

MALAYSIAN IBD REGISTRY - ULCERATIVE COLITIS 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 <small>* If Mykad/Mykid is not available, please complete Other ID document No.</small>	MyKad / MyKid	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	
	Other ID document No:		Specific type (eg. passport, of armed forces ID)
3. Address			
	Postcode:	Town/City:	State:
4a. Date of birth	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> (dd/mm/yy)		
4b. Age at notification <small>* (Auto Calculated)</small>	<input type="text"/> <input type="text"/>	Year(s)	<input type="text"/> <input type="text"/>
5. Gender	<input type="radio"/> Male <input type="radio"/> Female		
6. Ethnic group	<input type="radio"/> Malay <input type="radio"/> Chinese <input type="radio"/> Indian <input type="radio"/> Melanau <input type="radio"/> Iban <input type="radio"/> Bidayuh <input type="radio"/> Dusun <input type="radio"/> Orang asli <input type="radio"/> Kadazan <input type="radio"/> Murut <input type="radio"/> Bajau <input type="radio"/> Others _____		
7. Contact number	Home:	Mobile:	Office:
8. Level of education	<input type="radio"/> NIL <input type="radio"/> Primary <input type="radio"/> Secondary <input type="radio"/> Tertiary		
9. Household income	<input type="radio"/> B40 <i>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</i> <input type="radio"/> M40 <i>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</i> <input type="radio"/> T20 <i>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</i>		
10. Occupation	<input type="radio"/> Student <input type="radio"/> Working → <input type="radio"/> Government <input type="radio"/> Unemployed <input type="radio"/> Private / NGO <input type="radio"/> Retired → <input type="radio"/> Self-employed / Family business		

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SECTION 2: DIAGNOSIS

1. Year of Diagnosis	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	2. Age at Diagnosis * (Auto Calculated)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	Year(s)	<input type="text"/>	<input type="text"/>	Month(s)
	Year					Year(s)							

3. First clinical presentation suggestive of Ulcerative Colitis	<input type="checkbox"/> Abdominal pain	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	(mm/yyyy)
	<input type="checkbox"/> Diarrhea	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	(mm/yyyy)
	<input type="checkbox"/> Rectal bleed	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	(mm/yyyy)
	<input type="checkbox"/> Others _____	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	(mm/yyyy)

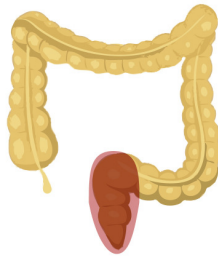
4. Diagnosis supported by	Findings		Date (dd/mm/yy)
	<input type="checkbox"/> Endoscopy	MAYO Score - An endoscopic scoring system for ulcerative colitis	
<input type="radio"/> Score 0		Normal or inactive disease	
<input type="radio"/> Score 1		Mild disease (erythema, decreased vascular pattern, mild friability)	
<input type="radio"/> Score 2		Moderate disease (marked erythema, absent vascular pattern, friability, erosions)	
<input type="radio"/> Score 3		Severe disease (spontaneous bleeding, ulceration)	
<input type="checkbox"/> Histology			<input type="text"/> / <input type="text"/> / <input type="text"/>
<input type="checkbox"/> Radiology			<input type="text"/> / <input type="text"/> / <input type="text"/>
<input type="checkbox"/> Surgery			<input type="text"/> / <input type="text"/> / <input type="text"/>
<input type="checkbox"/> Others			<input type="text"/> / <input type="text"/> / <input type="text"/>

5. Smoking history	<input type="radio"/> Current smoker → Number of packs year	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
	<input type="radio"/> Ex-smoker → Year of stop smoking	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
	<input type="radio"/> Non-smoker				

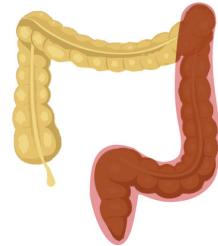
6. First degree family members with diagnosis of IBD	<input type="radio"/> No			
	<input type="radio"/> Yes →	FAMILY MEMBER	ULCERATIVE COLITIS (check if Yes)	CROHN'S DISEASE (check if Yes)
	<input type="checkbox"/> Father		<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/> Mother		<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/> Brother		<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/> Sister		<input type="checkbox"/>	<input type="checkbox"/>

SECTION 3: DISEASE CHARACTERISTICS

1. Extent of disease



- E1 - Proctitis
Involvement limited to the rectum



- E2 - Left side colitis
Involvement limited to the proportion of the colon distal to the splenic flexure



- E3 - Extensive colitis
Involvement extends proximal to the splenic flexure including pancolitis

2. Current disease activity

Simple Clinical Colitis Activity Index (SCCAI) (For Ulcerative Colitis patient)

SCCAI Score	0	1	2	3	4
1. Bowel frequency (per day)	<input type="radio"/> 1 - 3	<input type="radio"/> 4 - 6	<input type="radio"/> 7 - 9	<input type="radio"/> > 9	
2. Bowel frequency (per night)	<input type="radio"/> None	<input type="radio"/> 1 - 3	<input type="radio"/> 4 - 6		
3. Urgency of defecation	<input type="radio"/> Normal	<input type="radio"/> Hurry	<input type="radio"/> Immediately	<input type="radio"/> Incontinence	
4. Blood in stool	<input type="radio"/> None	<input type="radio"/> Trace	<input type="radio"/> Occasionally frank	<input type="radio"/> Usually frank	
5. General well being	<input type="radio"/> Very well	<input type="radio"/> Slightly below par	<input type="radio"/> Poor	<input type="radio"/> Very poor	<input type="radio"/> Terrible

6. Extraintestinal features (score 1 per item)

- Uveitis Pyoderma Gangrenoum Erythema Nodosum Arthritis

SCCAI Interpretation	
<input type="radio"/> < 3	In remission
<input type="radio"/> 3 - 5	Mild
<input type="radio"/> 6 - 9	Moderate
<input type="radio"/> ≥ 10	Severe

TOTAL SCORE : _____
* (Auto Calculated)

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SECTION 3: DISEASE CHARACTERISTICS (continue)

4. Associated disorders

- PSC
- Thromboembolic complication
- Others _____

SECTION 4: THERAPY

1. Medical (Long term/Maintenance Only)

Medication	Ongoing <i>Check if YES</i>	Date	Reason for stopping
<input type="checkbox"/> Corticosteroid	<input type="checkbox"/>	Date Start : <input type="text"/> / <input type="text"/> / <input type="text"/> Date Stop : <input type="text"/> / <input type="text"/> / <input type="text"/>	
<input type="checkbox"/> 5-ASA			
<input type="checkbox"/> Oral	<input type="checkbox"/>	Date Start : <input type="text"/> / <input type="text"/> / <input type="text"/> Date Stop : <input type="text"/> / <input type="text"/> / <input type="text"/>	
<input type="checkbox"/> Topical	<input type="checkbox"/>	Date Start : <input type="text"/> / <input type="text"/> / <input type="text"/> Date Stop : <input type="text"/> / <input type="text"/> / <input type="text"/>	
<input type="checkbox"/> Immunomodulator			
<input type="checkbox"/> Azathioprine	<input type="checkbox"/>	Date Start : <input type="text"/> / <input type="text"/> / <input type="text"/> Date Stop : <input type="text"/> / <input type="text"/> / <input type="text"/>	
<input type="checkbox"/> 6-mercaptopurine	<input type="checkbox"/>	Date Start : <input type="text"/> / <input type="text"/> / <input type="text"/> Date Stop : <input type="text"/> / <input type="text"/> / <input type="text"/>	
<input type="checkbox"/> Methotrexate	<input type="checkbox"/>	Date Start : <input type="text"/> / <input type="text"/> / <input type="text"/> Date Stop : <input type="text"/> / <input type="text"/> / <input type="text"/>	
<input type="checkbox"/> Tacrolimus	<input type="checkbox"/>	Date Start : <input type="text"/> / <input type="text"/> / <input type="text"/> Date Stop : <input type="text"/> / <input type="text"/> / <input type="text"/>	
<input type="checkbox"/> Cyclosporine	<input type="checkbox"/>	Date Start : <input type="text"/> / <input type="text"/> / <input type="text"/> Date Stop : <input type="text"/> / <input type="text"/> / <input type="text"/>	

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SECTION 4: THERAPY (continue)

Medication	Ongoing <i>Check if YES</i>	Date	Reason for stopping
<input type="checkbox"/> Biologics			
<input type="checkbox"/> Anti TNF			
<input type="checkbox"/> Infliximab	<input type="checkbox"/>	Date Start : <input type="text"/> / <input type="text"/> / <input type="text"/> Date Stop : <input type="text"/> / <input type="text"/> / <input type="text"/>	
<input type="checkbox"/> Adalimumab	<input type="checkbox"/>	Date Start : <input type="text"/> / <input type="text"/> / <input type="text"/> Date Stop : <input type="text"/> / <input type="text"/> / <input type="text"/>	
<input type="checkbox"/> Golimumab	<input type="checkbox"/>	Date Start : <input type="text"/> / <input type="text"/> / <input type="text"/> Date Stop : <input type="text"/> / <input type="text"/> / <input type="text"/>	
+ Add Medication			
<input type="checkbox"/> Anti Integrin			
<input type="checkbox"/> Vedolizumab	<input type="checkbox"/>	Date Start : <input type="text"/> / <input type="text"/> / <input type="text"/> Date Stop : <input type="text"/> / <input type="text"/> / <input type="text"/>	
+ Add Medication			
<input type="checkbox"/> Anti IL			
<input type="checkbox"/> Ustekinumab	<input type="checkbox"/>	Date Start : <input type="text"/> / <input type="text"/> / <input type="text"/> Date Stop : <input type="text"/> / <input type="text"/> / <input type="text"/>	
<input type="checkbox"/> Guselkumab	<input type="checkbox"/>	Date Start : <input type="text"/> / <input type="text"/> / <input type="text"/> Date Stop : <input type="text"/> / <input type="text"/> / <input type="text"/>	
+ Add Medication			
<input type="checkbox"/> JAK inhibitors _____	<input type="checkbox"/>	Date Start : <input type="text"/> / <input type="text"/> / <input type="text"/> Date Stop : <input type="text"/> / <input type="text"/> / <input type="text"/>	
<input type="checkbox"/> Others _____ _____ _____	<input type="checkbox"/>	Date Start : <input type="text"/> / <input type="text"/> / <input type="text"/> Date Stop : <input type="text"/> / <input type="text"/> / <input type="text"/>	
2. Surgical Resection	a. Surgical details		
	b. Surgical date	<input type="text"/> / <input type="text"/> / <input type="text"/> (mm/yyyy)	
	c. Resection	<input type="radio"/> No <input type="radio"/> Yes	
+ ADD SURGERY			

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SECTION 5: VACCINATION

1. Vaccine

	Date vaccinated
<input type="checkbox"/> Influenza	<input type="text"/> / <input type="text"/> (mm/yyyy)
<input type="checkbox"/> HPV	<input type="text"/> / <input type="text"/> (mm/yyyy)
<input type="checkbox"/> Hepatitis B	<input type="text"/> / <input type="text"/> (mm/yyyy)
<input type="checkbox"/> Pneumococcal	<input type="text"/> / <input type="text"/> (mm/yyyy)
<input type="checkbox"/> Varicella	<input type="text"/> / <input type="text"/> (mm/yyyy)
<input type="checkbox"/> Covid	<input type="text"/> / <input type="text"/> (mm/yyyy)