

A mixed method Irish study exploring the role of diet in IBD based on an online questionnaire and a patient panel opinion

Supplementary materials

Supplementary material 1: Online Questionnaire

Section 1: Participant Background

1. Gender (multiple choice)
2. Male
3. Female
4. Prefer not to say
5. Age (multiple choice)
 - a. 18-29
 - b. 30-39
 - c. 40-49
 - d. 50-65
 - e. Over 66
6. What is your weight in kilograms (kg) OR stone (st) - if weight is known (Please state the units below (e.g. 65 kg or 10.2 Stone))? _____
7. Units of weight (multiple choice)
 - a. Kilograms (kg)
 - b. Stone (st)
 - c. Pounds (lbs)
8. What is your height in centimetres (cm) OR feet (ft) - if height is known (Please state the units below (e.g. 5 ft 9 inches or 175 cm)? _____
9. Units of height stated (multiple choice)
 - a. Centimetres (cm)
 - b. Feet (ft)
10. Are you currently a smoker (multiple choice)
 - a. Yes
 - b. No
 - c. Ex – smoker
 - d. I am a casual smoker (1-2 cigarettes a week)

11. Are you currently taking antibiotics, or have you taken them within the last 6 months (multiple choice)
- Yes
 - No
12. Do you take any vitamin supplements (Based on the last month) (multiple choice)
- Yes, everyday
 - Yes, every now and again
 - No, never/ rarely
13. If yes (Do you take any vitamin supplements): Please tick which ones you take (You can select more than one option)
- Vitamin D
 - Vitamin B
 - Vitamin C
 - Vitamin E
 - Multi-vitamins
 - Other _____
14. Do you take any other supplements (Based on the last month) (multiple choice)
- Yes
 - No
 - Sometimes
15. If yes (Do you take any other supplements): Please tick which ones you take (You can select more than one option)
- Protein powder/flakes (whey, hemp, etc.)
 - Fish oils (omegas)
 - Probiotics
 - Iron
 - Zinc
 - Calcium
 - other _____
16. What category do you fit into (multiple choice)
- No known disease or condition (healthy)
 - Ulcerative Colitis (UC)
 - Crohn's Disease (CD)
 - Inflammatory Bowel Disease (IBD)/indeterminate
 - Other disease/ condition than IBD (CD/UC) or a digestive disorder

Section2: Inflammatory Bowel Disease (IBD) -Ulcerative colitis (UC), Crohn's Disease (CD) or indeterminate IBD

17. What is your current disease state (e.g. active (flare) or inactive (remission))
- Active (flare)
 - Inactive (remission)
18. What was the duration of your last flare
- Less than 1 month
 - 3-6 months
 - Longer than 6 months
 - Ongoing
 - Not sure
19. Are you currently taking any medication to treat your IBD (CD/UC)
- Yes
 - No
20. If yes to the previous question - Please tick which ones you take (You can select more than one option)
- Biologics and Biosimilars (such as Remicade/Infliximab (Inflectra), Humira/Adalimumab (Hulio or Amgevita), and Simponi/Golimumab)
 - Steroids (e.g Prednislone, Budesonide)
 - Immunosuppressants (such as Azathioprine (Imuran) and Mercaptopurine or 6-MP (Puri-nethol))
 - Over the counter medicines, (e.g. Analgesic/painkillers such as Paracetamol or NSAID's Ibuprofen, Naproxen)
 - I am taking prescription medication, but don't know what category they fit into (e.g. Asacolon, Mezavant)
21. Has your diet changed since you were diagnosed with an IBD (CD/UC)
- Yes, it has changed significantly
 - Yes, a small bit
 - Not significantly
22. Which is most accurate for you (You can select more than one option)
- You are more health conscious
 - You try to avoid a lot of different foods which cause you to go into flare
 - You avoid a lot of foods you consider to be unhealthy
 - You avoid lots of foods which according to information online or from a friend may cause a flare
 - Not much has changed

23. Do you have differences in eating patterns when your disease is active (flare) vs inactive (remission)
- No, not much
 - Slightly
 - Yes, totally. I eat very different items
 - Yes, I cannot eat much when in flare
24. If you avoid specific food(s) because you believe the food(s) may bring about a flare, what made you decide that the specific food(s) should be avoided (You can select more than one option.)
- Based on my own experience where the food caused me to go into flare
 - I was advised by a medical professional (doctor, dietitian or specialist nurse)
 - I found advice online (e.g. YouTube vlogger, blog, twitter forum)
 - I was advised by a friend
 - Other _____
25. How relevant do you consider your diet to your disease
- Highly relevant
 - Not that relevant
 - Somewhat relevant
 - Irrelevant
26. Have you tried any diets which you felt helped with the symptoms of your disease
- Yes
 - Slightly
 - Not really
 - No
27. If yes: Please write which diet _____

Section 3: Dietary Analysis

Instructions for dietary analysis section

This section should be answered based on an estimate of how often you eat at least **ONE portion/serving** of the following foods & drinks – based on **the last month**.

The specific **portions/serving** sizes are shown in example images before each section or else written beside the food or drink items individually.

The option range provided is as follows Never, 1/Month, 1/Week, 2-3/Week, 4-6/Week, 1/Day, 2/Day, 3-4/Day, and 5+/Day. On a phone, all options may not be visible; scroll to the right of the screen to see additional options.

If you wish to leave any specific note relevant to your answer(s), there is a comment box provided at the end. Feel free to add any additional information appropriate to your dietary habits.

Note: images of the weighed portion sizes were attached for reference

Meat and poultry

28. Whole meat: Beef, Lamb, Pork or Ham - roasts, steaks, joints, mince, chops (111 g)
29. Sausages, bacon, rashers, corned beef, meat pies/pastries, burger (2 sausages/ 3 rashers/bacon or 1 burger/ pie (80 g)
30. Whole meat: Chicken or Turkey (White meat) - steaks, roasts, joints, mince or portions (not in batter or breadcrumbs) (128 g)
31. Chicken/turkey nuggets/twizzlers, turkey burgers, chicken pies, or in batter or breadcrumbs (170 g)

Options: Never; 1/Month; 1/Week; 2-3/Week; 4-6/Week; 1/Day; 2/Day; 3-4/Day; 5+/Day

Fish and eggs

33. White fish - not in batter or breadcrumbs (119 g)
34. White fish in batter or breadcrumbs – like 'fish and chips' (160 g)
35. Oily fish – like herrings, sardines, salmon, trout, mackerel, fresh tuna (90 g)
36. Tinned tuna (80 g = small tin)
37. Eggs boiled, fried, or poached (1 medium egg (57 g))

Options: Never; 1/Month; 1/Week; 2-3/Week; 4-6/Week; 1/Day; 2/Day; 3-4/Day; 5+/Day

Fruits and salad (leaves)

38. Fruit - fresh, tinned or frozen (1 medium fruit: apple, orange, tomato, pear; or 2 small fruits: kiwi, plum, satsuma; or 1/2 cup blueberries, raspberries, strawberries, grapes, mango (80 g))
39. Dried fruits (1 small handful or 1/3 cup e.g., raisins, dried banana, dates (30 g))
40. Salad - not garnish added to a sandwich - see portion size above (80 g)

Options: Never; 1/Month; 1/Week; 2-3/Week; 4-6/Week; 1/Day; 2/Day; 3-4/Day; 5+/Day

Vegetables and legumes

41. Vegetables - tinned, fresh or frozen but not Potatoes (1/2 cup: carrots, onions, broccoli, cauliflower, sweet potato (80 g))
42. Potatoes - baked/roasted/grilled, mashed, boiled, (1/2 cup or 1 medium potato or 2 small potatoes (80 g))
43. Potatoes cooked in oil (fried or deep fat fried e.g. chips) - see portion size above (167 g)
44. Beans or pulses like chickpeas, peas, tofu, dahl, baked/ broad/ black beans - see portion size above (128 g)

Options: Never; 1/Month; 1/Week; 2-3/Week; 4-6/Week; 1/Day; 2/Day; 3-4/Day; 5+/Day

Sweets and snacks

45. Cakes, biscuits, chocolate, doughnuts, pastries, buns (slice of cakes, 6 biscuits, a doughnut/ bun or pastry (91 g))
46. Jellies, candies, sweets, chocolates (small packet (41 g))
47. Crisps (small bag – 25 g)
48. Ice cream or cream (1/2 cup/ small bowl full or 1 single ice cream cone (110 g))

Options: Never; 1/Month; 1/Week; 2-3/Week; 4-6/Week; 1/Day; 2/Day; 3-4/Day; 5+/Day

Nuts and seeds

49. Nuts and seeds (2 tablespoons peanut or nut butter) or 1/3 cup (small handful) of nuts or seeds e.g. cashews, walnuts, chia seeds, sesame seeds (30 g)

Options: Never; 1/Month; 1/Week; 2-3/Week; 4-6/Week; 1/Day; 2/Day; 3-4/Day; 5+/Day

Rice, pasta, bread and cereals (portion size written beside the foods individually)

50. Wholegrain carbohydrate products (2 slices brown bread, or 1 cup brown pasta/ rice (90 g))
51. White (Refined wheat) (2 slices of white bread, or 1 cup white pasta/ rice (90 g))
52. High fibre (1/3 cup All-Bran/flakes, Weetabix, shredded wheat etc.; 1/2 cup full cooked porridge or Muesli e.g. Country Store/Alpen (71 g))
53. Sugary/sugar-coated cereals (1/2 cup full e.g. Frosties, Crunchy nut cornflakes, cheerios, coco pops (30 g))

Options: Never; 1/Month; 1/Week; 2-3/Week; 4-6/Week; 1/Day; 2/Day; 3-4/Day; 5+/Day

Alternative milk or olive oil

54. Olive oil (on bread or for cooking) - 1 tablespoon full (12.6 g)
55. Different types of milk (e.g. oat, soya, almond, goat) - 1 plastic glass full (Please write the type of milk in the comment box) (207 g)

Options: Never; 1/Month; 1/Week; 2-3/Week; 4-6/Week; 1/Day; 2/Day; 3-4/Day; 5+/Day

56. If you drink/consume a different type of milk other than cows milk please specify which type in the box below

Dairy products

57. Cheese - see portion size above (99 g)
58. Full fat Butter/spread - 1 tablespoon full (14.18 g)
59. Low-fat Butter/spread - 1 tablespoon full (14.18 g)
60. Yogurt - (small yoghurt carton (99 g))
61. Milk (cows milk) – see portion size above (1 plastic glass full (207 g))

Options: Never; 1/Month; 1/Week; 2-3/Week; 4-6/Week; 1/Day; 2/Day; 3-4/Day; 5+/Day

Drinks

62. Soda and sugary drinks (Coke, Sprite, Fanta, 7-up, Pepsi, etc) (1 plastic glass full (200 ml))
63. Fruit Juice (apple, orange, tropical, etc.), not cordial or squash (1 plastic glass full (200 ml))

64. Energy Drinks (Lucozade, Red Bull) (1 plastic glass full (200 ml))

Options: Never; 1/Month; 1/Week; 2-3/Week; 4-6/Week; 1/Day; 2/Day; 3-4/Day; 5+/Day

Alcohol

65. Alcohol - 1 unit (glass wine, half pint beer or cider, 1 shot of spirit (8 g))

Options: Never; 1/Month; 1/Week; 2-3/Week; 4-6/Week; 1/Day; 2/Day; 3-4/Day; 5+/Day

Fast food meals (e.g. takeaway or shop-bought)

66. Burger, kebab, bacon/wedgy Roll (300 g)

67. Mexican fast food dishes (e.g., taco bell, chipotle, café Mexicano) (418 g)

68. Pizza (390 g)

69. Asian fast food (e.g., Chinese, Thai, Indian) (300 g)

Options: Never; 1/Month; 1/Week; 2-3/Week; 4-6/Week; 1/Day; 2/Day; 3-4/Day; 5+/Day

70. Please write any other foods you consume regularly which haven't been mentioned above (can be specific food items or takeaway meals) - This question is optional

71. Any specific comments you would like to add relating to a/ an item(s) you selected above

- This question is optional _____

Section 4: Role that diet plays

72. If other disease/ condition than IBD (UC/CD) - Please write which disease/ condition

73. How many different types of vegetables do you eat per week? e.g. types such as carrots, onions, broccoli, kale. Including all vegetables except potatoes

- a. < 1 (less than)
- b. 1-3
- c. 4-6
- d. 7-9
- e. >10 (more than)

74. How many different types of fruit do you eat per week? e.g. such as apples, oranges, blueberries, bananas
- < 1 (less than)
 - 1-3
 - 4-6
 - 7-9
 - >10 (more than)
75. Do you consider your overall diet to be
- Healthy
 - Unhealthy
 - Middle ground - a mix of healthy and unhealthy
 - Tailored to my disease (can't compare to general diets) - if you have an IBD (UC/ CD)
76. How relevant do you consider diet to your overall health status
- Highly relevant
 - Not that relevant
 - Somewhat relevant
 - Irrelevant
77. The most important components in a healthy diet are
- High amounts of protein (meat, cheese, milk, eggs, fish)
 - High amounts of fruits and vegetables
 - Mixed and varied diet; fruits, and veg; Carbohydrates (bread, pasta, rice); Protein (meat, fish, eggs, beans, seeds/nuts)
 - Animal protein (Meat and eggs) and carbohydrates (bread, pasta, potatoes, rice)
 - Other _____
78. Do you know what ingredients make up your meals
- No, I usually buy ready made meals
 - No, my partner/parent cook(s) my meals for me/ I mainly eat out
 - Yes, I do
 - Sometimes (50% yes, 50% no)
79. How many meals do you eat per day
- 1-2
 - Usually 3
 - Varies day to day depending on how I feel (with 1-3 times per day)
 - Varies day to day depending on how I feel (with 3-6 times per day)
 - I prefer to graze, eating small amounts throughout the day

80. What is your general portion size (lunch and dinner)
- 1 clenched fist
 - 3 clenched fists (fills half of a large plate)
 - 6 clenched fists (fills a full large plate)
 - No set size, varies meal to meal
81. Have you tried any specific diet
- Yes
 - No
82. If yes to the previous question, please specify which diets - You can select more than one option
- Low-FODMAP diet
 - ketogenic diet
 - Paleolithic diet
 - 5:2 diet
 - Gluten-free
 - Specific carbohydrate diet
 - Mediterranean diet
 - Other _____
83. How did you decide to undergo this/ these diet(s)
- I was advised by a medical professional (doctor, dietician or specialist nurse)
 - I found advice online (YouTube vlogger, blog, twitter forum etc.)
 - I was advised by a friend
 - Other _____
84. Did you feel that any of the diets noticeably improved your overall health
- Yes
 - Slightly
 - Not really
 - No
85. If yes, please write which specific diet(s) _____
86. Any additional information that is relevant to this questionnaire that you would like to add (which hasn't been asked above) - This question is optional

Supplementary material 2: Bioinformatics analysis of questionnaire (Phase I)

R (version 4.1.2) was employed with the Rstudio GUI (version 1.4.1717) for data handling, analysis, and statistical computations. Principal component analysis (PCA) was conducted on rank-normalised FFQ data using the stats and ggplot2 packages. PCA plots were generated to show clusters of samples based on their similarity, highlighting either foods and food groups (figure 2A) or individuals and their classification groups (control, active and inactive UC, active and inactive CD) (figure 2B). Food grouping was established using Spearman correlations (supplementary figure 1). PCA components PC1 and PC3, representing the most relevant foods and their variance, were selected for visualisation. MANOVA was employed to compare classification groups based on rank-normalised FFQ data. Categorical data were assessed using the chi-squared test for independence with the Vtable package, considering $p < 0.05$ as significant. Kruskal Wallis – rank based with F-test statistics were used for the macro- and micronutrient data with pairwise unpaired non-parametric t-test (Mann-Whitney U) and Bonferroni p-adjust between groups.

Supplementary material 3: Advertising and recruiting for the online questionnaire and PCP

A short video (bit.ly/APC_PPI) was produced to publicise the questionnaire and PPI study. Flyers and posters were distributed on social media platforms, including Twitter, Facebook, and Instagram; displayed in the gastroenterology department of Cork University Hospital (CUH); and emailed to members of Crohn's and Colitis Ireland (CCI).

Patients for the PCP were recruited through convenience sampling,^[23] with advertising conducted via social media channels and an in-person IBD patient engagement event organised by CUH. Participants interested (11 individuals) in becoming panel members contacted the study team, were screened against the inclusion criteria mentioned, and, if eligible (6 individuals), were invited to an in-person meeting (figure 1 and supplementary material: pre-meet) to ensure participants could work as a team. Following this, the terms of contract were discussed, and written consent forms outlining project details, required time commitment, and information regarding authorship were distributed to all panel members. Four of the five selected individuals stayed for the full duration of the project; one individual removed themselves due to personal issues, and their insights were no longer included. Eligible participants had a medical diagnosis of UC or CD, were available to attend fortnightly meetings, believed that diet played a role in their IBD journey, and expressed interest in exploring this role.

Supplementary material 4: Building trust through transparency

Transparency and effective communication were essential for building trust and facilitating patient engagement.[23], [24] Group work exercises and discussions were incorporated to enhance relational engagement among the panel members. Topics such as motivations for joining the project and preferred terminology were assessed, allowing everyone to feel comfortable speaking openly and honestly. Of note, the selection criteria for this project meant that the panel members who joined were motivated and passionate about this area of research.

Supplementary material 5: PCP meeting agendas and discussion prompts

Pre-meet - Purpose: To provide further details about the study and ensure that all participants could effectively operate in a group setting. **Execution:** Each individual was asked to bring an item of personal significance. As each person explained the significance of their item, their shared life experiences fostered a sense of togetherness among the group, for both researchers and people living with an IBD. This icebreaker also served to analyse group dynamics by observing participants' abilities to listen and interact with one another. Following this activity, the group was then provided with an overview of the project.

Meeting 1 - Purpose: To identify key aspects important to the PCP regarding diet, lifestyle and IBD. **Execution:** A 1.5-hour brainstorming session was conducted. As advised by experienced PPI research staff at UCC and externally during workshops, the initial brainstorming was kept broad to conduct genuine PPI and to avoid the panel being influenced by the research lead. To facilitate this, a list of general questions was provided. Participants answered these questions in pairs based on their personal experiences before regrouping for a collective discussion. It was emphasised that the questions were intended to aid discussion but were not restrictive.

Brainstorming questions

1. What is the purpose of food and our overall diet (e.g., the role that diet plays in our lives)?
2. Do you feel that diet has played a role in the (a) initiation and (b) progression of your IBD?
3. Has your diet changed since you were diagnosed?

- a) To improve IBD symptoms
 - b) To improve your overall health
4. When you think about diet, is it something that makes you happy or anxious? Fear of what to eat and the effect it might have on you
 5. Have you found any tips that have helped to improve your overall health and well-being (quality of life) since you were diagnosed? (This can be diet or lifestyle.)
 - a) Specific diet
 - b) Habits
 6. What type of diet do you think a person with an IBD should eat?
 7. If you could share anything insightful that you have learned about your experience of diet and your IBD with others who have IBD, what would that be?

During this initial brainstorming session, notes were taken by both the panel members and NH, and key points were noted down (NH). During the final 30 minutes, the panel were presented with the questionnaire dataset previously collected and analysed. The panel were asked to preliminarily select some of the graphs they felt were most important regarding diet and IBD and give opinions on any changes to means of analysis or visual representations of the data that they would like to support their narrative.

Meeting 2 - Purpose: To elucidate the panel's most important points and information identified in meeting 1 and to assist them in picking sections and figures for the paper.

Execution: Panel members were presented with their summary points from meeting 1 and received feedback from NH, utilising an iterative process to clearly distinguish their experiences for documentation in the manuscript. To allow the panel to delve deeper into the purpose of the project and paper, while being transparent about any uncertainties, they were provided with the following questions and asked to answer them individually:

1. What does this project mean to you/ why did you want to be involved?
2. Purpose of this written piece to you (paper)?
3. What are your uncertainties with the project or paper?

The researchers also answered the questions transparently. Subsequently, all questions and sections of the paper were discussed as a group. The panel strongly advocated for sharing more scientific information with patients, which led to the decision to co-create a blog series to highlight science communication and patient-to-patient tips on topics deemed important by the PCP. The panel outlined the sections for the manuscript, and due to some uncertainties and questions regarding restrictive diets, supplementation and dietary support, the panel requested that the dietician (MOK) and IBD/Diet/Microbiome Researcher (AV), attend Meeting 3.

Meeting 3 - Purpose: To clarify best dietary practices from a research perspective and identify the PCP's desires for future research in IBD. **Execution:** The first 30 minutes were dedicated to discussing dietary advice and frameworks for patients with the project dietician (MOK). Following this, panel members were each provided with different personas of patients with IBD (or soon to be diagnosed) and asked to answer the following questions:

1. What should future research focus on for finding the best outcome for _____ and future _____s? – *answered individually*
2. What are the main questions we want to be answered? – *answered in pairs*
3. If we turned these questions into research projects, what would be the main goal of these research projects? – *answered in pairs*

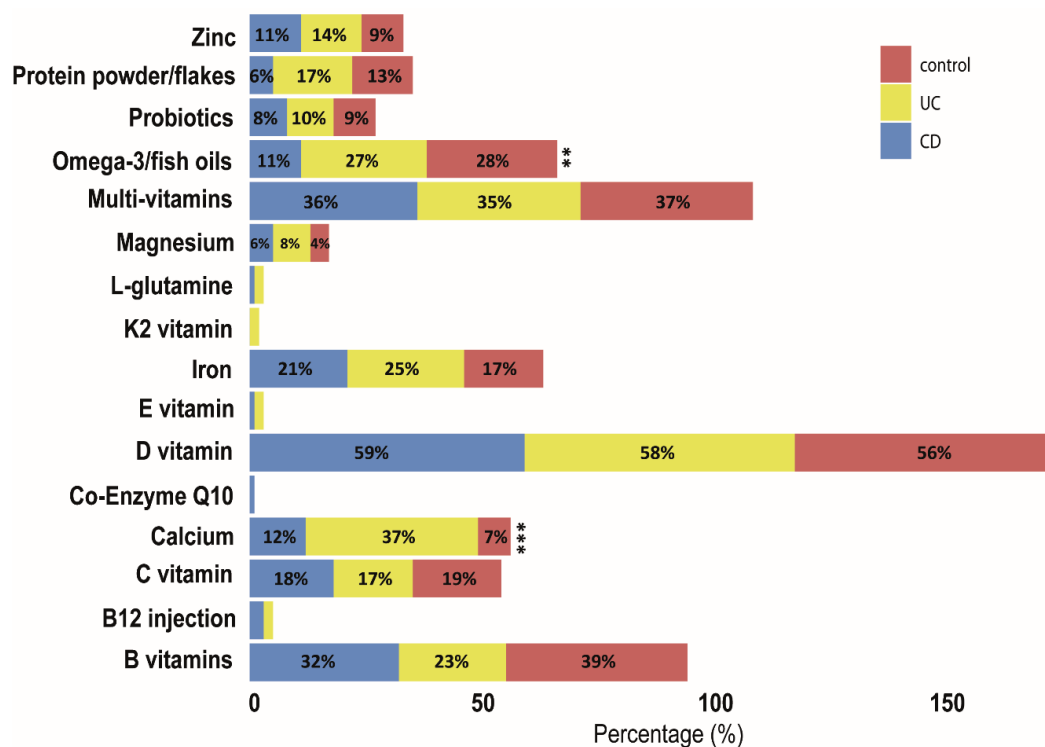
Finally, all answers were discussed as a group and summaries were noted. The findings from this are included in a sister publication (Hanrahan et al., submitted).

Meetings 4 & 5 - Purpose: Progress and complete all manuscript sections, content contained in the preview (Hanrahan et al., submitted) and the blog series. **Execution:** Different sections were allocated to panel members, who worked with the assistance and support of researchers. Additional reading resources were provided to aid in completing the allocated sections. In meeting 4, the PCP confirmed their curated lists of statements, highlighting their perspectives, and voted on based on their agreement with these statements.

Supplementary Data

Supplementary figure 1:

Supplementary figure 2:



Supplementary figure 2: Supplement use among online questionnaire respondents. The term supplements is used liberally to include multi- and single-vitamin supplements, probiotics and protein supplements. The percentage of individuals consuming a supplement within each group was calculated, and these percentages were compared between groups. p-values using Chi-squared test for independence ** $p <$

Supplementary table 1:

Supplementary table 1

Aspects of diet specific to the IBD cohort

	UC	CD
Group	[n = 52]	[n = 73]
Variable	N (%)	N (%)
Do you have differences in eating patterns when your disease is active (flare) vs inactive (remission)?		
Yes, I cannot eat much	21 (40.4)	32 (43.8)
Yes, I eat different things	13 (25)	12 (16.4)
Not much	5 (9.6)	11 (15.1)
Slightly	13 (25)	18 (24.7)
How relevant do you consider your diet to your disease?		
Irrelevant	4 (7.7)	2 (2.7)
Not that relevant	5 (9.6)	2 (2.7)
Somewhat relevant	21 (40.4)	28 (38.4)
Highly relevant	22 (42.3)	41 (56.2)
Which is most accurate for you (since you were diagnosed with an IBD (CD/UC))?		
Not much has changed	6 (11.5)	5 (6.8)
You are more health conscious	18 (34.6)	30 (41.1)
You avoid a lot of foods you consider to be unhealthy	14 (26.9)	14 (19.2)
You avoid lots of foods which according to information online or from a	3 (5.8)	5 (6.8)

friend may cause a flare

You try to avoid a lot of different foods which cause you to go into flare 33 (63.5) 50 (68.5)

Other: typed response (I avoid foods that cause issues with my
ostomy) 1 (1.9) 2 (2.7)

Section from the online questionnaire for responders with confirmed IBD (diagnosed by their
healthcare professional)