

What was the aim of the NETS^{1HD} study?



The aim of the NETS^{1HD} study was to identify which factors (also known as outcomes) are most important in deciding whether the treatment of a child's Hirschsprung's disease has been successful or not. Identifying which factors are most important makes it easier for researchers to work out what the best treatments are for children with Hirschsprung's disease.

Which factors were identified as important?

The factors that were identified as the ten most important are referred to as the NETS^{1HD} core outcome set. These factors are:

- Whether the child is able to control when and where they go for a poo (whether they are continent of faeces or not)
- A score which tells the doctor how well the child's bowels are working
- Whether the child needs any unplanned operations
- Whether the child needs enemas or washouts to help them open their bowels
- Whether the child experiences long-term psychological stress as a result of their Hirschsprung's disease
- Whether the child is able to control when and where they go for a wee (whether they are continent of urine or not)
- A score telling the doctor what the child's overall quality of life is like
- Whether the child has a permanent stoma
- Whether the child is admitted to hospital for the treatment of Hirschsprung's Associated Enterocolitis (a severe bowel infection)
- Whether the child dies

How were these ten factors identified?



Over 100 people with Hirschsprung's disease, parents of children with Hirschsprung's disease, paediatric surgeons, paediatricians, specialist nurses and researchers took part in the study. During a period of four months, these people were asked to complete three surveys in which they scored about 100 different factors according to how important they thought they were in deciding whether treatment of a child's Hirschsprung's disease had been successful or not. In each survey, people were given more information about how important other participants thought each factor was, and were asked if they would like to change their score based upon this information. These surveys allowed the research team to create a shortlist of factors that were important. At a face-to-face meeting in Leeds, a smaller group of people discussed this shortlist of factors in detail, and then re-scored each of them to decide which were important enough to include in the NETS1HD core outcome set.

What happens now?

All studies that are investigating treatments for Hirschsprung's disease should tell people what impact those treatments have on the factors included in the NETS1HD core outcome set. This will make it easier for doctors and patients to compare the benefits and drawbacks of each treatment.

A piece of work called the NETS2HD study is now starting and will run until October 2018. It will be looking at what life is like for children currently aged six who had one of the three main operations used for treating Hirschsprung's Disease: the Duhamel operation, the Soave operation and the Swenson operation. All of these operations are different ways of removing the abnormal bowel and then joining the remaining bowel back together again.

The study will use the new NETS1HD core outcome set and the results should be available in the middle of 2019. For instance we can learn what percentage of infants having a Soave operation need a permanent stoma, or what percentage of infants having a Duhamel operation have to have an unplanned re-operation.

Where can I get more information?

The full scientific paper and NETS1HD report can be downloaded from

<http://adc.bmj.com/content/archdischild/early/2017/08/07/archdischild-2017-312901.full.pdf>



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