

# **BRITISH INTESTINAL FAILURE REGISTRY**

## **INFORMATION LEAFLET (12– 16 year olds)**

You are being invited to take part in a research survey. This survey will collect information about children from all over the United Kingdom who are fed intravenously through a special tube in to their vein for more than 27 days during their stay in hospital.

### **Why are we doing this survey?**

Some children may need to be fed intravenously (through a special tube in to their vein) for a long time, because their guts are not working properly. At the moment we do not know how many children in the United Kingdom are getting their food this way and for how long. So we are doing a survey of all the children in the United Kingdom who are fed intravenously for more than 27 days during their stay in hospital.

We will collect information about:

- Where they live
- How old they are
- Why they need to be fed like this
- How long they are fed like this

We hope this will let us plan the best way to look after people with these kind of problems in the future.

### **Why have I been chosen?**

You have been chosen to take part in this survey because you have been fed intravenously for more than 27 days. So we would like your permission to add your details to the survey.

### **What will I have to do?**

You will not need to do anything to take part in the study. We just need you to fill in a form allowing us collect your details.

### **Who will know my information?**

**All information collected about you will be stored in a computer database. A company called Streets Heaver Healthcare Computing will make sure all your information is kept secure in the database. Your full name and address will NOT be stored.**

Doctors and researchers will use the information from the survey

**How will it help me?**

Being in this study will not help you, but the new information may help other patients with the same problem as you in the future.

**Will I Receive any money if I take part in this study?**

You will not receive any money for taking part in this study.

**Do I have to take part?**

You choose with your parents/guardian if you want to take part. You can also stop taking part at any time without giving a reason. If you both decide not to take part or want to stop taking part in the study you will still receive the same care as usual. Being a part of this study will not interfere in any other studies you might be already taking part in.

**What will happen to the results of the survey?**

The results may be written about in medical journals and will be to improve how children are cared for in the United Kingdom.

If you have any more questions about this study you can speak to:

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,  
3<sup>rd</sup> Floor, Registry Office,  
Institute of Child Health  
Birmingham Children's Hospital  
Whittall Street  
B4 6NH  
Michelle.Gabriel@bch.nhs.uk  
Telephone: 0121 3338733

**If you agree to take part you can sign the consent form with your parents/guardian.**