

Information for Participation

EUROKIDS Paediatric Inflammatory Bowel Disease Registry

Dear _____,

We have asked your parents for their permission for you to participate in a study. With this letter, we explain what this study is about, so that you can understand better what it means for you to participate.

We want you to participate because you have recently been diagnosed Crohn's disease or ulcerative colitis (both are forms of inflammatory bowel diseases (IBD)). Before your parents have to give permission for your participation, they will also be given more detailed information about what it means for you to participate.

1. General Information

This study will collect data from your patient file (like your height/weight and what was seen during your first endoscopy) and enter it into a database alongside data from all the other children and adolescents also diagnosed with IBD.

2. Why do we want this data from you?

We hope that your data can help us to create a better idea of the different types of IBD. The more data we collect, the more we can learn.

3. What is expected of you

You do not have to do anything or come to the hospital for extra examinations or blood tests! All that is needed is permission to access your patient file. You will not even notice that you are part of the study, and you can also stop your participation in the study at any time.

4. Your privacy

No information that could identify you, like your name, will be entered into the database. The only information entered into the database from your patient file is to do directly with IBD, like your symptoms, your diagnosis, what your endoscopy showed.

5. Questions

If you have any questions, discuss them with your parents. If you still have more questions after this, you can ask your doctor. Once your parents have read all the information given to them, they will then be asked to sign if they give permission or not for you to participate. After that, you won't be asked to give anything more for this study.