

IBD Eurokids Update

Web-based Data Registration

User Manual 2021

EUROKIDS

The Paediatric IBD Porto Group
 **ESPGHAN**

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EUROKIDS

Prospective registry of newly diagnosed paediatric and adolescent patients with Crohn's disease, ulcerative colitis or IBD-unclassified.

Login EUROKIDS

Username

Password

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Introduction

Dear colleague, dear EUROKIDS participant,

Welcome to the updated EUROKIDS web-based registry of the Paediatric IBD Porto group of the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN)!

The original EUROKIDS registry was initiated in 2004 by the Porto IBD working group of ESPGHAN, in parallel to the publication of the initial Porto Criteria (IBD Working Group of ESPGHAN, 2005). Whilst this original registry was online from 2004 to 2019, over 5000 Paediatric IBD patients were registered by 74 participating centres across 24 countries.

The updated EUROKIDS registry is designed to help make clear classifications of IBD colitis in paediatric cases (aged below 18 years) when you have doubts upon whether it is Crohn's disease (CD), ulcerative colitis (UC), atypical UC, or IBD-unclassified (IBD-U). The classification system used is based upon the Revised Porto Criteria (Levine et al, 2014) and the subsequent publication on paediatric IBD classes (Birimberg et al, 2017). You can find the 23-point scale classification criteria on the EUROKIDS website (Registration → Overview → IBD Classes).

The online and prospective registration of patients in the EUROKIDS database is open to both members and non-members of ESPGHAN, within and outside of Europe.

Aims of the updated EUROKIDS Registry:

- To audit and evaluate the diagnostic work-up of paediatric patients with IBD
- To describe the phenotype of paediatric patients with IBD
- To prospectively evaluate the 2014 revised Porto criteria as published by the Paediatric IBD Porto group of ESPGHAN

As this is a prospective registry, please remember:

- Only new patients are eligible (diagnosis of IBD made after joining the EUROKIDS study)
- Register patients within 3-months of diagnostic date (date of first diagnostic endoscopy)
- Completely and correctly fill-in the relevant fields for your patients (those marked with an asterisk are mandatory)
 - If uncertain or experiencing problems with the system, contact Prof. Dr. (Hankje) Escher: j.escher@erasmusmc.nl

Website link: <https://www.eurokidsibd.com/>

Entering a New Patient into the Database

Login

1. Enter your login details and you will be redirected to the homepage
2. Click 'Registration' (on top handlebar) → New registration

Patient Information

1. Patient information

Patient ID
10010

Name of centre *

Country *

Gender *
☐ Male
☐ Female

Month of birth *
Year of birth *

Onset of symptoms
Specific date *
☐ Yes, month/year
☐ No, estimate

IBD diagnosis date
Month *
Year *
Family history of IBD *
☐ Yes ☐ No ☐ Unknown

Ethnicity
Country of birth *
Country reporting
Ethnicity *
☐ White European
☐ Africa-Caribbean
☐ Asian
☐ Arab
☐ Other mixed
☐ Other, specify

Chief complaint(s) of patient
Leading to suspicion of IBD

Gastrointestinal symptoms (from mouth to anus) *	Growth failure or pubertal delay *	Extra intestinal manifestation(s) *	Other
<input type="radio"/> yes <input type="radio"/> no <input type="radio"/> unknown	<input type="radio"/> yes <input type="radio"/> no <input type="radio"/> unknown	<input type="radio"/> yes <input type="radio"/> no <input type="radio"/> unknown	<input type="text"/>

Additional patient information *
☐ * Significant growth delay (height velocity less than - 2SDS)
☐ Positive ASCA in the presence of negative pANCA
☐ Non-bloody diarrhea
☐ ASCA not measured
☐ None of above

1. Patient study ID will be automatically assigned (please save study ID in conjunction with your patient's identification details in a separate file that is accessible to only your centre because – without recording the corresponding patient identity to the anonymous number study ID – it won't be possible for you to match them up at a later date as the EUROKIDS registry does not record names)
2. Name of centre: choose your centre from the options list, the country will appear automatically
3. Gender: select male or female
4. Month of birth & year of birth: fill-in

Onset of Symptoms

1. Select either the specific date (month & year) or estimate check-box for when the symptoms started and fill-in the subsequent box

IBD Diagnosis date

1. Enter the month and year for when the diagnosis was made (date of first diagnostic endoscopy)
 - Age at onset in year/months will automatically be calculated
2. Family history: choose yes (if first degree relative has IBD), no, or unknown.

Ethnicity

1. Enter the country of birth and ethnicity of patient

Chief complaint(s) of patient

1. Select all complaints/symptoms that led to the suspicion of IBD.
 - If 'yes' for 'Extra intestinal manifestation(s)' is selected, an additional pop-up asking for specific manifestations will appear.

Growth status at diagnosis

2. Growth status at diagnosis

Height (cm) *	Weight (kg) *	Body Mass Index
<input type="text"/>	<input type="text"/>	<input type="text" value="0.00"/>
Height for age SDS ⓘ	Weight for height SDS ⓘ	Missing information
<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Height unknown
		<input type="checkbox"/> Weight unknown

1. Enter the height (in centimetres) and weight (in kilograms) of the patient
 - BMI will automatically be calculated
2. Height for age SDS and weight for height SDS will not be calculated automatically, but can be filled in using your national reference data (not mandatory)
 - If height and weight are not measured, select unknown (but preferably height and weight should be measured!)

Work-up

3. Work-up

Which procedures were performed at or within 3 months of diagnosis

Upper GI endoscopy *	<input type="radio"/> yes <input type="radio"/> no
Colonoscopy *	<input type="radio"/> yes <input type="radio"/> no
intubation of the terminal ileum *	<input type="radio"/> yes <input type="radio"/> no
MR-Enterography *	<input type="radio"/> yes <input type="radio"/> no
Abdominal ultrasound	<input type="radio"/> yes <input type="radio"/> no
Capsule endoscopy	<input type="radio"/> yes <input type="radio"/> no
Single/double balloon enteroscopy	<input type="radio"/> yes <input type="radio"/> no
Abdominal CT	<input type="radio"/> yes <input type="radio"/> no
Small bowel follow through (SBFT)	<input type="radio"/> yes <input type="radio"/> no
Other	<input type="text"/>

1. Check 'yes' for all the procedures performed and 'no' for ones not performed
 - o If 'no' is selected for 'upper GI endoscopy', 'colonoscopy', 'intubation of the terminal ileum' and/or 'MR-enterography', a pop-up will appear asking for a reason for why these tests were not performed: either choose from the options or fill-in text at 'other'.

Disease extent and localisation

- What appears needing to be filled in depends on what was selected during the Work-Up section

- **Abnormal** → abnormal findings consistent with IBD
- **Normal** → findings not consistent with IBD/ just normal findings
- **Not visualised** → test not performed/ this location was not seen during endoscopy

(i.e. which procedure were performed)

4. Disease extent and localisation

Visual

Mouth *

- ☐ Aphthous ulcers
- ☐ Orofacial granulomatosis
- ☐ Normal

Upper endoscopy

Oesophagus *

- ☐ Abnormal
- ☐ Normal
- ☐ Not Visualised

Stomach *

- ☐ Abnormal
- ☐ Normal
- ☐ Not Visualised

Duodenum *

- ☐ Abnormal
- ☐ Normal
- ☐ Not Visualised

Capsule endoscopy or enteroscopy

Jejunum *

- ☐ Abnormal
- ☐ Normal
- ☐ Not visualised

Ileum (not terminal) *

- ☐ Abnormal
- ☐ Normal
- ☐ Not visualised

(ileo)colonoscopy

Terminal ileum *

- ☐ Abnormal
- ☐ Normal
- ☐ Not visualised

Cecum *

- ☐ Abnormal
- ☐ Normal
- ☐ Not visualised

Ascending colon *

- ☐ Abnormal
- ☐ Normal
- ☐ Not visualised

Transverse colon *

- ☐ Abnormal
- ☐ Normal
- ☐ Not visualised

Descending colon *

- ☐ Abnormal
- ☐ Normal
- ☐ Not visualised

Sigmoid *

- ☐ Abnormal
- ☐ Normal
- ☐ Not visualised

Rectum *

- ☐ Abnormal
- ☐ Normal
- ☐ Not visualised

Anus

Anus *

- ☐ Abnormal
- ☐ Normal

General endoscopic/histological features of the colon

Endoscopic/histological features of the colon *

- ☐ Macroscopically AND microscopically normal appearing segments of colon (except for rectal sparing and cecal patch)
- ☐ Relative patchiness (=Macroscopically normal colon but with microscopic inflammation in between inflamed mucosa)
- ☐ Reverse gradient of mucosal inflammation (proximal more inflammation than distal, except rectal sparing)
- ☐ Complete (macroscopic and microscopic) rectal sparing
- ☐ None of above

Visual → what you see with your own eyes (so not during endoscopy)

1. Select from the list what you could see in the mouth

Upper endoscopy

Oesophagus *	Stomach *	Duodenum *
<input checked="" type="radio"/> Abnormal	<input type="radio"/> Abnormal	<input type="radio"/> Abnormal
<input type="radio"/> Normal	<input checked="" type="radio"/> Normal	<input checked="" type="radio"/> Normal
<input type="radio"/> Not Visualised	<input type="radio"/> Not Visualised	<input type="radio"/> Not Visualised

Oesophagus details

Oesophagus *	Small, not deep ulcerations *	Deep ulceration *
<input checked="" type="checkbox"/> Small, not deep ulcerations, including aphthous ulcerations	<input type="radio"/> None of below	<input type="radio"/> None of below
<input checked="" type="checkbox"/> Deep ulceration	<input type="checkbox"/> Helicobacter Pylori	<input type="checkbox"/> Helicobacter Pylori
<input type="checkbox"/> Cobblestoning	<input type="checkbox"/> NSAIDs treatment	<input type="checkbox"/> NSAIDs treatment
<input type="checkbox"/> Stenosis	<input type="checkbox"/> Celiac disease	<input type="checkbox"/> Celiac disease

Upper endoscopy → what you see during upper endoscopy

1. At all listed locations (oesophagus, stomach, duodenum) select whether what you saw was abnormal (consistent with IBD) or normal
 - If 'abnormal' is selected for any location, a pop-up for that location will appear with a check-list of details for the abnormal findings.
 - If 'abnormal' is selected for a location and details of that abnormality then selected in the subsequent pop-up, more details will be asked for certain fields.

Capsule endoscopy or enteroscopy (only appears if indicated to have been performed in the work-up

Capsule endoscopy or enteroscopy

Jejunum *	Ileum (not terminal) *
<input checked="" type="radio"/> Abnormal	<input checked="" type="radio"/> Abnormal
<input type="radio"/> Normal	<input type="radio"/> Normal
<input type="radio"/> Not visualised	<input type="radio"/> Not visualised

Jejunum details

Jejunum *	Small, not deep ulcerations *
<input checked="" type="checkbox"/> Small, not deep ulcerations, including aphthous ulcerations	<input type="radio"/> None of below
<input type="checkbox"/> Significant inflammation	<input type="checkbox"/> Helicobacter Pylori
	<input type="checkbox"/> NSAIDs treatment
	<input type="checkbox"/> Celiac disease

Ileum details

Ileum *	Small, not deep ulcerations *
<input checked="" type="checkbox"/> Small, not deep ulcerations, including aphthous ulcerations	<input type="radio"/> None of below
<input type="checkbox"/> Significant inflammation (more than a few scattered erosions) on capsule endoscopy	<input type="checkbox"/> Helicobacter Pylori
	<input type="checkbox"/> NSAIDs treatment
	<input type="checkbox"/> Celiac disease

section)

- At both listed locations (Jejunum, ileum (not terminal)) select whether what you saw was abnormal (consistent with IBD), normal, or not visualised
 - If 'abnormal' is selected for any location, a pop-up for that location will appear with a check-list of details for the abnormal findings.
 - If 'abnormal' is selected for a location and details of that abnormality are then selected in the subsequent pop-up, more details will be asked for certain fields (as other, non-IBD causes of these abnormalities may (co-)exist (e.g H. Pylori, celiac disease, etc)).

(ileo)colonoscopy

Terminal ileum *	Cecum *	Ascending colon *	Transverse colon *	Descending colon *	Sigmoid *	Rectum *
<input type="radio"/> Abnormal	<input type="radio"/> Abnormal	<input type="radio"/> Abnormal	<input type="radio"/> Abnormal	<input type="radio"/> Abnormal	<input type="radio"/> Abnormal	<input type="radio"/> Abnormal
<input type="radio"/> Normal	<input type="radio"/> Normal	<input type="radio"/> Normal	<input type="radio"/> Normal	<input type="radio"/> Normal	<input type="radio"/> Normal	<input type="radio"/> Normal
<input type="radio"/> Not visualised	<input type="radio"/> Not visualised	<input type="radio"/> Not visualised	<input type="radio"/> Not visualised	<input type="radio"/> Not visualised	<input type="radio"/> Not visualised	<input type="radio"/> Not visualised

(Ileo)colonoscopy

- At all listed locations (terminal ileum, cecum, ascending colon, transverse colon, descending colon, sigmoid, and rectum) select whether what you saw was abnormal (consistent with IBD), normal, or not visualised.
 - If 'abnormal' is selected for any location, a pop-up for that location will appear with a check-list of details for the abnormal findings.
 - If 'abnormal' is selected for a location and details of that abnormality are then selected in the subsequent pop-up, more details will be asked for certain fields (as other, non-IBD causes of these abnormalities may (co-)exist (e.g H. Pylori, celiac disease, etc)).

Anus

Anus *
☒ Abnormal
☐ Normal

Anus details
Anus *
☐ Large inflamed skin tag(s)
☐ Fistula or abscess

Anus

- Select abnormal (consistent with IBD) or normal for your findings
 - If abnormal is selected, a pop-up will appear that makes you tick "large inflamed skin tags" and/or "fistula or abscess". Any other abnormalities (such as fissure or haemorrhoids) do not need to be recorded as these are not relevant for the diagnosis of IBD.

General endoscopic/ histological features of the colon

General endoscopic/histological features of the colon

Endoscopic/histological features of the colon *

- ☐ Macroscopically AND microscopically normal appearing segments of colon (except for rectal sparing and cecal patch)
- ☐ Relative patchiness (=Macroscopically normal colon but with microscopic inflammation in between inflamed mucosa)
- ☐ Reverse gradient of mucosal inflammation (proximal more inflammation than distal, except rectal sparing)
- ☐ Complete (macroscopic and microscopic) rectal sparing
- ☐ None of above

1. Select any and/or all endoscopic/histological features of the colon that were found.

Histology

Upper GI histology

Oesophagus *

- ☐ Abnormal
- ☐ Normal
- ☐ Not biopsied

Stomach *

- ☐ Abnormal
- ☐ Normal
- ☐ Not biopsied

Duodenum *

- ☐ Abnormal
- ☐ Normal
- ☐ Not biopsied

Lower GI Histology

Terminal ileum *

- ☐ Abnormal
- ☐ Normal
- ☐ Not biopsied

Cecum *

- ☐ Abnormal
- ☐ Normal
- ☐ Not biopsied

Ascending colon *

- ☐ Abnormal
- ☐ Normal
- ☐ Not biopsied

Transverse colon *

- ☐ Abnormal
- ☐ Normal
- ☐ Not biopsied

Descending colon *

- ☐ Abnormal
- ☐ Normal
- ☐ Not biopsied

Sigmoid *

- ☐ Abnormal
- ☐ Normal
- ☐ Not biopsied

Rectum *

- ☐ Abnormal
- ☐ Normal
- ☐ Not biopsied

Radiology

Jejunum *

- ☐ Abnormal
- ☐ Normal
- ☐ Not visualised

Ileum *

- ☐ Abnormal
- ☐ Normal
- ☐ Not visualised

Terminal ileum *

- ☐ Abnormal
- ☐ Normal
- ☐ Not visualised

Upper GI Histology

1. For each listed location, select either 'abnormal', 'normal', or 'not biopsied'.
 - o If 'abnormal' is selected for any location, a pop-up for that location will appear with a check-list of details for the abnormal findings.

Lower GI Histology

1. For each listed location, select either 'abnormal', 'normal', or 'not biopsied'.
 - a. If 'abnormal' is selected for any location, a pop-up for that location will appear with a check-list of details for the abnormal findings.

Radiology

1. For each listed location, select either 'abnormal', 'normal', or 'not visualised'.
 - a. If 'abnormal' is selected for any location, a pop-up for that location will appear with a check-list of details for the abnormal findings.

Classification

Class 1	Class 2	Class 3
1	1	2
Diagnosis Isolated Colonic CD (Crohn's disease)		
Is this diagnosis correct? *		
<input type="radio"/> Agree with final diagnosis		
<input type="radio"/> Do not agree		
<input type="radio"/> Will perform additional work-up		

Classification

- The number of findings relevant to each class of the 23-point criteria for PIBD will appear automatically (Class 1, Class 2, Class 3).
 - Diagnosis as generated by the algorithm based upon this classification will appear automatically
1. You will be asked to indicate if you agree with the diagnosis generated, so if the diagnosis you made initially matches this automatically generated one.
 - a. If 'Do not agree' is selected, a pop-up will appear asking for the correct diagnosis according to you.
 2. Depending on what is decided as the final diagnosis, a pop-up will appear asking for details on the Paris Classification. This pop-up differs depending on if it is UC or CD that is declared the final diagnosis.

Paris Classification

Following the diagnosis section, further questions will be present concerning the Paris Classification of your patient.

- It is not mandatory to fill this out, only if the Paris classification is known for the patient.
- Separate Paris Classifications are present depending on if it is a diagnosis of CD or UC (including IBD-U).

Paris Classification UC

Extent ⓘ
<input type="radio"/> E1 (Ulcerative proctitis)
<input type="radio"/> E2 (Left-sided UC, distal to splenic flexure)
<input type="radio"/> E3 (extensive, hepatic flexure distally)
<input type="radio"/> E4 (Pancolitis (proximal to hepatic flexure)
Severity ⓘ
<input type="radio"/> S0 (never severe)
<input type="radio"/> S1 (Ever severe)

- If the final diagnosis is confirmed as a form of UC or IBD-U, fill out the Paris Classification pop-up related to UC by selecting which option for extent and severity describes the exact classification of the patient's UC.

Paris Classification CD

Age at diagnosis

- ☐ A1a (0–<10 years)
- ☐ A1b (10–<17 years)
- ☐ A2 (17–40)
- ☐ A3 (>40 years)

Location

- ☐ L1 (distal 1/3 ileum/ limited cecal disease)
- ☐ L2 (colonic)
- ☐ L3 (ileocolonic)
- ☐ L4a (upper disease proximal to ligament Treitz)
- ☐ L4b (upper disease distal to ligament of Treitz and proximal to distal 1/3 ileum)

L4, L4a/L4b may coexist with L1, L2, and L3, respectively

Behaviour

- ☐ B1 (nonstricturing, nonpenetrating)
- ☐ B2 (stricturing)
- ☐ B3 (penetrating)
- ☐ B2B3 (both penetrating and stricturing disease, either at the same or different times)
- ☐ P (perianal disease modifier)

Growth

- ☐ G0 (no evidence of growth delay)
- ☐ G1 (growth delay)

- If the final diagnosis is confirmed as a form of CD, fill out the Paris Classification pop-up related to CD by selecting which option for age, location, behaviour, and growth describes the exact classification of the patient's CD.
- Location:
 - Multiple options can be clicked for this question.
 - L4, L4a/L4b may be selected together with L1, L2, or, L3, respectively.

Submit

- If all fields are completed and correctly filled-in, click 'submit' at the bottom of the page to finalise your entry into the database.
- Submit officially enters the patient into the database for good, whereas the 'save' button allows the patient entry to still be edited until all information is filled in and can officially be submitted into the database.

References

Levine A, Koletzko S, Turner D, Escher JC, Cucchiara S, de Ridder L, Kolho KL, Veres G, Russell RK, Paerregaard A, Buderus S, Greer ML, Dias JA, Veereman-Wauters G, Lionetti P, Sladek M, Martin de Carpi J, Staiano A, Ruemmele FM, Wilson DC; European Society of Pediatric Gastroenterology, Hepatology, and Nutrition. ESPGHAN revised Porto criteria for the diagnosis of inflammatory bowel disease in children and adolescents. *J Pediatr Gastroenterol Nutr.* 2014 Jun;58(6):795-806.

Birimberg-Schwartz L, Zucker DM, Akriv A, Cucchiara S, Cameron FL, Wilson DC, Lazowska I, Yianni L, Paul SP, Romano C, Kolacek S, Buderus S, Pærregaard A, Russell RK, Escher JC, Turner D; Pediatric IBD Porto group of ESPGHAN. Development and Validation of Diagnostic Criteria for IBD Subtypes Including IBD-unclassified in Children: a Multicentre Study From the Pediatric IBD Porto Group of ESPGHAN. *J Crohns Colitis.* 2017 Sep 1;11(9):1078-1084.