# **IBD Eurokids Update**

# **Web-based Data Registration**

### **User Manual 2021**

## **EUROKIDS**

PUBLICATIONS

ABOUT US

CONTACT



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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				
Login				

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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

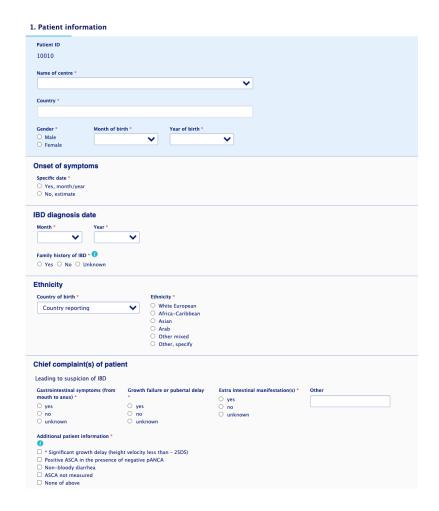
Website link: https://www.eurokidsibd.com/

#### **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**



- 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)
  - O 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.
  - o 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



- 1. Enter the height (in centimetres) and weight (in kilograms) of the patient
  - o 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)
  - o 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 *  yes  no
Colonoscopy *  yes  no
intubation of the terminal ileum *  yes  no
MR-Enterography *  O yes  O no
Abdominal ultrasound  yes  no
Capsule endoscopy O yes O no
Single/double balloon enteroscopy  yes  no
Abdominal CT O yes O no
Small bowel follow through (SBFT)  yes  no
Other

- 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 exten	nt and localisatio	n					
Visual							
Mouth * Aphthous ulcers Orofacial granulo Normal	omatosis						
Upper endoscop	ру						
Oesophagus * Abnormal Normal Not Visualised	Stomach •      Abnormal     Normal     Not Visualised	Duodenum *      Abnormal     Normal     Not Visualised					
Capsule endosc	opy or enterosco	рру					
Jejunum *	Ileum (not terminal) *  Abnormal  Normal  Not visualised						
(ileo)colonoscop	ру						
Terminal ileum *      Abnormal     Normal     Not visualised	Cecum *	Ascending colon * Abnormal Normal Not visualised	Transverse colon * Abnormal Normal Not visualised	Descending colon * Abnormal Normal Not visualised	Sigmoid *      Abnormal     Normal     Not visualised	Rectum * O Abnormal O Normal O Not visualised	
Anus							
Anus *  Abnormal  Normal							
General endosco	opic/histological	features of the	colon				
Macroscopically / rectal sparing and Relative patchine inflammation in b	ss (=Macroscopically no between inflamed muco of mucosal inflammatio	mal appearing segment ormal colon but with mid sa) on (proximal more inflan	croscopic				

#### Visual $\rightarrow$ what you see with your own eyes (so not during endoscopy)

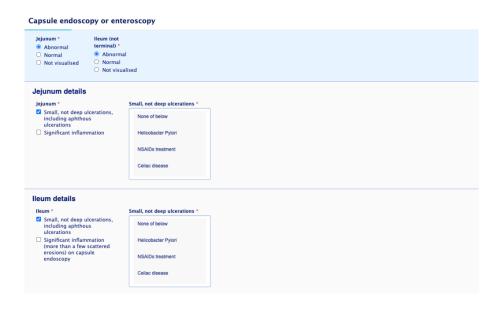
1. Select from the list what you could see in the mouth



Upper endoscopy  $\rightarrow$  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
  - 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.
    - 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



section)

- 1. 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



#### (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.
  - 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.
  - o 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

- 1. Select abnormal (consistent with IBD) or normal for your findings
  - o 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 *			E	Ei	Ei	Er	En	ne	d	os	sco	ор	ic/	hi	to	log	jic	al	fe	atı	ıre	s (	of	the	e c	ol	on	*																																		
<ul> <li>Macroscopically AND microscopically normal appearing segments of colon (except for rectal sparing and cecal patch)</li> </ul>																								ca	lly	n	or	ma	l a	оре	ar	in	g	se	gn	nei	nt	S	of	f c	:ol	lor	n (	ex	ce	ep	t i	for	r													
<ul> <li>Relative patchiness (=Macroscopically normal colon but with microscopic inflammation in between inflamed mucosa)</li> </ul>																													al c	olo	n	bι	ut	wi	th	m	ic	rc	os	co	p	ic																				
<ul> <li>Reverse gradient of mucosal inflammation (proximal more inflammation than distal, except rectal sparing)</li> </ul>																				cc	sa	Lii	nfl	an	ım	ıat	ioi	n ()	oro	xir	nal	l n	no	re	in	fla	ım	nn	na	atio	or	n t	ha	n	di	st	al	l,														
Complete (macroscopic and microscopic) rectal sparing				$\Box$				)	(	Со	om	np	let	e (	ma	cr	DS4	co	pi	: a	nc	m	ic	ros	sco	op'	ic)	re	cta	sp	oar	rin	g																													
□ None of above				$\Box$				)	١	No	on	ie i	of	ab	ov	2																																														

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 * O Abnormal O Normal O Not biopsied	Duodenum *  Abnormal  Normal  Not biopsied				
Lower GI Histolo	gy					
Terminal ileum *      Abnormal     Normal     Not biopsied	Cecum * O Abnormal O Normal O Not biopsied	Ascending colon *  Abnormal  Normal  Not biopsied	Transverse colon *      Abnormal     Normal     Not biopsied	Descending colon *  Abnormal  Normal  Not biopsied	Sigmoid * O Abnormal O Normal O Not biopsied	Rectum * O Abnormal Normal Not biopsied
Radiology						
Jejunum * O Abnormal O Normal O Not visualised	Ileum * O Abnormal O Normal O 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.

# Class 1 Class 2 Class 3 1 1 2 Diagnosis Isolated Colonic CD (Crohn's disease) Is this diagnosis correct? \* Agree with final diagnosis Do not agree Will perform additional work-up

#### Classification

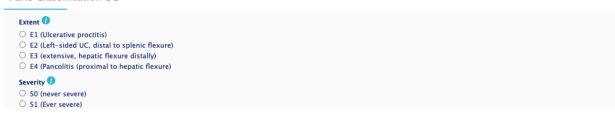
- The number of findings relevant to each class of the 23-point criteria for PIBD will appear automatically (Class 1, Class 2, Class 3).
- Diagnosis as generated by the algorithm based upon this classification will appear automatically
- 1. You will be asked to indicate if you agree with the diagnosis 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

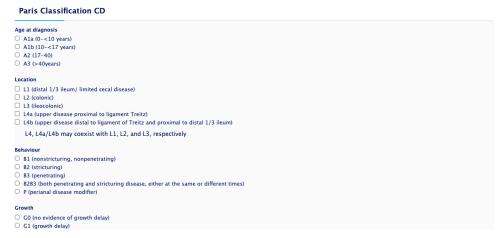
Following the diagnosis section, further questions will be present concerning the Paris Classification of your patient.

- 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



- 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.



- 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.