reporting bias. **Each of these problems makes it harder to decide how to interpret results from a study**. At the moment, all of these problems are occurring in Hirschsprung's Disease research.

How will the NETS1HD study solve these problems?

The NETS1HD study will develop a **core outcome set for Hirschsprung's Disease**. A **core outcome set** is a list of outcome measures that should be reported as a minimum in every study looking at a particular condition. Using core outcome sets in research **addresses the problems caused by having a choice of many different outcome measures**.

Core outcome sets are developed through a **Delphi Process**. A Delphi process involves a group of experts, usually consisting of **people with the condition or their parents, doctors, nurses and researchers** being guided through a series of steps to identify the outcome measures that are **most important to the group as a whole**, and hence that should be included in the core outcome set.

By developing a core outcome set for Hirschsprung's Disease we hope to make it easier to interpret the results of research and understand which treatments are best for patients.

Registration for the NETS[1HD] study

Registration to take part in the study has gone fantastically. At present, **over 100 people have signed up to** take part, including:

• 61 Parents of children with Hirschsprung's Disease

• 10 People with Hirschsprung's Disease

• 27 Paediatric Surgeons

• 11 Other clinicians

Registration will stay open until the end of the first week in February, so if you know anyone else who is interested in taking part, please ask them to go to *www.npeu.ox.ac.uk/nets/taking-part* to sign up. We are particularly interested in hearing from more **neonatologists and paediatric gastroenterologists.**

What happens next?

In the **second week in February**, you will be emailed a link to an online questionnaire. In this questionnaire, you will be asked to **score a series of outcome measures from 1-9** based on how important you think each one is in deciding how well the overall treatment of someone's Hirschsprung's Disease has worked. This questionnaire will form the first phase of the Delphi process. **In phases two and three of the Delphi** process you will be asked to re-score these outcome measures, each time being given more information about how other groups of people have scored them.

What is the end result of the NETS[1HD] Study?

On the 21st of June, we will hold a meeting in Leeds, to which 40 people who are representative of everyone taking part in the study will be invited. The results of the Delphi process will be discussed in detail at this meeting, after which we will be able to identify a short list of outcome measures which will form the **core outcome set for Hirschsprung's Disease**. In the future, researchers will try to work out which treatments are best for children with Hirschsprung's disease by comparing them using the **NETS[1HD] core outcome set**.

Other core outcome sets - gastroschisis

In the **NETS[1G]** study, which we are just starting the registration process for, we will be developing a core outcome set for use in **gastroschisis**. Therefore, if you know anyone who might be interested in helping with that study, please pass on the information, and ask them to register at *www.npeu.ox.ac.uk/nets/taking-part*

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