Round one of the NETS¹ᴴᴰ study has now closed, and we would like to thank everyone for completing the questionnaire, we greatly appreciate your time.

What happens now?

You have been allocated to **one of three panels** of participants, either the neonatal panel, the non-neonatal panel, or the personal experience panel. Within the **neonatal panel**, are paediatric surgeons and neonatologists, within the **non-neonatal panel** are paediatricians, specialist nurses, and researchers, and in the **personal experience panel**, are people with Hirschsprung's Disease and their parents.

Later this week, you will receive an email with a link to the round two questionnaire. In this, we will ask you to score each outcome measure again, using the same 1-9 scale. However, this time we will also show you a graph that describes how other people in your panel scored that outcome measure in round one. We would now ask you to base your score on how important **you** think each outcome measure is **in light of how the other people in your panel scored it last time.**

You will see one graph for each outcome measure, and there are three parts to each graph:

1. The bars show the percentage of people in your panel giving a particular score to that outcome measure in round one. Each bar is a different score.
2. The blue circle represents the average score your panel gave to that outcome measure in round one.
3. The yellow box shows the score you gave the outcome measure in round one.

Below is an **example** graph:
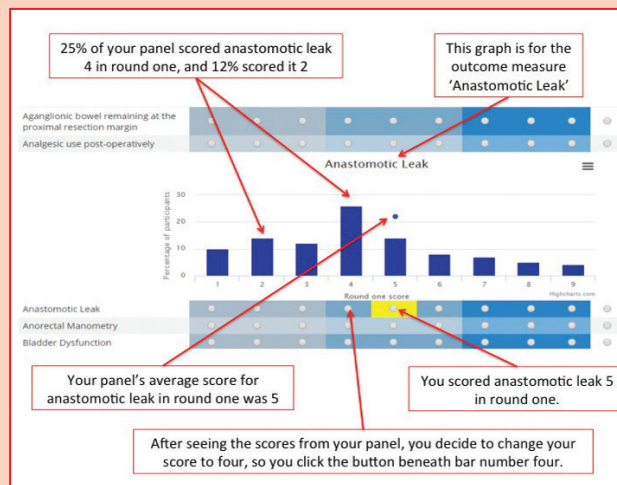
Feedback from round one

Lots of useful comments were left in round one. We have used these comments to refine the outcome measures we ask about in round two, and have answered some of the common questions below.

How were the outcome measures in round one chosen?

Before starting the NETS1HD study, we identified *every study published in the last five years* that compared two treatments for Hirschsprung's Disease. The 73 outcome measures you scored in round one were the *73 outcome measures that those studies investigated.*

A lot of these outcome measures looked at complications that can occur for people with Hirschsprung's Disease. We just want to reassure people that many of these will only ever apply to a very small proportion of people with Hirschsprung's Disease.

Why are some of the outcome measures very similar?

This is because there can be *many different ways of looking at the same outcome measure.* For example, some researchers will compare two different treatments for Hirschsprung's Disease by looking at how many infants develop pneumonia after the operation, how many develop a blockage in their bowel, and how many develop a collection of pus. All of these outcomes can be classed as a *'post-operative complication'.* Instead of comparing two treatments by looking at each of these outcome measures individually, some researchers will instead compare them by looking at how many infants develop *any* post-operative complication.

By asking you to score each of the individual outcome measures, and the more general collective outcome measure, we can work out if there are specific individual outcome measures you think are important, or whether the general outcome measure is as important as the individual ones.

What time period are you interested in?

We are looking to identify outcomes that you think are important in determining the *overall success of Hirschsprung's Disease treatment.* We are interested in outcomes regardless of the time point at which they occur. Therefore, if there are outcomes that occur *immediately after the operation* that you think are important in determining the overall success of Hirschsprung's Disease treatment, please tell us about them. Likewise, if there are outcomes that are more relevant later in life that you think are important, please also tell us about them. In the consensus meeting, we will discuss which outcomes are *appropriate in different age groups*, and also discuss *how best to measure each outcome.*

Developing a core outcome set for gastroschisis

We are still recruiting for the NETS1G study to develop a core outcome set for use in gastroschisis. We hope to start phase one of this study in July, so if you know anyone who may be interested in taking part, please ask them to register at *www.npeu.ox.ac.uk/nets/taking-part*

Who is working on the studies?

Both the Hirschsprung's Disease and gastroschisis core outcome sets are being developed by a team containing surgeons and researchers.

Ben Allin

Ben is training as a paediatric surgeon, and is taking three years out to study for a PhD in Oxford. He has an interest in developing new research methods for use in paediatric surgery, and is working on both the Hirschsprung's Disease and gastroschisis core outcome sets.

Tim Bradnock

Tim is a consultant paediatric surgeon in Glasgow. He has a specialist interest in Hirschsprung's Disease, and along with Gregor and Simon, is one of the clinical leads for the Hirschsprung's Disease study.

Nigel Hall

Nigel is a consultant paediatric surgeon in Southampton, and is an associate Professor of paediatric surgery at the University of Southampton. He founded the Paediatric Surgery Trainees Research Network, has a specialist interest in gastroschisis, and along with Sean, is the clinical lead on the gastroschisis study.

Simon Kenny

Simon is a consultant paediatric surgeon at Alder Hey Children's Hospital. He is an honorary senior lecturer at the University of Liverpool, and has an interest in regenerative medicine and outcomes in paediatric surgery and urology. Along with Tim and Gregor, he is one of the clinical leads on the Hirschsprung's Disease study.

Marian Knight

Marian is a Professor of Maternal and Child population Health in Oxford. Her focus is on using national observational studies to address clinical questions concerning rare and severe complications of pregnancy and early childhood. She will oversee both the Hirschsprung's Disease and gastroschisis studies.

Sean Marven

Sean is a consultant paediatric surgeon in Sheffield. He has a specialist interest in gastroschisis and minimally invasive surgery, and has been involved in large-scale gastroschisis research over the past ten years. Along with Nigel, he is the clinical lead on the gastroschisis study.

Andrew Ross

Andrew is training as a paediatric surgeon, and will be working on the gastroschisis study. He has an interest in developing more collaborative approaches to paediatric surgical research, and is on the steering committee for the Paediatric Surgery Trainees Research Network.

Gregor Walker

Gregor is a consultant paediatric surgeon in Glasgow. He has a specialist interest in Hirschsprung's Disease, and was clinical lead on the BAPS-CASS Hirschsprung's Disease study. Along with Tim and Simon, he is one of the clinical leads for the Hirschsprung's Disease core outcome set study.

www.npeu.ox.ac.uk/nets/taking-part