

UK Biobank

Digestive health web-based questionnaire

Version 1.1

<http://www.ukbiobank.ac.uk/>

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This document details the rationale and procedure for administration of the digestive health web-based questionnaire for UK Biobank.

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1 Introduction – scientific rationale

At the end of 2015, UK Biobank was approached by a group of gastroenterologists and other leaders in the field, who were keen to enhance UK Biobank's phenotyping of digestive disorders. Along with representatives from UK Biobank, this Working Group devised the questionnaire (see section 2).

IBS is common and can be conceptualised as a spectrum of waxing and waning symptoms throughout a lifetime. Most people will experience some of these symptoms at intervals, but it is their frequency and intensity which leads to a diagnosis of IBS. Although these encompass predominantly abdominal symptoms, IBS often occurs in the context of many other complaints (including, for example, urinary frequency and recurrent headaches as well as anxiety and depression). Some patients with IBS have a somatisation disorder and, for many, the IBS symptoms have a major adverse impact on quality of life and ability to work.

Given that many people do not get a formal clinical diagnosis of IBS, or even visit their general practitioner with their symptoms, the Working Group recommended that UK Biobank collect self-reported information that captures abdominal and associated symptoms.

Within IBS there exists significant heterogeneity, particularly relating to the existence of a sub-group of 'post-infectious IBS' where there is usually an acute infective trigger. It was therefore felt important to capture information around the time of onset of symptoms. It also captures information regarding the impact of IBS symptoms on respondent's quality of life and ability to work.

The questionnaire (Appendix 1) is largely based on established validated measures and reproducible clinical scales, although some changes were necessary where existing measures were thought to have shortcomings. It incorporates a number of items which have been previously tested and validated in cohorts of patients with IBS as well as in population-based studies. This work has been conducted by members of the team involved in the development of this questionnaire, and by others.

2 List of main contributors

Dr Miles Parkes, Consultant Gastroenterologist, Cambridge

Prof Peter Whorwell, Professor of Medicine & Gastroenterology, University of Manchester

Prof Robin Spiller, Professor of Gastroenterology, University of Nottingham

Dr Nicholas Kennedy, Consultant Gastroenterologist and Honorary Clinical Senior Lecturer, Exeter

Professor Elizabeth Soilleux, Associate Professor of Pathology, University of Oxford

3 Content

The following table provides details of the tools/scales used in digestive health questionnaire.

The full list of questions can be found in Appendix 1.

4 Piloting

4.1: The digestive health questionnaire is largely comprised of scales which have been widely used in clinical and research settings.

4.2: Prior to administration in the whole cohort, the invitation to complete the questionnaire was sent to 10,000 UK Biobank participants in order to assess acceptability and questionnaire duration. Minor modifications to wording were made following the receipt of participant feedback.

Domain/question topic	Purpose	Source/tool	Notes about source/tool	Reference
Section A: Introductory checks	To confirm personal details To ascertain whether participant has had a diagnosis of IBS	Bespoke	None	None
Section B: Symptoms of IBS.	To record the principal symptoms of IBS and their frequency in order to ascertain whether participants have symptoms indicative of IBS	Rome III criteria	Diagnostic criteria for IBS developed by the Rome Foundation on Functional Gastrointestinal Disorders. It is an international gold standard for diagnosing IBS.	¹
Section C: Severity of IBS.	To record and score the symptoms of IBS in order to assess the severity of IBS symptoms	IBSSS	The IBS Severity Scoring system (IBSSS) was developed and validated in 1997. Since then it has been widely used in both the clinical and research setting. It is a validated tool for assessing the severity of IBS symptoms.	²
Section D: Bowel habits and impact of IBS on working life.	To further assess the degree of bowel dysfunction and impact of their IBS on their working life	IBSSS	The IBSSS is a validated tool for assessing severity of IBS symptoms.	²
Section E: Other medical complaints.	To record the many other symptoms from which people with IBS can suffer and allow an assessment of comorbidities	PHQ12	The Patient Health Questionnaire 12 is a modification of the PHQ 15 for use with patients with IBS. It records and scores many of the somatic symptoms from which IBS patients commonly suffer. It is a validated tool to assess comorbidities.	³
Section F: Other health problems, associations and risk factors for IBS	To record non-abdominal symptoms not captured by the PHQ which are commonly found in people with IBS	Bespoke	These questions complement the PHQ12 by asking about a range of other potential comorbidities.	None
Section G: Onset of IBS symptoms.	Helps to identify sub-group of patients with post-infectious IBS (where the aetiology may be different to 'standard' IBS)	Bespoke	None	None

Section H: Free text box	To enable participants to add further information about their digestive health	--	Comment box was included in response to comments received during the piloting of the UK Biobank Mental Health Questionnaire. However, UK Biobank does not intend to release these comments to researchers at the current time.	
End	This last page contains a link to the IBS network in case participants need further support quickly. It also suggests that they contact their GP if they would like any further help.	--	None	None

5 Administration

5.1: UK Biobank's re-contact approach for those participants with an email address as follows:

- an initial invitation email (which included a hyperlink to their personalised questionnaire);
- a reminder email to non-responders sent 2 weeks after the initial invite;
- a reminder to partial responders (i.e. who only completed part of the questionnaire) 2 weeks after they started the questionnaire;
- a 'last-chance' reminder sent to non-responders 4 months after the initial invite.

5.2: 95.3% of participants completed the questionnaire in less than 20 minutes.

5.3: Overall, 331,832 participants were sent an email invitation, of whom 172,949 (52.1%) fully completed the questionnaire (as of July 2018). A further 3,396 participants accessed the questionnaire via the participant website without having received an email invite (because they have not provided UK Biobank with a valid email address or completed the questionnaire via the participant website prior to an invite being sent).

5.4: Participants for whom we do not have an email address were encouraged via the annual newsletter (sent Q3 2017) to complete the online questionnaire by logging directly onto the participant website.

5.5: Email invitations are also routinely sent to those participants who have recently updated their email address (and who have not yet completed the questionnaire). We therefore anticipate that data will continue to accrue for a small number of participants.

5.6: Please note that UK Biobank has identified a small number of possible mismatches in the linkage of the questionnaire (e.g., where participants who share an email address, or a computer/tablet may have completed their partner's questionnaire). These data have not been released.

6 References

1. Longstreth GF, Thompson WG, Chey WD, Houghton LA, Mearin F, Spiller RC. Functional bowel disorders. *Gastroenterology* 2006; 130(5):1480-1491.
2. Francis CY, Morris J, Whorwell PJ. The irritable bowel severity scoring system: a simple method of monitoring irritable bowel syndrome and its progress. *Aliment Pharmacol Ther* 1997; 11(2):395-402.
3. Spiller RC, Humes DJ, Campbell E, Hastings M, Neal KR, Dukes GE et al. The Patient Health Questionnaire 12 Somatic Symptom scale as a predictor of symptom severity and consulting behaviour in patients with irritable bowel syndrome and symptomatic diverticular disease. *Aliment Pharmacol Ther* 2010; 32(6):811-820.

Appendix 1: Questions and format of the questionnaire

Introduction

Section A: Introductory checks. 3 questions.

Section B: Symptoms of IBS. 3-10 questions.

Section C: Severity of IBS. 4-7 questions.

Section D: Bowel habits and impact of IBS on working life. 5 questions.

Section E: Other medical complaints. 14 questions.

Section F: Other health problems, associations and risk factors for IBS. 7 questions.

Section G: Onset of IBS symptoms. 0-7 questions.

End page provides links to support.

Q. No	Field ID	Stem	Responses
		Help us to understand IBS - more than just bellyache.	
		Irritable Bowel Syndrome (IBS) is an extremely common abdominal complaint. In fact, it is one of the most common reasons why people visit their GP. Some people suffer severe symptoms with a huge impact on their lives, whilst others experience only mild or intermittent symptoms, for example, when stressed. We need to know more about the causes of IBS if we are going to get better treatments.	
INTRO		UK Biobank provides a unique opportunity to better understand IBS. We hope to combine the results of this questionnaire with other information you have provided to gain a deep understanding of the risk factors, triggers and underlying causes of IBS.	Next
		Please answer all the following questions even if you do not have IBS – having information from people who have no IBS symptoms is critical to allowing us to better understand the information from people who do	

suffer with IBS. The questionnaire is split into sections, each section having a slightly different purpose. You may notice that there is some overlap in a few questions; this is necessary to ensure that all the information we collect is completely reliable.

To help you as you work your way through the questionnaire: - Next

- Most devices will allow you to click or tap the description beside a choice button to select it
 - Click or tap on this sentence
 - Click /tap here and over here
 - A slider allows you to select a value from a range. Click or tap or drag the slider pointer until your chosen value is displayed.
 - The progress bar at the bottom of each page (see below) is split into blocks, with each block representing a different section of the questionnaire.
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Section A: Introductory checks

Q. No	Field ID	Stem	Response
AIntro		This questionnaire is participant specific. It should only be completed by you	
		First, we need to check a few things.	
A1		Please confirm your month and year of birth	[Select one from] 01 = January 02 = February 03 = March 04 = April 05 = May 06 = June 07 = July 08 = August 09 = September 10 = October 11 = November 12 = December

			[Select one from] an integer between 1934 and 1971.
A2		Please confirm your sex	[Select one from] 01 = Male 02 = Female
A3	21024	Have you ever been diagnosed with IBS?	[Select one from] 01 = Yes 00 = No DK= Do not know DA = Prefer not to answer
AINTROrestart		Now let's continue from where you left off....	Where participant logs off and then back on, INTROrestart will display
ACLOSE		Now let's start with a few general questions about IBS	Will display on all newly started questionnaires
SECTION B: Symptoms of IBS			
Q. No	Field ID	Stem	Responses
BINTRO		This section relates to whether or not you have symptoms of IBS	
B1	21025	In the last 3 months , how often did you have discomfort or pain anywhere in your abdomen?	[Select one from] 00 = Never 01 = Less than one day a month 02 = One day a month 03 = Two to three days a month 04 = One day a week 05 = More than one day a week 06 = Every day DA = Prefer not to answer
B1a	21026	Did this discomfort or pain occur only during your menstrual bleeding and not at other times?	[Select one from] 01 = Yes 00 = No NA = Not Applicable DA = Prefer not to answer
B1b	21027	Have you had this discomfort or pain 6 months or longer?	[Select one from] 01 = Yes 00 = No DA = Prefer not to answer
B1c	21028	How often did this discomfort or pain get better or stop after you had a bowel movement?	[Select one from] 00 = Never or rarely 01 = Sometimes

			02 = Often 03 = Most of the time 04 = Always DA = Prefer not to answer
B1d	21029	When this discomfort or pain started, did you have more frequent bowel movements?	[Select one from] 00 = Never or rarely 01 = Sometimes 02 = Often 03 = Most of the time 04 = Always DA = Prefer not to answer
B1e	21030	When this discomfort or pain started, did you have less frequent bowel movements?	[Select one from] 00 = Never or rarely 01 = Sometimes 02 = Often 03 = Most of the time 04 = Always DA = Prefer not to answer
B1f	21031	When this discomfort or pain started, were your stools (bowel movements) looser?	[Select one from] 00 = Never or rarely 01 = Sometimes 02 = Often 03 = Most of the time 04 = Always DA = Prefer not to answer
B1g	21032	When this discomfort or pain started, how often did you have harder stools?	[Select one from] 00 = Never or rarely 01 = Sometimes 02 = Often 03 = Most of the time 04 = Always DA = Prefer not to answer
B2	21033	In the last 3 months, how often did you have hard or lumpy stools?	[Select one from] 00 = Never or rarely 01 = Sometimes 02 = Often 03 = Most of the time 04 = Always DA = Prefer not to answer
B3	21034	In the last 3 months, how often did you have loose, mushy or watery stools?	[Select one from] 00 = Never or rarely 01 = Sometimes

Section C: Severity of IBS			
Q. No	Field ID	Stem	Responses
CINTRO		This section allows us to assess the severity of any IBS symptoms you currently have (i.e. have had in the last 3 months). Again, please fill it in even if you do not have IBS.	02 = Often 03 = Most of the time 04 = Always DA = Prefer not to answer
C1	21035	Do you currently (in the last 3 months) suffer from abdominal (tummy) pain?	[Select one from] 01 = Yes 00 = No DA = Prefer not to answer
C1a	21036	How severe is your abdominal pain? <i>Please move the slider to choose a number from 0 to 10, with 0 meaning "no pain" and 10 meaning "very severe".</i>	[Using VAS, select one from] No pain 0 1 2 3 4 5 6 7 8 9 10 Very severe DA = Prefer not to answer
C1b	21037	Please move the slider to select the number of times that you get the pain every 10 days . <i>For example, if you choose 4 it means that you get pain 4 out of 10 days. If you get pain every day enter 10.</i>	[Using VAS, Select one from] No days with pain 0, 1, 2, 3, 4, 5, 6, 7, 8, 9, 10 days with pain DA = Prefer not to answer
C2	21038	Do you currently suffer from abdominal distension? (bloating, swollen or tight tummy) <i>Women please ignore distension related to your period.</i>	[Select one from] 01 = Yes 00 = No DA = Prefer not to answer
C2a	21039	How severe is your abdominal distension/tightness? <i>Please move the slider to choose a number from 0 to 10, with 0 meaning "no distension" and 10 meaning "very severe".</i>	[Using VAS, select one from] No distension 0 1 2 3 4 5 6 7 8 9 10 Very severe distension DA = Prefer not to answer
C3	21040	How happy /satisfied are you with your bowel habits? <i>Please move the slider to choose a number from 0 to 10, with 0 meaning "very happy" and 10 meaning "very unhappy".</i>	[Using VAS, select one from] Very happy 0 1 2 3 4 5 6 7 8 9 10 Very unhappy DA = Prefer not to answer

C4	21041	<p>Please indicate how much abdominal pain or discomfort or altered bowel habits are affecting or interfering with your life in general.</p> <p><i>Please move the slider to choose a number from 0 to 10, with 0 meaning “not at all” and 10 meaning “completely”.</i></p>	<p>[Using VAS, select one from]</p> <p>Not at all 0 1 2 3 4 5 6 7 8 9 10 Completely</p> <p>DA = Prefer not to answer</p>
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SECTION D: Bowel habits and impact of IBS on working life

Q. No	Field ID	Stem	Responses
D1	21042	What is the greatest number of times you open your bowels per day ?	<p>DBOX1: Integer box 1 to 40</p> <p>DBOX1 & “time(s) per day”</p> <p>OR</p> <p>DA = Prefer not to answer</p>
D2	21043	What is the least number of times you open your bowels per week ?	<p>DBOX2: Integer box 0 to 150</p> <p>DBOX2 & “time(s) per week”</p> <p>OR</p> <p>DA = Prefer not to answer</p> <p>[Answer to D2 must be ≤ 7 x answer to D1]</p>
D3	21044	What is the average number of times you open your bowels per day ?	<p>DBOX3: Integer box 0 to 20</p> <p>DBOX3 & “time(s) per day”</p> <p>OR</p> <p>DA = Prefer not to answer</p> <p>[Answer to D3 must be ≤ answer to D1]</p>
BLOCK D4		In the last year approximately how many weeks were you:	<p>Display with D4a and D4b</p>
D4a	21045	<p>Absent from work due to IBS?</p> <p><i>Please answer “0” if you have IBS but it doesn’t prevent you going to work.</i></p>	<p>DBOX4: Integer box 0 to 52</p> <p>DBOX4 & “weeks”</p> <p>OR</p> <p>01 = I have given up work be cause of IBS</p> <p>OR</p> <p>NA = I do not work (e.g. retired, unemployed, homemaker)</p> <p>OR</p> <p>DA = Prefer not to answer</p>

			[Answer to D4a+D4c≤52]
			[Select one from] 01 = January 02 = February 03 = March 04 = April 05 = May 06 = June 07 = July 08 = August 09 = September 10 = October 11 = November 12 = December 01 = DK = Do not know
D4b	21046	When was this?	[Select one from] a year between year of birth (response to A1) +10 years and the current year.

D4c	21047	At work but suffering because of IBS? <i>Please answer "52" if your IBS affects you all the time at work.</i> <i>Please answer "0" if your IBS does not affect you at work.</i>	DBOX7: Integer box 0 to 52 DBOX7 & "weeks" OR DA = Prefer not to answer [Answer to D4a+D4c≤52]r
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SECTION E: Other medical complaints

Q. No	Field ID	Stem	Responses
EINTRO		This section is about other complaints you might have.	
BLOCK E1		During the past 3 months , how much have you been bothered by any of the following problems?	Display throughout questions E1a to E1n
E1a	21048	Back pain	[Select one from] 00 = Not bothered at all 01 = Bothered a little 02 = Bothered a lot DA = Prefer not to answer
E1b	21049	Pain in your arms, legs, or joints (knees, hips etc.)	[Select one from] 00 = Not bothered at all 01 = Bothered a little 02 = Bothered a lot

			DA = Prefer not to answer
E1c	21050	Menstrual cramps or other problems with your periods	[Select one from] 00 = Not bothered at all 01 = Bothered a little 02 = Bothered a lot DA = Prefer not to answer NA = Not applicable
E1d	21051	Headaches	[Select one from] 01 = Bothered a little 02 = Bothered a lot DA = Prefer not to answer
E1e	21052	Chest pain	[Select one from] 00 = Not bothered at all 01 = Bothered a little 02 = Bothered a lot DA = Prefer not to answer
E1f	21053	Dizziness	[Select one from] 00 = Not bothered at all 01 = Bothered a little 02 = Bothered a lot DA = Prefer not to answer
E1g	21054	Fainting spells	[Select one from] 00 = Not bothered at all 01 = Bothered a little 02 = Bothered a lot DA = Prefer not to answer
E1h	21055	Feeling your heart pound or race	[Select one from] 00 = Not bothered at all 01 = Bothered a little 02 = Bothered a lot DA = Prefer not to answer
E1i	21056	Shortness of breath	[Select one from] 00 = Not bothered at all 01 = Bothered a little

			02 = Bothered a lot DA = Prefer not to answer
E1j	21057	Pain or problems during intercourse	[Select one from] 00 = Not bothered at all 01 = Bothered a little 02 = Bothered a lot DA = Prefer not to answer NA = Not applicable
E1k	21058	Urinary frequency or bladder irritability	[Select one from] 00 = Not bothered at all 01 = Bothered a little 02 = Bothered a lot DA = Prefer not to answer
E1l	21059	Nausea	[Select one from] 00 = Not bothered at all 01 = Bothered a little 02 = Bothered a lot DA = Prefer not to answer
E1m	21060	Feeling tired all the time or having low energy	[Select one from] 00 = Not bothered at all 01 = Bothered a little 02 = Bothered a lot DA = Prefer not to answer
E1n	21061	Trouble sleeping	[Select one from] 00 = Not bothered at all 01 = Bothered a little 02 = Bothered a lot DA = Prefer not to answer
SECTION F: Other health problems, associations and risk factors			
Q. No	Field ID	Stem	Responses
FINTRO		This section is made up of a mix of questions relating to other health problems, associations and risk factors for IBS.	
F1	21062	Have you ever been offered or sought treatment for anxiety?	[Select one from] 01 = Yes 00 = No DA = Prefer not to

			answer
F2	21063	Have you ever been offered or sought treatment for depression?	[Select one from] 01 = Yes 00 = No DA = Prefer not to answer
F3	21064	Do you have a sensitive stomach?	[Select one from] 01 = Yes 00 = No DK = Do not know DA = Prefer not to answer
F4	21065	Do you have a family history of IBS in your parents / siblings / children?	[Select one from] 01 = Yes 00 = No DK = Do not know DA = Prefer not to answer
F5	21066	Were you born by Caesarian section?	[Select one from] 01 = Yes 00 = No DK = Do not know DA = Prefer not to answer
F6	21067	During childhood or as a teenager did you receive long-term or recurrent courses (3 or more per year) of antibiotics (for example for tonsillitis or acne)?	[Select one from] 01 = Yes 00 = No DK = Do not know DA = Prefer not to answer
F7	21068	Have you been diagnosed with coeliac disease/ gluten sensitivity?	[Select one from] 01 = Yes 00 = No DK = Do not know DA = Prefer not to answer
F8	21069	When you were diagnosed with coeliac disease/ gluten sensitivity was this:	[Select one from] 01 = Self-diagnosis from symptoms 02= Doctor diagnosis from symptoms 03 = By means of a blood test only? 04 = By means of endoscopy only? 05 = By means of a blood test and endoscopy? DA = Prefer not to answer

SECTION G: Onset of IBS symptoms

Q. No	Field ID	Stem	Responses
GINTRO		This section is about when your	

		abdominal symptoms very first started.	
G1	21070	Did your IBS symptoms start suddenly, over one or a few days, or did they come on gradually?	[Select one from] 01 = Started suddenly 02 = Came on gradually 03 = Cannot remember DA = Prefer not to answer
G2	21071	When your IBS symptoms first began (or up to two weeks before), were you diagnosed with an infectious illness ('tummy bug')?	[Select one from] 01 = Yes 00 = No DA = Prefer not to answer
G2a	21072	Please select the infection from this list:	[Select one from] 01 = Salmonella 02 = Shigella 03 = Campylobacter 04 = Virus 05 = Other 06 = Do not know DA = Prefer not to answer
BLOCK G3		When your IBS symptoms first began (or up to two weeks before), did you have any of the following symptoms?	Display throughout questions G3a to G3d
G3a	21073	Fever	[Select one from] 01 = Yes 00 = No DA = Prefer not to answer
G3b	21074	Diarrhoea	[Select one from] 01 = Yes 00 = No DA = Prefer not to answer
G3c	21075	Bloody diarrhoea	[Select one from] 01 = Yes 00 = No DA = Prefer not to answer
G3d	21076	Vomiting	[Select one from] 01 = Yes 00 = No DA = Prefer not to answer
SECTION H: End page			
Q. No	Field ID	Stem	Responses
H1		Please use the space below to tell us any further important information relevant to this	Text box: 1000 characters

	questionnaire.
	Please note: after you press the Save and finish button below, you will no longer be able to change your answers.
CLOSE	<p>Many thanks for answering these questions. A better understanding of the causes of IBS is an important step towards improving treatment of this difficult condition.</p> <p>If you have concerns about any of the issues covered in the questionnaire, we suggest that you contact your General Practitioner or visit https://www.theibsnetwork.org/ where you will find further information about IBS.</p> <p>You may now close this browser tab, if you so wish.</p>

Close browser tab;
or
Click on 'Go back to the participant area';
or
Click on 'Go to the UK Biobank Home Page'

Note that there is one data field on showcase that does not appear in this table.

Description: When digestive health questionnaire completed

Notes: Date and time when digestive health questionnaire completed

Field ID: 21023