

1. Patient personal details

Insurance number:.....
Name:.....
Phone number:.....
E-mail address:.....
Age:

Time of questioning:(year, month, day)

2. Diagnosis:

Do you still consider the patient to have IBD? Yes / No

If yes: **Has the classification changed over the past year?** (e.g. from IBD-U to CD) Yes / No

If yes: Crohn disease / ulcerative colitis / IBDU

If no, **the new diagnosis:**.....

3. Anamnesis / risk factors

Actual education: elementary school / vocational school / secondary school

Smoking: Yes / No

If yes: amount (cigarettes/day):.....

For how many years?:.....

Alcohol consumption: Yes / No

If yes: frequency: occasionally/monthly/weekly/daily

amount (g/day):.....

Since when? (years).....

alcohol consumption in the last 2 weeks (g):.....

Guide for estimation of the amount:

1 dl beer (4.5 vol. %) = ~3.5 g alcohol

1 dl wine (12.5 vol. %) = ~10 g alcohol

1 dl hard drink (50 vol. %) = ~40 g alcohol

Caffeine consumption: Yes / No

If yes, in what form do you consume caffeine?

Coffee: Yes / No

If yes, how often do you consume coffee? occasionally / monthly / weekly / daily

How much do you consume?.....(1 dose = one espresso or long coffee)

Instant Coffee: Yes / No

If yes, how often do you consume instant coffee? occasionally / monthly / weekly / daily

How much do you consume?.....(1 dose = one packet)

Tee (black or green): Yes / No

If yes, how often do you consume tee? occasionally / monthly / weekly / daily

How much do you consume?.....(1 dose =2 dl)

Energy drink: Yes / No

If yes, how often do you consume energy drink? occasionally / monthly / weekly / daily

How much do you consume?.....(1 dose = 2,5 dl)

Coca-cola: Yes / No

If yes, how often do you consume coca-cola? occasionally / monthly / weekly / daily

How much do you consume?.....(1 dose =3,3 dl)

Caffeine tablet: Yes / No

Country:
City:
Hospital:
Doctor:
Blood sample code:
Date of blood sampling:

If yes, how often do you consume caffeine tablet? occasionally / monthly / weekly / daily
How many do you consume?.....(1 dose =1 tablet= 100 mg)

Drug abuse: Yes / No *Prescribed medication should not be included here.*

If yes, what kind of drug did you consume?

Party drugs: (pl. Amfetamin, Ecstasy, Gina, Mefedron): Yes / No

If yes, how much did you take?How many years ago?.....

Light drugs: (LSD, Marihuana, Hasis): Yes / No

If yes, how much did you take?How many years ago?.....

Hard drugs: (Crack, Heroin, Cocain, Opium): Yes / No

If yes, how much did you take?How many years ago?.....

Medicines: (Diazepám, Cetamin, Codein): Yes / No

If yes, how much did you take?How many years ago?.....

Designer drugs: (Mefedron, sintetic cannabinoids): Yes / No

If yes, how much did you take?How many years ago?.....

Oral contraceptive usage: Yes / No

If yes, when did you take oral contraceptives? before IBD diagnosis/ at the time of IBD diagnosis

If yes, total duration of Oral contraceptive usage..... (in months)

4. 3rd month control

Is this the the 3rd month control? Yes / No

Is the patient in remission according to....?

clinical symptoms (PCDAI/PUCAI 10 alatt) Yes / No

laboratory Yes / No

faecal calprotectin Yes / No

imaging Yes / No

If yes: MRE / US / Capsule endoscopy / other:.....

endoscopy Yes / No

Was the induction therapy nutritional therapy ? Yes / No

If yes: exclusive enteral nutrition (EEN) / CDED + partial enteral nutrition / other:.....

Did the patient go through the nutritional therapy? Yes / No

If no, why not? The patient did not tolerate it / it was not effective

Other nutritional therapy was tried? Yes / No

If yes, which? EEN / CDED + partial enteral nutrition / other:.....

Did the patient go through it? Yes / No

It was effective? Yes / No

5. Main events since the last completed form

Was any examination/intervention recently performed, which was not recorded in the IBD registry? Yes / No

If yes: surgical intervention / endoscopy / imaging / other:.....

Date of it:..... (file can be attached)

According to your answer, please fill out the further necessary form(s): form E; I; S

Have any of the following applied recently? perianal lesion / extraintestinal manifestation / pregnancy / complication / other:.....

According to your answer, please fill out the further necessary form(s): form C; P

Perianal lesion: skin tag / fissura / abscess / fistula / other:.....

CD with fistula:

type of the fistula: simple / complex

localization of the fistula: perianal / rectovaginal / entero-enteral / enterocutan / enterovesical

determination of fistula type: physical state / endoscopy / images of the pelvic: (MRE / Ultrasound)
/ EUA: rectal examination in anaesthesia

number of fistula:.....(number)

Type of extraintestinal manifestation(s): uveitis / pyoderma gangrenosum / erythema nodosum /
arthritis / arthralgia / osteoporosis / sclerotic cholangitis / autoimmun hepatitis / other:

Has the patient experienced relapse recently? Yes / No

If yes, How many times?.....

Was the PUCAI during the relapse >65? Yes / No

Has the Paris classification changed recently? Yes / No

If yes:

Age at diagnosis: **A1a:** 0 to <10 yr / **A1b** 10 to <17 yr / **A2:** 17 - 40 yr

In case of CD:

Localization: L1: distal 1/3 ileal + limited cecal disease / **L2:** colonic / **L3:** ileocolonic **L4a:**
upper disease proximal to ligament of Treitz / **L4b** upper disease distal to ligament of Treitz

Behaviour: B1: non-stricturing, non-penetrating / **B2:** stricturing / **B3:** penetrating / **B2B3:** both
penetrating and structuring disease either at the same or different times

Growth: G0: no evidence of growth delay / **G1:** growth delay

In case of UC and IBD-U:

Localization: E1: ulcerative proctitis / **E2:** left-sided UC (distal to splenic flexure) / **E3:** extensive
colitis (hepatic flexure distally) / **E4:** pancolitis (proximal to hepatic flexure) cannot be judged, no
complete colonoscopy was performed

Severity: S0 (PUCAI < 65) / **S1** (PUCAI ≥ 65)

Has the patient recently experienced: steroid dependency / steroid refractory / no

Was the patient recently admitted to the hospital due to IBD? Yes / No

If yes, **What was the reason?** disease relapse / complication / other.....

Was dose modification needed at any of the currently taken drugs? Yes / No

if yes: dose elevation / dose reduction / frequency increase / frequency decrease

Which drug's dose was modified?.....

New dose of the drug?.....

Dosage:.....

Dosage interval: daily / weekly

Unit: g, mg, NE, packet, piece

Was the discontinuation of a currently taken drug needed? Yes / No

If yes, the name of the drug:.....

the reason for the discontinuing: side effect / intolerance / infusion reaction / primary nonresponse / secondary loss of response / financial reasons / refractory / dependency / infection / other.....

If side effect, name it:.....

If infection, name it:

Was the initiation of a completely new drug(s) needed? Yes / No

If yes, name of the drug:.....

active substance:.....

dose:

unit: g / mg / NE / packet / piece

dosage:

dosage interval: daily / weekly

method of administration: intravenous / per os / subcutan / cone / enteral / rectal (enema)

other consideration:

the reason for starting a new drug: disease activity / ineffectiveness of the currently taken drug(s) / due to the patient's complaints / intolerance of the currently taken drug(s) / fistula formation

6. Current drug therapy

the name of the drug:.....

active substance:.....

dose:.....

unit of measure: gramm / milligram / NE / packet / piece

in case of liquid, concentration:.....

dosage:.....

dosage interval: daily / weekly

method of administration: intravenous / per os / subcutan / cone / enteral / rectal (enema)

other consideration:

the name of the drug:.....

active substance:.....

dose:.....

unit of measure: gramm / milligram / NE / packet / piece

in case of liquid, concentration:.....

dosage:.....

dosage interval: daily / weekly

method of administration: intravenous / per os / subcutan / cone / enteral / rectal (enema)

other consideration:

the name of the drug:.....

active substance:.....

dose:.....

unit of measure: gramm / milligram / NE / packet / piece

in case of liquid, concentration:.....

dosage:.....

dosage interval: daily / weekly

method of administration: intravenous / per os / subcutan / cone / enteral / rectal (enema)

other consideration:

Does the patient take any formula? Yes / No

- If yes: exclusive enteral nutrition: Yes / No
- partial enteral nutrition: Yes / No
- partial enteral nutrition + CDED (Crohn's disease exclusion diet): Yes / No
- other:.....
- quantity of the formula (ml)

Is iron substitution needed? Yes / No

If yes, the name of the applied iron substitution:.....
the way of intake: intravenous / per os

Does the patient follow any kind of diet? Yes / No

If yes, what kind of diet does the patient keep?.....

Has the patient been transferred to adult care? Yes / No

- If yes, transition / transfer
- If transition: number of transition visit:(number)
- If transfer: Was there telephone consultation with a gastroenterologist? Yes / No

7. Status, present complaints

- Weight:**..... (kg)
- Height:**..... (m)
- BMI:**.....(kg/m²)
- Percentile:**..... (pc)

Pediatric Crohn's Disease Activity Index (PCDAI)

1. ANAMNESIS

Abdominal pain:

- none 0 point
- mild, does not interfere with activities 5 point
- moderate / severe, affect activities 10 point

Number of stools per day

- 0-1x, no blood 0 point
- 1-2x, semi formed, small blood or 2-5x, liquid 5 point
- ≥6 liquid, gross blood, or nocturnal diarrhea 10 point

General well-being of the child

- Well, no limitations of activities 0 point
- Occasional difficulty in maintaining age-appropriate activities 5 point
- frequent limitation of activity 10 point

2. Laboratory

Hematocrit:

- > 34% 0 point
- 30-33% 2,5point
- < 29% 5 point

We (mm/h) or CRP (mg/l):

- < 20 0 point
- 20-50 2,5 point
- > 50 5 point

Albumin (g/l):

- > 35 0 point
- 31-34 5 point
- < 30 10 point

3. Physical examination

Weight development

Adequate growth	0 point
Held weight, 1-9% weight loss	5 point
Weight loss $\geq 10\%$	10 point

Lack of length growing

< 1 SD	0 point
1-2 SD	5 point
> 2 SD	10 point

Abdomen

No tenderness, no mass	0 point
Tenderness; or mass, without abdominal pain	5 point
Tenderness/ abdominal pain, mass	10 point

Perirectal disease

None	0 point
1-2 indolent fistulae, scant drainage, and no tenderness	5 point
Active fistula, abscess	10 point

Extraintestinal manifestation (*Fever $\geq 38.5^{\circ}\text{C}$ (101.3°F) for 3 days over past week, arthritis, uveitis, erythema nodosum, or pyoderma gangrenosum*)

None	0 point
1	5 point
≥ 2	10 point

Results

PCDAI scores (min 0 - max 100 point):

<i>Total remission, no activation</i>	<i>< 10</i>
<i>Mild activity</i>	<i>11-30</i>
<i>Severe, expressed activity</i>	<i>31-100</i>

Pediatric Ulcerative Colitis Activity Index (PUCAI)

Abdominal pain:

None	0 point
Mild, pain can be ignored	5 point
Moderate / severe pain cannot be ignored	10 point

Rectal bleeding

None	0 point
Small amount only, in <50% of stools	10 point
Small amount only, in >50% of stools	20 point
Large amount, in >50% of stools	30 point

Stool consistency of most stools

Formed	0 point
Partially formed	5 point
Completely unformed	10 point

Number of stools / 24h

0-2	0 point
3-5	5 point
6-8	10 point
> 8	15 point

Nocturnal stools

No	0 point
Yes	10 point

General well-being of the child

No limitations of activity	0 point
Occasional limitations of activity	5 point
Severe restricted activity	10 point

Results

PUCAI scores (min 0 – max 85):.....

<i>Total remisison, no activity</i>	<i>< 10</i>
<i>mild activity</i>	<i>10-34</i>
<i>moderate activity</i>	<i>35-64</i>
<i>severe activity</i>	<i>65<</i>

MINI index

Stool (previous week)

0-1 normal or liquid stool without blood	0 point
≤2 stool with blood, or 2-5 liquid stool	4 point
Large amount of blood, or > 5 liquid stool, or nocturnal stool	8 point

Fecal calprotectin

<50 ug/g	-3 point
50-99,9 ug/g	0 point
100-299,9 ug/g	5 point
300-599,9 ug/g	7 point
600-899,9 ug/g	9 point
>900 ug/g	12 point

ESR and CRP (assess both of them or just one)

We < 10 mm/h or CRP <5mg/L	0 point
30 >We> 10 mm/h or 10 > CRP> 5 mg/L	1 point
50 > We > 30 mm/h or 30 > CRP>10 mg/L	2 point
We > 50 mm/h or CRP>30 mg/L	5 point

Results

MINI index scores (min -3 – max 25 point):.....

cut off: < 6 mucosal healing, > 8 mucosal inflammation

Activity of CD with fistula: PDAI (perianal disease activity index):
Does the patient sexually active? Yes / No / not known

QUESTIONS		Points
1	<p>Discharge: 0 = no discharge; 1 = minimal mucous discharge; 2 = moderate mucous or purulent discharge; 3 = substantial discharge; 4 = gross fecal soiling</p>	
2	<p>Pain/ restriction of activities: 0 = no activity restriction; 1 = mild discomfort, no restriction; 2 = moderate discomfort, some limitation activities; 3 = marked discomfort, marked limitation; 4 = severe pain, severe limitation</p>	
3	<p>Restriction of sexual activity: 0 = no restriction in sexual activity; 1 = slight; 2 = moderate; 3 = marked; 4 = unable to engage in sexual activity</p>	
4	<p>Type of the perianal disease: 0 = no perianal disease/ skin tags; 1 = anal fissure or mucosal tear; 2 = <3 perianal fistula; 3 = >3 perianal fistula; 4 = anal sphincter ulceration or fistula with significant undermining of skin</p>	
5	<p>Degree of infiltration: 0 = no; 1 = minimal induration; 2 = moderate induration; 3 = substantial induration; 4 = abscess</p>	
PDAI score:		

8. Serum tests

Erythrocyte sedimentation rate (We) (mm/h)	
CRP (mg/l)	
Blood	Yes / No
WBC count (G/l)	
RBC count (T/l)	
Hemoglobin (g/l)	
Hematocrit (%)	
MCV	
Platelet count (G/l)	
Ions	Yes / No
Sodium (mmol/l)	
Potassium (mmol/l)	
Calcium (mmol/l)	
Magnesium (mmol/l)	
Phosphate (mmol/l)	
Chloride (mmol/l)	
Iron (umol/l)	
Pancreas	Yes / No
Glucose (mmol/l)	
Alfa amilase (U/l)	
Lipase (U/l)	
Renal function	Yes / No
Urea nitrogen (Carbamid / BUN) (mmol/l)	
Creatinin (umol/l)	
eGFR	
Liver function	Yes / No
Total bilirubin (umol/l)	
Direct/conjugated bilirubin (umol/l)	
Indirect bilirubin (umol/l)	
ASAT / GOT (U/l)	
ALAT / GPT (U/l)	
Gamma GT (U/l)	
Alkaline phosphatase (U/l)	
Lactate dehydrogenase LDH (U/l)	
Protrombin (%)	
Protrombin INR	
Metabolism	Yes / No
Cholesterol (mmol/l)	
Triglicerides (mmol/l)	
Uric acid (umol/l)	
TSH (mU/l)	
HgbA1C (%)	
Proteins	Yes / No
Total protein (g/l)	
Albumin (g/l)	
Globulin alfa1 (g/l)	
Globulin alfa2 (g/l)	
Globulin beta (g/l)	

Globulin gamma (g/l)	
Fibrinogen (g/l)	
IBD	Yes / No
Calprotectin (µg/g)	
Procalcitonin (ng/ml)	
IgA (g/l)	
IgM (g/l)	
IgG (g/l)	
Ferritin (ug/l)	
Transferrin saturation (%)	
B12 level (pmol/l)	
Folic acid (nmol/l)	
ASCA IgA	
ASCA IgG	
ANA	
pANCA	
IgG4 (g/l)	
CEA (ug/l)	
CA 19-9 (U/ml)	
Infliximab TL (ug/ml)	
Adalimumab TL (ug/ml)	
Anti-Infliximab antibody (ug/ml)	
Anti-Adalimumab antibody (ug/ml)	
Vvt.6-TGN (pmol/8x108 RBC)	

9. Other comments

Are there any information which is not uploaded above? Yes / No
 If yes, Comments related to the patient:.....
 (File upload is possible)