

Understanding NICE guidance

Information for people who use NHS services

Surgical lengthening of the bowel for children with short bowel syndrome

NICE 'interventional procedures guidance' advises the NHS on when and how new surgical procedures or procedures that use electromagnetic radiation (such as X-rays, lasers and gamma rays) can be used.

This leaflet is about when and how surgical lengthening of the bowel can be used to treat children with short bowel syndrome (SBS) in the NHS in England, Wales, Scotland and Northern Ireland. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence).

NICE has produced this guidance because the procedure is quite new. This means that there is not a lot of information yet about how well it works, how safe it is and which patients will benefit most from it.

This leaflet is written to help parents or carers whose children have been offered this procedure to decide whether to agree (consent) to it or not. It does not describe SBS or the procedure in detail – a member of your child's healthcare team should also give you full information and advice about these. The leaflet includes some questions you may want to ask your child's doctor to help you reach a decision. A source of further information and support is on the back page.

Interventional procedures guidance makes recommendations on the safety of a procedure and how well it works. The guidance does not cover whether or not the NHS should fund a procedure. Decisions about funding are taken by local NHS bodies (primary care trusts and hospital trusts) after considering how well the procedure works and whether it represents value for money for the NHS.



What has NICE said?

While the evidence on the safety of this procedure is adequate, there are still uncertainties about how well it works. If your child's doctor wants to use bowel lengthening to treat short bowel syndrome (SBS), they should make sure that extra steps are taken to explain the uncertainty about how well it works, as well as the potential risks of the procedure. This should happen before you are asked to agree to your child having the procedure. You should be given this leaflet and other written information as part of the discussion. There should also be special arrangements for monitoring what happens to your child after the procedure.

NICE has said that this procedure should be carried out by a team of doctors with experience of treating SBS. NICE has also said that the procedure should only be carried out in children who are otherwise likely to need to be fed intravenously (called parenteral nutrition) for a long time.

NICE is asking doctors to send information about every child who has the operation and what happens to them afterwards to a central store of information at Children's Hospital Boston in the USA so that the safety of the procedure and how well it works can be checked over time.

Other comments from NICE

The available evidence about safety was based on studies of small numbers of children, but this procedure seems to be as safe as other types of operation for this group of very poorly children.

This procedure may not be the only possible treatment for short bowel syndrome. Your healthcare team should talk to you about whether it is suitable for your child and about any other treatment options available.

Surgical lengthening of the bowel

The procedure is not described in detail here – please talk to your child's specialist for a full description.

Some children have an abnormally short bowel. The medical name for this condition is short bowel syndrome (SBS). It can cause nutritional problems because the shortened bowel means that the body cannot digest or absorb food properly. Children with SBS have to be fed by infusion into the veins (intravenously).

The aim of the operation is to lengthen the small bowel to help the body digest food better. The operation is done under a general anaesthetic. The surgeon uses a special instrument which cuts and staples the bowel. The surgeon cuts and staples the bowel first on one side, then the other, and then continues the cutting and stapling on alternate sides of the bowel. At the end of the operation the bowel has a zigzag appearance, making it longer than it was before the operation.

Your child's doctor may use the medical name for this operation, which is the serial transverse enteroplasty procedure, often shortened to STEP.

What does this mean for my child?

If your doctor has offered surgical bowel lengthening for SBS, they should tell you that NICE has decided that the benefits and risks are uncertain. This does not mean that the procedure should not be done, but that your child's doctor should fully explain what is involved in having the procedure and discuss the possible benefits and risks with you. You should only be asked if you want your child to have this procedure after this discussion has taken place. You should be given written information, including this leaflet, and have the opportunity to discuss it with your child's doctor before making your decision.

NICE has also decided that more information is needed about this procedure so it has recommended that some details should be collected about every patient who has this procedure in England and Wales. These details will be held confidentially and will not include patients' names. The information will be used only to see how safe the procedure is and how well it works. If you want your child to have this procedure, you will be asked to agree to your child's details being entered into an electronic database for this purpose. A doctor looking after your child will fully explain the purpose of collecting the data and what details will be held (all information will be held according to the Data Protection Act). You will be asked to sign a consent form. If you do not agree to the details being entered into an electronic database, your child can still have the procedure.

You may want to ask the questions below

- What does the procedure involve?
- What are the benefits my child might get?
- How good are my child's chances of getting those benefits? Could having the procedure make my child feel worse?
- Are there alternative procedures?
- What are the risks of the procedure?
- Are the risks minor or serious? How likely are they to happen?
- What care will my child need after the operation?
- What happens if something goes wrong?
- What may happen if my child doesn't have the procedure?

Summary of possible benefits and risks

Some of the benefits and risks seen in the studies considered by NICE are briefly described below. NICE looked at six studies on this procedure.

How well does the procedure work?

The aim of the procedure is to lengthen the bowel. Three studies, recording the results of 51 patients in total, showed the bowel length increased by between 17 cm and 47 cm on average.

You might decide to have this procedure, to have a different procedure, or not to have a procedure at all.

The idea behind the procedure is that if the bowel is lengthened, the child will be able to absorb more nutrients from food in their bowel and not have to be fed intravenously. In one study, 21 patients were totally reliant on intravenous feeding before the operation. After the operation, 10 of them no longer needed intravenous feeding. The degree of reliance on intravenous feeding to gain adequate nutrition was also reduced in other studies after the operation.

In one of the studies, 3 patients died after the operation and 3 needed a bowel or bowel and liver transplant. In another study, 1 patient died as a result of damage to their liver.

One expert adviser said that this operation is one of a range of options, and none of them have been shown to work. Most expert advisers said that, for some children, SBS improves without treatment.

Risks and possible problems

There were no long-term complications reported at up to 15 months after the operation.

The expert advisers said that they thought this is a low-risk operation. They said that potential problems include leaking from where the staples had been inserted, blockage of the bowel, bruising, abscess, fluid building up around the lungs, the need for transplant, and death.

More information about short bowel syndrome

Your local Patient Advice and Liaison Service (PALS) may also be able to give you further advice and support.

About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating different medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider how well an interventional procedure works and how safe it is, and ask the opinions of expert advisers. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see www.nice.org.uk/aboutguidance

This leaflet and the full guidance aimed at healthcare professionals are available at www.nice.org.uk/IPG232

You can order printed copies of this leaflet from the NHS Response Line (phone 0870 1555 455 and quote reference N1340).