

**Supplementary Material 1.** A questionnaire study on dietary practices and beliefs in South Asian patients with inflammatory bowel disease

## A Questionnaire Study on Dietary Practices and Beliefs in South Asian patients with Inflammatory Bowel Disease

(Version 1.0, 24<sup>th</sup> January 2019)

Research ID _____
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Date (Day/Month/Year) _____ / _____ / _____
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**Questions for the research team to complete**

Please circle the appropriate number.

**Example:**

1. Yes	2. No
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**Q1. Does the patient have Ulcerative colitis (UC), Crohn’s Disease (CD) or IBD unspecified?**

1. UC	2. CD	3. IBDU
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**Q2. What is the extent of this patient’s disease?**

Please complete table 2.1 for UC or 2.2 for CD

<b>2.1 Ulcerative Colitis (please circle)</b>	
E1	Ulcerative proctitis: limited to rectum
E2	Left-sided UC: distal to splenic flexure
E3	Extensive UC: extends proximal to splenic flexure
<b>2.2 Crohn’s Disease</b>	
<b>Age (please circle)</b>	
A1	16 years or younger
A2	17-40 years
A3	>40 years
<b>Location (please circle)</b>	
L1	Terminal ileum
L2	Colon
L3	Ileocolonic
L4	Upper GI
<b>Behaviour (please circle)</b>	
B1	Non-stricturing/Non-penetrating
B2	Stricturing
B3	Penetrating

**Q3. Which medications is this patient on for IBD?**

1. Oral 5-aminosalicylic acids (Mesalazine or Sulfasalazine)	1. Yes	2. No
2. Immunomodulators (Azathioprine, Mercaptopurine, or Methotrexate)	1. Yes	2. No
3. Biologics (Infliximab, Adalimumab, Golimumab, Vedolizumab, etc)	1. Yes	2. No
4. Topical 5-aminosalicylic acids (Enema or suppository)	1. Yes	2. No
5. Others (please specify _____)	1. Yes	2. No

**Q4. Latest investigation results within last 3 months (if performed).**

	Result	Date performed
CRP		
Faecal Calprotectin		
Flexible Sigmoidoscopy/Colonoscopy		
Abdominal Radiology (USS/CT/MRI)		

**Q5. Disease Activity Score (Please complete 5.1 for UC and 5.2 for CD)**

<b>5.1 Ulcerative Colitis (please circle)</b>	
<b>A. Stool Frequency (Total number of stools/day)</b>	
0	Normal number of stools for this patient
1	1-2 stools/day more than normal for this patient
2	3-4 stools/day more than normal for this patient
3	≥ 5 stools/day more than normal for this patient
<b>B. Rectal Bleeding</b>	
0	No blood seen
1	Streaks of blood seen with < 50% of stools
2	Obvious blood seen with ≥ 50% of stools
3	Blood alone passed

<b>5.2 Crohn's Disease</b> (Please circle score)	
<b>General well-being</b>	Very well = 0
	Slightly below par = 1
	Poor = 2
	Very poor = 3
	Terrible = 4
<b>Abdominal Pain</b>	None = 0
	Mild = 1
	Moderate = 2
	Severe = 3
<b>Number of liquid stools per day</b>	_____
<b>Complications</b>	None = 0
	Arthralgia = 1
	Uveitis = 1
	Erythema nodosum = 1
	Aphthous ulcers = 1
	Pyoderma gangrenosum = 1
	Anal fissure = 1
	New fistula = 1
	Abscess = 1
<b>Total Score</b>	

**Questions for patients**

Please circle the appropriate number.

(Example)

1. Yes	2. No
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**Q1. How many years ago were you diagnosed with Inflammatory Bowel Disease (IBD)?**

_____ years
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**Q2. Do you consider that diet is the initiating factor for Inflammatory Bowel Disease?**

1. Yes	2. No
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If your answer is **No**, please go to **Q3**

**Q2-2. If Yes, what is the source of this information? (Choose as many as apply)**

1.	Your own experience
2.	Gastroenterologist / IBD specialist
3.	General practitioner
4.	IBD nurse specialist / other nurse
5.	Dietitian
6.	Internet (patient support organization such as Crohn's and Colitis UK)
7.	Internet (Other websites)
8.	Information leaflet / book for IBD
9.	Other patients with Ulcerative Colitis
10.	Other patients with Crohn's disease
11.	Family
12.	Friends
13.	Social media
14.	Television or Radio
15.	Newspapers and magazines
16.	Other, please specify .....

**Q3. Have you had a relapse of Inflammatory Bowel Disease within the last 1 year?**

(In **ulcerative colitis** relapse is the presence of **rectal bleeding with increased bowel habits**. In **Crohn’s disease** relapse is the presence of **abdominal pain with or without increased bowel habits and rectal bleeding**)

1. Yes	2. No
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**Q4. Do you consider that a dietary factor has ever triggered a relapse of your Inflammatory Bowel Disease?**

1. Yes	2. No
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If your answer is **No**, please go to **Q5**

**Q4-2. If Yes, which food or drink do you think triggered the relapse? (Choose as many as apply)**

1.	Fatty Foods
2.	White meat (e.g. chicken)
3.	Red meat (e.g. beef, lamb, pork)
4.	Milk or milk products
5.	Raw vegetables or raw fruit
6.	Fish
7.	Spicy Foods
8.	Sweet foods
9.	Alcohol
10.	Carbonated drinks
11.	Coffee
12.	Tea
13.	Other, please specify .....

**Q5. Do you consider that diet triggers a relapse of Inflammatory Bowel Disease?**

1. Yes	2. No
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**Q6. Do you avoid certain foods or drink to try and prevent relapse of Inflammatory Bowel Disease?**

1. I <u>always</u> avoid	2. I <u>sometimes</u> avoid	3. I <u>do not</u> avoid
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If you answered “**I do not avoid**” please go to **Q7**

**Q6-2. If you always or sometimes avoid certain foods or drink to prevent a relapse of Inflammatory Bowel Disease, which food or drink do you avoid (see options on next page)?**

**A. Fatty Foods**

1. I <u>always</u> avoid	2. I <u>sometimes</u> avoid	3. I <u>do not</u> avoid
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If you answered “**I do not avoid**” please go to **B**

**A-2. If you always or sometimes avoid fatty foods to prevent a relapse, what is the source of this information? (Choose as many as apply)**

1.	Your own experience
2.	Gastroenterologist / IBD specialist
3.	General practitioner
4.	IBD nurse specialist / other nurse
5.	Dietitian
6.	Internet (patient support organization such as Crohn’s and Colitis UK)
7.	Internet (Other websites)
8.	Information leaflet / book for IBD
9.	Other patients with Ulcerative Colitis
10.	Other patients with Crohn’s disease
11.	Family
12.	Friends
13.	Social media
14.	Television or Radio
15.	Newspapers and magazines
16.	Other, please specify .....

**B. White meat (e.g. chicken)**

1. I <u>always</u> avoid	2. I <u>sometimes</u> avoid	3. I <u>do not</u> avoid
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If you answered “**I do not avoid**” please go to **C**

**B-2. If you always or sometimes avoid white meat to prevent a relapse, what is the source of this information? (Choose as many as apply)**

1.	Your own experience
2.	Gastroenterologist / IBD specialist
3.	General practitioner
4.	IBD nurse specialist / other nurse
5.	Dietitian
6.	Internet (patient support organization such as Crohn’s and Colitis UK)
7.	Internet (Other websites)
8.	Information leaflet / book for IBD
9.	Other patients with Ulcerative Colitis
10.	Other patients with Crohn’s disease
11.	Family
12.	Friends
13.	Social media
14.	Television or Radio
15.	Newspapers and magazines
16.	Other, please specify .....

**C. Red Meat (e.g. beef, lamb, pork)**

1. I <u>always</u> avoid	2. I <u>sometimes</u> avoid	3. I <u>do not</u> avoid
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If you answered “**I do not avoid**” please go to **D**

**C-2. If you always or sometimes avoid red meat to prevent a relapse, what is the source of this information? (Choose as many as apply)**

1.	Your own experience
2.	Gastroenterologist / IBD specialist
3.	General practitioner
4.	IBD nurse specialist / other nurse
5.	Dietitian
6.	Internet (patient support organization such as Crohn’s and Colitis UK)
7.	Internet (Other websites)
8.	Information leaflet / book for IBD
9.	Other patients with Ulcerative Colitis
10.	Other patients with Crohn’s disease
11.	Family
12.	Friends
13.	Social media
14.	Television or Radio
15.	Newspapers and magazines
16.	Other, please specify .....

**D. Milk or milk products**

1. I <u>always</u> avoid	2. I <u>sometimes</u> avoid	4. I <u>do not</u> avoid
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If you answered “**I do not avoid**” please go to **E**

**D-2. If you always or sometimes avoid milk or milk products to prevent a relapse, what is the source of this information? (Choose as many as apply)**

1.	Your own experience
2.	Gastroenterologist / IBD specialist
3.	General practitioner
4.	IBD nurse specialist / other nurse
5.	Dietitian
6.	Internet (patient support organization such as Crohn’s and Colitis UK)
7.	Internet (Other websites)
8.	Information leaflet / book for IBD
9.	Other patients with Ulcerative Colitis
10.	Other patients with Crohn’s disease
11.	Family
12.	Friends
13.	Social media
14.	Television or Radio
15.	Newspapers and magazines
16.	Other, please specify .....

**E. Raw vegetables or raw fruit**

1. I <u>always</u> avoid	2. I <u>sometimes</u> avoid	3. I <u>do not</u> avoid
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If you answered “I do not avoid” please go to **F**

**E-2. If you always or sometimes avoid raw vegetables or raw fruit to prevent a relapse, what is the source of this information? (Choose as many as apply)**

1.	Your own experience
2.	Gastroenterologist / IBD specialist
3.	General practitioner
4.	IBD nurse specialist / other nurse
5.	Dietitian
6.	Internet (patient support organization such as Crohn’s and Colitis UK)
7.	Internet (Other websites)
8.	Information leaflet / book for IBD
9.	Other patients with Ulcerative Colitis
10.	Other patients with Crohn’s disease
11.	Family
12.	Friends
13.	Social media
14.	Television or Radio
15.	Newspapers and magazines
16.	Other, please specify .....

**F. Fish**

1. I <u>always</u> avoid	2. I <u>sometimes</u> avoid	3. I <u>do not</u> avoid
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If you answered “I do not avoid” please go to **G**

**F-2. If you always or sometimes avoid fish to prevent a relapse, what is the source of this information? (Choose as many as apply)**

1.	Your own experience
2.	Gastroenterologist / IBD specialist
3.	General practitioner
4.	IBD nurse specialist / other nurse
5.	Dietitian
6.	Internet (patient support organization such as Crohn’s and Colitis UK)
7.	Internet (Other websites)
8.	Information leaflet / book for IBD
9.	Other patients with Ulcerative Colitis
10.	Other patients with Crohn’s disease
11.	Family
12.	Friends
13.	Social media
14.	Television or Radio
15.	Newspapers and magazines
16.	Other, please specify .....



**G. Spicy Foods**

1. I <u>always</u> avoid	2. I <u>sometimes</u> avoid	3. I <u>do not</u> avoid
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If you answered “**I do not avoid**” please go to **H**

**G-2. If you always or sometimes avoid spicy foods to prevent a relapse, what is the source of this information? (Choose as many as apply)**

1.	Your own experience
2.	Gastroenterologist / IBD specialist
3.	General practitioner
4.	IBD nurse specialist / other nurse
5.	Dietitian
6.	Internet (patient support organization such as Crohn’s and Colitis UK)
7.	Internet (Other websites)
8.	Information leaflet / book for IBD
9.	Other patients with Ulcerative Colitis
10.	Other patients with Crohn’s disease
11.	Family
12.	Friends
13.	Social media
14.	Television or Radio
15.	Newspapers and magazines
16.	Other, please specify .....

**H. Sweet Foods**

1. I <u>always</u> avoid	2. I <u>sometimes</u> avoid	3. I <u>do not</u> avoid
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If you answered “**I do not avoid**” please go to **I**

**H-2. If you always or sometimes avoid sweet foods to prevent a relapse, what is the source of this information? (Choose as many as apply)**

1.	Your own experience
2.	Gastroenterologist / IBD specialist
3.	General practitioner
4.	IBD nurse specialist / other nurse
5.	Dietitian
6.	Internet (patient support organization such as Crohn’s and Colitis UK)
7.	Internet (Other websites)
8.	Information leaflet / book for IBD
9.	Other patients with Ulcerative Colitis
10.	Other patients with Crohn’s disease
11.	Family
12.	Friends
13.	Social media
14.	Television or Radio
15.	Newspapers and magazines
16.	Other, please specify .....

**I. Alcohol**

1. I <u>always</u> avoid	2. I <u>sometimes</u> avoid	3. I <u>do not</u> avoid
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If you answered “**I do not avoid**” please go to **J**

**I-2. If you always or sometimes avoid alcohol to prevent a relapse, what is the source of this information? (Choose as many as apply)**

1.	Your own experience
2.	Gastroenterologist / IBD specialist
3.	General practitioner
4.	IBD nurse specialist / other nurse
5.	Dietitian
6.	Internet (patient support organization such as Crohn’s and Colitis UK)
7.	Internet (Other websites)
8.	Information leaflet / book for IBD
9.	Other patients with Ulcerative Colitis
10.	Other patients with Crohn’s disease
11.	Family
12.	Friends
13.	Social media
14.	Television or Radio
15.	Newspapers and magazines
16.	Other, please specify .....

**J. Carbonated Drinks**

1. I <u>always</u> avoid	2. I <u>sometimes</u> avoid	3. I <u>do not</u> avoid
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If you answered “**I do not avoid**” please go to **K**

**J-2. If you always or sometimes avoid carbonated drinks to prevent a relapse, what is the source of this information? (Choose as many as apply)**

1.	Your own experience
2.	Gastroenterologist / IBD specialist
3.	General practitioner
4.	IBD nurse specialist / other nurse
5.	Dietitian
6.	Internet (patient support organization such as Crohn’s and Colitis UK)
7.	Internet (Other websites)
8.	Information leaflet / book for IBD
9.	Other patients with Ulcerative Colitis
10.	Other patients with Crohn’s disease
11.	Family
12.	Friends
13.	Social media
14.	Television or Radio
15.	Newspapers and magazines
16.	Other, please specify .....

**K. Coffee**

1. I <u>always</u> avoid	2. I <u>sometimes</u> avoid	3. I <u>do not</u> avoid
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If you answered “**I do not avoid**” please go to **L**

**K-2. If you always or sometimes avoid coffee to prevent a relapse, what is the source of this information? (Choose as many as apply)**

1.	Your own experience
2.	Gastroenterologist / IBD specialist
3.	General practitioner
4.	IBD nurse specialist / other nurse
5.	Dietitian
6.	Internet (patient support organization such as Crohn’s and Colitis UK)
7.	Internet (Other websites)
8.	Information leaflet / book for IBD
9.	Other patients with Ulcerative Colitis
10.	Other patients with Crohn’s disease
11.	Family
12.	Friends
13.	Social media
14.	Television or Radio
15.	Newspapers and magazines
16.	Other, please specify .....

**L. Tea**

1. I <u>always</u> avoid	2. I <u>sometimes</u> avoid	3. I <u>do not</u> avoid
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If you answered “**I do not avoid**” please go to **M**

**L-2. If you always or sometimes avoid tea to prevent a relapse, what is the source of this information? (Choose as many as apply)**

1.	Your own experience
2.	Gastroenterologist / IBD specialist
3.	General practitioner
4.	IBD nurse specialist / other nurse
5.	Dietitian
6.	Internet (patient support organization such as Crohn’s and Colitis UK)
7.	Internet (Other websites)
8.	Information leaflet / book for IBD
9.	Other patients with Ulcerative Colitis
10.	Other patients with Crohn’s disease
11.	Family
12.	Friends
13.	Social media
14.	Television or Radio
15.	Newspapers and magazines
16.	Other, please specify .....

**M. Other (please specify .....**)

1. I <u>always</u> avoid	2. I <u>sometimes</u> avoid	3. I <u>do not</u> avoid
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If you answered “I do not avoid” please go to Q7

**M-2. If you always or sometimes avoid other foods or drinks to prevent a relapse, what is the source of this information? (Choose as many as apply)**

1.	Your own experience
2.	Gastroenterologist / IBD specialist
3.	General practitioner
4.	IBD nurse specialist / other nurse
5.	Dietitian
6.	Internet (patient support organization such as Crohn’s and Colitis UK)
7.	Internet (Other websites)
8.	Information leaflet / book for IBD
9.	Other patients with Ulcerative Colitis
10.	Other patients with Crohn’s disease
11.	Family
12.	Friends
13.	Social media
14.	Television or Radio
15.	Newspapers and magazines
16.	Other, please specify .....

**Q7. Do you consider that consuming certain foods, drink, or nutritional supplements can prevent a relapse of Inflammatory Bowel Disease?**

1. Yes	2. No
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**Q8. Do you actually consume certain foods, drink, or nutritional supplements to prevent a relapse of Inflammatory Bowel Disease?**

1. Yes	2. No
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If you answered No please go to Q9

**Q8-2. If Yes, which foods, drink, or nutritional supplements do you consume?**

Foods or drinks such as:
Nutritional supplements such as:

**Q8-3. What are your sources of the information regarding consuming certain foods, drink, or nutritional supplements for relapse prevention?**

(Choose as many as apply)

1.	Your own experience
2.	Gastroenterologist / IBD specialist
3.	General practitioner
4.	IBD nurse specialist / other nurse
5.	Dietitian
6.	Internet (patient support organization such as Crohn's and Colitis UK)
7.	Internet (Other websites)
8.	Information leaflet / book for IBD
9.	Other patients with Ulcerative Colitis
10.	Other patients with Crohn's disease
11.	Family
12.	Friends
13.	Social media
14.	Television or Radio
15.	Newspapers and magazines
16.	Other, please specify .....

**Q9. Do you consider the recommended diet in relapse of Inflammatory Bowel Disease to be same as that in remission of Inflammatory Bowel Disease?**

1. Yes	2. No
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**Q10. Do you consider the recommended diet in preventing relapse of Ulcerative Colitis to be same as that in preventing relapse in Crohn's disease?**

1. Yes	2. No	3. I don't know
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**Q11. When you search information for dietary recommendations, are you able to find specific advice for Inflammatory Bowel Disease?**

1. Yes	2. No
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If your answer is **No** please move to **Q12**

**Q11-2. If Yes, please specify the information resources.**

**Q12. Do you avoid the same menu as the other members of the family living with you to prevent a relapse of Inflammatory Bowel Disease?**

1. I <u>always</u> avoid	2. I <u>sometimes</u> avoid	3. I <u>do not</u> avoid
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**Q13. Do you avoid eating out for fear of causing a relapse of Inflammatory Bowel Disease?**

1. I <u>always</u> avoid	2. I <u>sometimes</u> avoid	3. I <u>do not</u> avoid
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**Q14. Have you heard of or tried any of these specific diets? (please circle)**

<b>Gluten free diet</b>	1. I have <b>heard</b> of this	2. I have <b>tried</b> this
<b>Lactose free diet</b>	1. I have <b>heard</b> of this	2. I have <b>tried</b> this
<b>Low FODMAPs diet</b>	1. I have <b>heard</b> of this	2. I have <b>tried</b> this
<b>Specific carbohydrate diet</b>	1. I have <b>heard</b> of this	2. I have <b>tried</b> this
<b>Anti-inflammatory diet</b>	1. I have <b>heard</b> of this	2. I have <b>tried</b> this
<b>Paleolithic diet</b>	1. I have <b>heard</b> of this	2. I have <b>tried</b> this

Finally, some questions about you.

**Q15. Are you male or female?**

1. Male	2. Female
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**Q16. Please tell us your age?**

 years old

**Q17. How tall are you?**

 cm

**Q18. What is your weight?**

 kg

**Q19. In which country were you born?**

If you were born outside of the UK please move to **Q20**.

**Q19.1 If you were born in the UK, were your parents also born in the UK?**

1. Yes	2. No
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**Q20. With which South Asian ethnicity do you identify yourself (please circle)?**

1.	Indian
2.	Pakistani
3.	Sri Lankan
4.	Bangladeshi
5.	Nepalese
6.	Mixed (please specify .....
7.	Other (please specify .....

**Q21. Do you have any other medical conditions for which you need to avoid certain types of foods or drink? For example diabetes mellitus, high cholesterol, hypertension.**

3. Yes	4. No
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If Yes please specify .....

**Q22. Who do you live with?**

1. Family	2. Alone	3. Others
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**Q23. Are you working full-time or part-time?**

1. Full-time	2. Part-time	3. Unemployed	4. Retired
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**Q24. What is your highest level of educational qualification?**

1. O-levels/GCSEs
2. A-levels
3. University degree
4. Other professional qualifications e.g. diploma

**Q25. Do you feel you are limited in your choices with foods or drink because of cost or income?**

1. Yes	2. No
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**Thank you for taking the time to complete this questionnaire.**