MALAYSIAN IBD REGISTRY - CROHN'S DISEASE
Notification Form (Proforma-A)

Office use:

Centre/PatientID:

Instruction:
Where check boxes are provided, check (√) one or more boxes. Where radio buttons are provided, check (√) one box only.

Reporting Centre ______________________ **ii) Date of Notification** ___ / ___ / ___ *(dd/mm/yy)*

SECTION 1: PATIENT DETAILS

1. Name	
2. Identification Card number ** If Mykad/Mykid is not available, please complete Other ID document No.*	*MyKad / MyKid* ______ - ___ - ____ *Other ID document No:* ______ *Specific type (eg.passport, of armed forces ID)* ______
3. Address	 Postcode: Town/City: State:
4a. Date of birth	___ / ___ / ___ *(dd/mm/yy)*
4b. Age at notification * *(Auto Calculated)*	___ *Year(s)* ___ *Month(s)*
5. Gender	○ Male ○ Female
6. Ethnic group	○ Malay ○ Chinese ○ Indian ○ Melanau ○ Iban ○ Bidayuh ○ Dusun ○ Orang asli ○ Kadazan ○ Murut ○ Bajau ○ Others________
7. Contact number	Home: Mobile: Office:
8. Level of education	○ NIL ○ Primary ○ Secondary ○ Tertiary
9. Household income	○ B40 *Represents the Bottom 40% – low-income earners* *Bottom tier income earners account for 40% of the country's total income* *Bottom tier families have an income of less than RM4850 monthly* ○ M40 *Represents the Medium 40% – average income earners* *Medium tier income earners account for 40% of the country's total income* *Medium tier families have an income of between RM4850 to RM10959 monthly* ○ T20 *Represents the Top 20% – top income earners* *Top tier income earners account for 20% of the country's total income* *Top tier families have an income higher than RM10959 monthly*
10. Occupation	○ Student ○ Working → ○ Government / ○ Private / NGO / ○ Self-employed / Family business ○ Unemployed ○ Retired →

SECTION 2: DIAGNOSIS

1. Year of Diagnosis	_ _ _ _ Year	2. Age at Diagnosis * (Auto Calculated)	_ _ Year(s) _ _ Month(s)

3. First initial clinical presentation suggestive of IBD

Presentation	Date
☐ Abdominal pain	_ _ / _ _ _ _ (mm/yyyy)
☐ Diarrhea	_ _ / _ _ _ _ (mm/yyyy)
☐ Rectal bleed	_ _ / _ _ _ _ (mm/yyyy)
☐ Abscess	_ _ / _ _ _ _ (mm/yyyy)
☐ Failure to thrive	_ _ / _ _ _ _ (mm/yyyy)
☐ Weight loss	_ _ / _ _ _ _ (mm/yyyy)
☐ Bowel obstruction	_ _ / _ _ _ _ (mm/yyyy)
☐ Fistula	_ _ / _ _ _ _ (mm/yyyy)
☐ Others___________ ___________	_ _ / _ _ _ _ (mm/yyyy)

4. Diagnosis supported by

	Findings	Date (dd/mm/yy)
☐ Endoscopy		_ _ / _ _ / _ _
☐ Histology		_ _ / _ _ / _ _
☐ Radiology		_ _ / _ _ / _ _
☐ Surgery		_ _ / _ _ / _ _
☐ Others		_ _ / _ _ / _ _

5. Smoking history

◯ Current smoker →	Number of packs year	_ _ _ _
◯ Ex-smoker →	Year of stop smoking	_ _ _ _
◯ Non-smoker		

SECTION 2: DIAGNOSIS (continue)

6. First degree family members with diagnosis of IBD

No Yes

FAMILY MEMBER	ULCERATIVE COLITIS (check if Yes)	CROHN'S DISEASE (check if Yes)
Father		
Mother		
Brother		
Sister		

SECTION 3: DISEASE CHARACTERISTICS

1. Location

- L1 - Ileal
- L2 - Colonic
- L3 - Ileocolonic
- L4 - Upper GI

2. Behaviour

- B1 - Non-stricturing , Non-penetrating
- B2 - Stricturing
- B3 - Penetrating/Fistulizing
- P - Perianal

3. Current disease activity

Harvey Bradshaw Index (HBI)

HBI Score	0	1	2	3	4	5
1. General well being	Very well	Slightly below par	Poor	Very poor	Terrible	
2. Abdominal pain	None	Mild	Moderate	Severe		
3. Number of liquid stools per day	0 - 1	2 - 3	4 - 5	6 - 7	8 - 9	10+
4. Abdominal mass	None	Dubious	Definite	Definite and tender		

5. Complications (score 1 per item)

Arthralgia Uveitis Erythema nodosum Aphthous ulcers
Pyoderma gangrenosum Anal fissure New fistula Abscess

TOTAL SCORE :______________

* *(Auto Calculated)*

HBI Interpretation	
< 5	Remission
5 - 7	Mildly active
8 - 16	Moderately active
≥ 16	Severely active

4. Associated disorders

- PSC
- Thromboembolic complication
- Others____

SECTION 4: THERAPY

1. Medical (Long term/ Maintenance Only)

Medication	Ongoing Check if YES	Date	Reason for stopping
☐ **Corticosteroid**	☐	*Date Start :* / / *Date Stop :* / /	
☐ **5-ASA**			
☐ Oral	☐	*Date Start :* / / *Date Stop :* / /	
☐ Topical	☐	*Date Start :* / / *Date Stop :* / /	
☐ **Immunomodulator**			
☐ Azathioprine	☐	*Date Start :* / / *Date Stop :* / /	
☐ 6-mercaptopurine	☐	*Date Start :* / / *Date Stop :* / /	
☐ Methotrexate	☐	*Date Start :* / / *Date Stop :* / /	
☐ Tacrolimus	☐	*Date Start :* / / *Date Stop :* / /	
☐ Cyclosporine	☐	*Date Start :* / / *Date Stop :* / /	
☐ **Biologics**			
☐ **Anti TNF**			
☐ Infliximab	☐	*Date Start :* / / *Date Stop :* / /	
☐ Adalimumab	☐	*Date Start :* / / *Date Stop :* / /	
☐ Golimumab	☐	*Date Start :* / / *Date Stop :* / /	
+ Add Medication			

SECTION 4: THERAPY (continue)

Medication	Ongoing *Check if YES*	Date	Reason for stopping
☐ **Anti Integrin**			
☐ Vedolizumab	☐	*Date Start :* / / *Date Stop :* / /	
+ Add Medication			
☐ **Anti IL**			
☐ Ustekinumab	☐	*Date Start :* / / *Date Stop :* / /	
☐ Guselkumab	☐	*Date Start :* / / *Date Stop :* / /	
+ Add Medication			
☐ **JAK inhibitors** ____________ ____________	☐	*Date Start :* / / *Date Stop :* / /	
☐ **Others**________ ____________ ____________ __________	☐	*Date Start :* / / *Date Stop :* / /	

2. Surgical

☐ Surgical

	Details	Date (dd/mm/yy)
☐ a. Resection		/ /
☐ b. Perianal		/ /
	☐ Incision and Drainage	/ /
	☐ Seton	/ /
	☐ Fistulotomy	/ /
	☐ Others________________________ ____________________________	/ /
☐ **Others**________ ____________		/ /

+ ADD SURGERY

SECTION 5: VACCINATION

1. Vaccine

	Date vaccinated
Influenza	/ (mm/yyyy)
HPV	/ (mm/yyyy)
Hepatitis B	/ (mm/yyyy)
Pneumococcal	/ (mm/yyyy)
Varicella	/ (mm/yyyy)
Covid	/ (mm/yyyy)