

# **GORUK: Gastroschisis Outcome Registry UK**

Dear Parent / Guardian

## **What is the National Outcome Audit of Gastroschisis?**

In order to make sure that patients receive the best possible outcomes from their gastroschisis surgery, surgeons in the United Kingdom anonymously upload the data about each operation to a central database. Your surgeon is committed to improving outcomes for this procedure and enters data into this database. This database is run by the British Association of Paediatric Surgeons - a charitable organization committed to improving the outcomes of surgery for children together with Dendrite Clinical Systems Ltd, a specialist supplier of clinical databases.

## **What is the data used for?**

- (1) To allow surgeons to demonstrate that their surgery is effective. This means that all surgeons performing gastroschisis repairs in the United Kingdom will match a defined standard.
- (2) To allow surgeons to find the best treatments for gastroschisis. The database records different aspects of each operation and allows us to find out what treatments work best.

## **Why do you want to record my child's NHS number?**

It is much more useful if we can store your child's NHS number. This is a unique number that everyone in the United Kingdom has. Every time a patient has a procedure performed or is admitted to hospital for treatment, this is recorded using the NHS number. This means that if your child is admitted for further surgery or a complication following surgery, we will be able to record this, even if your child is treated at a different hospital. It is also an important check that all patients are being entered on the database.

## **Why do you want my mobile phone number?**

From time to time we will send you a survey that will allow you to feedback on the results of your child's surgery. We will not share your phone number with any third party.

## **Is this database secure?**

Yes. The data is kept on NHS servers and is password protected with industry standard protection.

## **Will you share this information with others?**

We will not share any patient specific data. Anonymous summary information will be shared with the public, with surgeons, hospitals and regulators in the form of reports.

## **Consent:**

I, the undersigned, acting as a guardian/representative of .....  
give my consent for the British Association of Paediatric Surgeons to store my child's NHS number for the sole purpose of analysing outcomes from gastroschisis surgery.

**Signed:** ..... **Date:** .....

**Name(Capitals):**..... **Relationship:**.....