

Parent Information Sheet

Study Title: Intestinal Failure Survey

You are being invited to take part in a survey. Before you decide it is important for you to understand why the survey is being done and what it will involve. Please take time to read the following information carefully. Please ask if there is anything that is not clear, or if you would like more information.

Thank you for reading this.

Purpose of study

Some infants and children require intravenous feeding, occasionally long-term. At present, we do not know how many infants and children in the United Kingdom require this form of treatment, nor do we know how long it may be needed for. We are therefore carrying out a survey of all infants and children who have been on intravenous feeding for more than 27 days as an inpatient. We propose to register their name, date of birth and a postcode on a register, together with details of why and how long intravenous feeding is needed, and the reasons why intravenous feeding is stopped.

This information will enable us to plan national services for children who need long-term intravenous feeding in a much more effective way.

Why have I been chosen?

Your child has been on intravenous feeding for more than 27 days and we would therefore like to enter their details on the register. We anticipate that about 250 similar children will be entered on the register each year.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to allow your child's details to be entered on the register, you will be given this information sheet to keep and be asked to sign a consent form, if you decide to take part you are still free to withdraw your permission at any time without giving a reason. This will not affect the standard of care your child receives.

What will happen to me if I take part?

Nothing further. We will consult your child's medical records every 6 months in order to obtain the necessary information from there.

Will my child's details be kept confidential?

If you consent for you child to take part in the survey, their medical records will be inspected from time to time by the doctors looking after your child and information passed on to a central register (maintained by Streets Heaver Healthcare Computing). The details will remain confidential and will be held on a secure database. Your child's full name and address **will not** be stored.

What will happen to the results of the survey?

The results will be published in the medical literature and made available to health service planners.

Who is organising he research?

The research is being organised by the British society of Paediatric Gastroenterology, Hepatology and Nutrition and the British Association of Paediatric Surgeons. These organisations are responsible for promoting high quality care for infants with gastrointestinal disease, including those requiring intravenous feeding.

Contact for further information

In the first instance, you should speak to the consultant who is looking after your child. However, further information can be obtained from the study co-ordinator:

Dr John Puntis,
Dept of Paediatrics,
Room 142, B Floor, Clarendon
Wing
Leeds General Infirmary
Leeds
LS2 9NS
Telephone: 0113 3923828

Miss Michelle Gabriel,
Registry Manager,
3rd Floor, Registry Office,
Whittle Street,
Birmingham,
B4 6NH
Michelle.Gabriel@bch.nhs.uk
Telephone: 0121 3338733

Thank you for taking the time to read this information sheet. You will be given a copy of this sheet and a copy of the signed consent to keep.