# **UK Biobank**

# Health and well-being web-based questionnaire

Version 1.2

http://www.ukbiobank.ac.uk/ 16th August 2023



This document details the rationale and procedure for administration of the health and well-being web-based questionnaire for UK Biobank. This version (1.2) includes links to the specific data-fields that relate to each questionnaire item in the Appendix table, and supersedes version 1.1.

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#### 1. Introduction – scientific rationale

In 2021, the UK Biobank imaging enhancements working group requested the collection of information about UK Biobank participants' COVID symptoms. However, subsequent analysis of GP data from 102,769 UK Biobank participants living in England revealed that electronic GP data did not contain comprehensive information about incident symptoms of COVID-19 (particularly taste and smell disorder). It was therefore decided to obtain information about the impact of the COVID-19 pandemic on health and well-being directly from participants.

The overall aims of administering this questionnaire were:

- (i) to capture data on possible symptoms and impacts of long COVID;
- (ii) to enable comparisons of symptoms experienced by participants who have objective measures of previous COVID-19 disease (obtained through medical or vaccination records) with those who do not.

## 2. List of contributors

In addition to the guidance related to the list of symptoms provided by Dr Katrina Davis and Professor Matthew Hotopf of King's College London and the South London and Maudsley NHS Foundation Trust on behalf of UK Biobank, advice was also sought from the following clinicians and academics:

- Dr Athena Akrami Group Leader, Sainsbury Wellcome Centre, University College
  London (non-clinical cognitive neuroscientist and co-lead on the patient-led long
  COVID patient survey 'Characterizing long COVID in an international cohort: 7 months
  of symptoms and their impact').
- Professor Nisreen Alwan MBE Professor in Public Health, University of Southampton (public health researcher with lived experience, research and patient advocacy expertise in long COVID).
- Dr Timothy Nicolson Clinical Senior Lecturer in Neuropsychiatry, Institute of Psychiatry, Psychology and Neuroscience, King's College London; and head of long COVID clinic at King's College Hospital (co-lead on NIHR-funded international initiative with WHO to develop a core outcome set to optimise and standardise measurement of

- long COVID; and collaborator on a range of research studies investigating neurological and psychiatric complications of COVID-19).
- Dr Claire Steves Clinical Senior Lecturer, King's College London; Consultant Geriatrician at Guy's and St Thomas's NHS Foundation Trust; and Deputy Director (Clinical) for TwinsUK.
- Prof Helen Ward Clinical Professor of Public Health, Imperial College London.
- Dr Christina Atchison Principal Clinical Academic Fellow, Faculty of Medicine,
   School of Public Health, Imperial College London.

#### 3. Content

The questionnaire includes questions on COVID-19 symptoms and impact drawn from the Wellcome COVID-19 questionnaire (<a href="https://www.bristol.ac.uk/alspac/covid-19/wellcome-covid-19/">https://www.bristol.ac.uk/alspac/covid-19/wellcome-covid-19/</a>) as well as from surveys used in other large cohort studies, for example, REACT, TwinsUK and the ZOE COVID Study. We also consulted researchers developing a CORE outcome set for long COVID, to ensure that the symptoms included were those most relevant to long COVID. Some of the questions on mental well-being have been asked of UK Biobank participants in previous questionnaires, and these are identified in Appendix 1. A detailed guide to the sources of all questions used in the questionnaire and experts consulted is included below.

The following table provides details of the sources of questions used in the health and well-being questionnaire.

Q. ID	Source	Authors	Available at
HT1	Q1.2.1 and Q2.2.1 of Wellcome Trust Longitudinal Population Studies (LPS) Questionnaire Resource v0.5, June 2021	Questionnaire provided by Wellcome Longitudinal Population Study COVID- 19 Steering Group and Secretariat (221574/Z/20/Z)	https://www.bristol.ac.uk/alspac/covid- 19/wellcome-covid-19/
	TwinsUK COVID-19 Health and Personal Experiences (CoPE) Questionnaire, v55	Department of Twin Research & Genetic Epidemiology, King's College London	From TwinsUK study team
	Office for National Statistics (ONS) COVID-19 infection survey of the UK general population	Office for National Statistics and the University of Oxford (UK), delivered by IQVIA (USA)	https://www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/case-record-forms
	World Health Organization (WHO) Global COVID-19 Clinical Platform Case Report Form (CRF) for Post COVID Condition (Post COVID-19 CRF)	Health Care Readiness Unit, WHO	https://www.who.int/publications/i/item/glob al-covid-19-clinical-platform-case-report- form-(crf)-for-post-covid-conditions-(post- covid-19-crf-)
	Prof Matthew Hotopf and Dr Katrina Davis' work on long COVID	Developed in conjunction with the UK Biobank Mental Health Outcomes Consortium and external experts on long COVID and outcome measures. Submitted to UK Biobank's Strategic Oversight Committee in support of application to undertake second mental health questionnaire (now relabelled as mental well-being questionnaire, 2022)	Internal document
	UK Biobank mental well-being questionnaire 2022	Developed in conjunction with Prof Matthew Hotopf and Dr Katrina Davis at KCL, in collaboration with UKB Mental Health Outcomes Consortium. Given favourable ethical opinion by North West - Haydock REC, amendment 01, August 2021	Questionnaire developed for online use via the University of Oxford's Online Questionnaire Sharing (OQS) Service
	COVID-19 rapid guideline: managing the long-term effects of COVID-19	NICE guideline covering the identification, assessment and management of the long-term effects of COVID-19	https://www.nice.org.uk/guidance/ng188

	BMJ Best Practice: Coronavirus disease 2019 (COVID-19)	BMJ Best Practice Guidance provided for medical professionals	https://bestpractice.bmj.com/topics/en- gb/3000201/complications
	Real-time Assessment of Community Transmission Long COVID (REACT-LC) survey 2022	Faculty of Medicine, Imperial College London	https://www.imperial.ac.uk/medicine/resear ch-and-impact/groups/react- study/studies/react-long-covid/
HT2	Developed by UK Biobank		
HT3	Developed by UK Biobank, using response options taken from UK Biobank mental well-being questionnaire work with Hotopf/Davis		
PHQ	Patient Health Questionnaire for Depression and Anxiety	Developed by Drs. Robert L. Spitzer,	https://www.phqscreeners.com/select-
4	(PHQ-4)	Janet B.W. Williams, Kurt Kroenke and	<u>screener</u>
		colleagues, with an educational grant	
		from Pfizer Inc. No permission required	
		to reproduce, translate, display or distribute	
EL1	Amended version of Q2.2.15 of Wellcome Trust LPS	Questionnaire provided by Wellcome	https://www.bristol.ac.uk/alspac/covid-
	Questionnaire Resource v0.5, June 2021 (response	Longitudinal Population Study COVID-	19/wellcome-covid-19/
	options amended and presented in a different format)	19 Steering Group and Secretariat (221574/Z/20/Z)	
EL2	Q2.2.16 of Wellcome Trust LPS Questionnaire Resource	Questionnaire provided by Wellcome	https://www.bristol.ac.uk/alspac/covid-
	v0.5, June 2021 (responses presented in a different order)	Longitudinal Population Study COVID-	19/wellcome-covid-19/
		19 Steering Group and Secretariat (221574/Z/20/Z)	
C1	Developed by UK Biobank		

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

# 4. Piloting

Prior to inviting all participants with a contact email address (approximately 330,000) to complete it, UK Biobank piloted this questionnaire with 10,000 participants to ensure that the online platform and procedures were adequately robust and that the questionnaire was acceptable in terms of content and length.

### 5. Administration

- **5.1:** The questionnaire administration process for UK Biobank participants with an email address was as follows:
- an initial invitation email (which included a hyperlink to their personalised questionnaire);
- a reminder email to non-responders sent two weeks after the initial invitation;
- a reminder email sent to partial responders (i.e. those who had only completed part of the questionnaire) two weeks after they started the questionnaire;
- a 'last-chance' invitation sent to non-responders four months after the initial invitation.
- **5.2:** Ninety six per cent of participants completed the questionnaire in 20 minutes or less.
- **5.3:** As of 20<sup>th</sup> May 2023, there were 201,684 participants who had fully completed the online questionnaire out of a total of 333,427 participants sent an email invitation.
- **5.4:** Participants for whom UK Biobank did not have an email address were encouraged via the information in the 2022 newsletter and on the UK Biobank website to complete the online questionnaire by logging in to the participant website. A further 1,094 participants accessed the questionnaire via the participant website in this way, without having received an email invitation.
- **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:** Data were removed from participants who failed the identity check at the beginning of the online questionnaire: that is, the dates of birth they provided did not match UK Biobank records. These amounted to 3% of all respondents.

# **Appendix 1: Questions and format of the questionnaire**

# Health & well-being questionnaire

#### Introduction (INTRO1)

The past few years have been very challenging for a lot of us and it is important for us to understand how people's health has been affected. We would therefore like to ask for your help by providing us with some information about your health and well-being at the moment.

Q.ID	Field ID	Stem	Question identical to previous questionnaire*	Question similar to previous questionnaire	Responses
Identity che	ck		1	1	
ID_INTRO 1		This questionnaire is participant specific. It should only be completed by the person named on the email invitation OR the person who logged in to the participant website.  We just want to check your date of birth. This is so that we can double-check that this questionnaire has been completed by the correct person (and not, for example, by someone who shares an email address with you).			
ID_INTRO 2		Please enter your details below:			
ID_DAY		Day of birth:			[DropdownList1: 31 choices 1 – 31.]
ID_MONTH		Month of birth:			[DropdownList2: 12 choices for months: "January" to "December".]
ID_YEAR		Year of birth:			[Text box allowing integer values and it allows selection of an integer between 1934 and 1971.]
Your health	today	1	l	1	ı
HTINTRO1	These que	stions are about health issues that you may have at the r	noment.		

HTBLOCK1		[List of questions to be split over several pages. Following to be displayed at top of each page. Page titles indicated in italics in list below]  Are you currently suffering from any of the following health issues (that are new or have worsened in recent weeks)?	
HT1	28600 28603 28606 28609 28612 28615 28618 28621 28624 28627 28630	[PT002=Gastrointestinal]  a. A decrease in appetite b. Nausea and/or vomiting c. Gastrointestinal issues e.g. diarrhoea, constipation  [PT003=Eyes and ENT] d. Vision problems e. A loss or change in sense of smell f. A loss or change in sense of taste g. A sore or painful throat h. Nasal congestion i. Tinnitus j. Hearing loss k. Other hearing issues  [PT004=Pain] I. Headaches	[For each of issues HT1.a to HT1.ss, if response=Yes (01), select one from 00-01. DK, DA are exclusive.]  00=No  01=Yes  DK(-1)=Do not know  DA(-3)=Prefer not to answer
	20033	i. Heaudulles	

HT1 cont	<u>28636</u>	n. Neck pain/stiff neck
	<u>28639</u>	n. Back pain
	<u>28642</u>	o. Chest pain
	<u>28645</u>	o. Pain on breathing
	<u>28648</u>	ą. Abdominal pain/tummy ache
	<u>28651</u>	. Leg pain
	<u>28654</u>	s. Muscle pain/achy muscles
	<u>28657</u>	. Joint pain or swelling of joint(s)
	<u>28660</u>	ı. Bone pain
		PT005=Cardio-thoracic]
	<u>28663</u>	A persistent cough
	<u>28666</u>	v. Phlegm production/a chesty cough
	<u>28669</u>	t. Tightness in the chest
	<u>28672</u>	Chest pressure/'heaviness'
	<u>28675</u>	Heart issues e.g. palpitations (unusual peating of the heart), tachycardia (increased heart ate)
	<u>28678</u>	na. Postural tachycardia (increased heart rate after sitting or standing up)
	28681	bb. Dizziness/light-headedness
	<u>28684</u>	cc. Shortness of breath or trouble breathing affecting normal activities)
		PT006=Sleep and energy]

HT1 cont	28687	dd. Difficulty sleeping
	<u>28690</u>	ee. Night sweats
	<u>28693</u>	ff. Unrestful sleep
	<u>28696</u>	gg. Mild fatigue (e.g. feeling more tired than usual)
	<u>28699</u>	hh. Severe fatigue (e.g. unable to get out of bed)
	28702	ii. 'Post-exertional symptom exacerbation' (i.e. an immediate or delayed and significant worsening of existing symptoms following physical or mental exertion).
		[PT007=Skin and allergies]
	<u>28705</u>	jj. Skin issues e.g. raised, red itchy areas, new rash
	<u>28708</u>	kk. Red/purple sores or blisters on your feet (including toes)
	28711	II. New allergy or intolerance e.g. swelling of the face or lips, food intolerance, intolerance to medication
		[PT008=Body temperature]
	<u>28714</u>	mm. Fever (feeling too hot)
	<u>28717</u>	nn. Chills (feeling too cold)
		[PT009=Thoughts and feelings]

HT1 cont	<u>28720</u>	oo. Problems thinking e.g. 'brain fog', memory problems, difficulty concentrating, decreased alertness, confusion	
	<u>28723</u>	pp. Problems communicating e.g. difficulty speaking or putting your thoughts into words	
	28726	qq. Problems relating to mood, anxiety and emotions e.g. feeling 'down', anxious or irritable	
		[PT010=Sensory and neurological]	
	<u>28729</u>	rr. Weakness of muscles or difficulty moving arms and legs	
	<u>28732</u>	ss. Numbness or tingling somewhere in the body, e.g. 'pins and needles'	
HTBLOCK2		[PT011=Duration of issue]	
		How long have you been suffering from [issue]? Please include the total time spent experiencing the issue (if it has been coming and going, then include the overall time since the start of the problem).	
HT2			
	<u>28601</u>	a. A decrease in appetite	[For each of issues HT1.a to HT1.ss, if response=Yes (01) select one from 00-01. DK, DA are exclusive.]
	<u>28604</u>	b. Nausea and/or vomiting	01=Less than two weeks
	<u>28607</u>	c. Gastrointestinal issues	02=Two to three weeks
	<u>28610</u>	d. Vision problems	03=Four to twelve weeks
	<u>28613</u>	e. A loss or change in sense of smell	04=More than twelve weeks
	<u>28616</u>	f. A loss or change in sense of taste	DK(-1)=Do not know
	<u>28619</u>	g. A sore or painful throat	
	<u>28622</u>	h. Nasal congestion	DA(-3)=Prefer not to answer

HT2 cont	28625	i.	Tinnitus		
	28628	j.	Hearing loss		
	<u>28631</u>	k.	Other hearing issues		
	28634	1.	Headaches		
	<u>28637</u>	m.	Neck pain/stiff neck		
	<u>28640</u>	n.	Back pain		
	<u>28643</u>	0.	Chest pain		
	<u>28646</u>	p.	Pain on breathing		
	<u>28649</u>	q.	Abdominal pain/tummy ache		
	<u>28652</u>	r.	Leg pain		
	<u>28655</u>	s.	Muscle pain/achy muscles		
	<u>28658</u>	t.	Joint pain or swelling of joint(s)		
	<u>28661</u>	u.	Bone pain		
	<u>28664</u>	v.	A persistent cough		
	<u>28667</u>	w.	Phlegm production/a chesty cough		
	<u>28670</u>	x.	Tightness in the chest		
	<u>28673</u>	y.	Chest pressure/'heaviness'		
	<u>28676</u>	z.	Heart issues		
	<u>28679</u>	aa.	Postural tachycardia		
	<u>28682</u>	bb.	Dizziness/light-headedness		
	<u>28685</u>	cc.	Shortness of breath or trouble breathing		
	28688	dd.	Difficulty sleeping		
	<u>28691</u>	ee.	Night sweats		

HT2 cont	<u>28694</u>	ff. Unrestful sleep
	28697	gg. Mild fatigue
	28700	hh. Severe fatigue
	28703	ii. 'Post-exertional symptom exacerbation'
	<u>28706</u>	jj. Skin issues
	28709	kk. Red/purple sores or blisters on your feet
	28712	II. New allergy or intolerance
	<u>28715</u>	mm. Fever (feeling too hot)
	28718	nn. Chills (feeling too cold)
	<u>28721</u>	oo. Problems thinking
	28724	pp. Problems communicating
	28727	qq. Problems relating to mood, anxiety etc
	28730	rr. Weakness of muscles
	<u>28733</u>	ss. Numbness or tingling
HTBLOCK3		[PT012=Impact of issue]
		To what extent is [issue] affecting you?
		[Replicate issues from HT1, if response=Yes (01)]
НТ3		
	<u>28602</u>	a. A decrease in appetite [For each of issues HT1.a to HT1.ss, if response=Yes (01) select one from 00-01. DK, DA are exclusive.]
	<u>28605</u>	b. Nausea and/or vomiting  b. Nausea and/or vomiting  00=It is not limiting me
	<u>28608</u>	c. Gastrointestinal issues
	<u>28611</u>	d. Vision problems  01=It is causing me to avoid, reduce or spread out my usual activities
	<u>28614</u>	e. A loss or change in sense of smell DK(-1)=Do not know

HT3 cont	28617	f.	A loss or change in sense of taste		DA(-3)=Prefer not to answer
	28620	g.	A sore or painful throat		
	<u>28623</u>	h.	Nasal congestion		
	<u>28626</u>	i.	Tinnitus		
	<u>28629</u>	j.	Hearing loss		
	<u>28632</u>	k.	Other hearing issues		
	<u>28635</u>	I.	Headaches		
	<u>28638</u>	m.	Neck pain/stiff neck		
	<u>28641</u>	n.	Back pain		
	<u>28644</u>	0.	Chest pain		
	<u>28647</u>	p.	Pain on breathing		
	<u>28650</u>	q.	Abdominal pain/tummy ache		
	<u>28653</u>	r.	Leg pain		
	<u>28656</u>	s.	Muscle pain/achy muscles		
	<u>28659</u>	t.	Joint pain or swelling of joint(s)		
	<u>28662</u>	u.	Bone pain		
	<u>28665</u>	v.	A persistent cough		
	<u>28668</u>	w.	Phlegm production/a chesty cough		
	<u>28671</u>	x.	Tightness in the chest		
	<u>28674</u>	y.	Chest pressure/'heaviness'		
	<u>28677</u>	z.	Heart issues		
	<u>28680</u>	aa.	Postural tachycardia		
	<u>28683</u>	bb.	Dizziness/light-headedness		

HT3 cont	<u>28686</u>	CC.	Shortness of breath or trouble breathing		
	<u>28689</u>	dd.	Difficulty sleeping		
	<u>28692</u>	ee.	Night sweats		
	<u>28695</u>	ff.	Unrestful sleep		
	<u>28698</u>	gg.	Mild fatigue		
	<u>28701</u>	hh.	Severe fatigue		
	<u>28704</u>	ii.	'Post-exertional symptom exacerbation'		
	<u>28707</u>	jj.	Skin issues		
	<u>28710</u>	kk.	Red/purple sores or blisters on your feet		
	<u>28713</u>	II.	New allergy or intolerance		
	<u>28716</u>	mm.	Fever (feeling too hot)		
	<u>28719</u>	nn.	Chills (feeling too cold)		
	<u>28722</u>	00.	Problems thinking		
	<u>28725</u>	pp.	Problems communicating		
	<u>28728</u>	qq.	Problems relating to mood, anxiety etc		
	<u>28731</u>	rr.	Weakness of muscles		
	<u>28734</u>	SS.	Numbness or tingling		
PHQ-4 INTRO	We would li	like to kno	ow about how you have been feeling recently		
BLOCK PHQ-4 1		bother	the last <b>2 weeks</b> , how often have you been red by any of the following problems? [4 ions on one page].		
PHQ-4 1a	28735	Feelin	g nervous, anxious or on edge	Field ID 20506 (Mental health questionnaire)	Select one from the following for each of the statements] 01=Not at all 02=Several days 03=More than half the days

				04=Nearly every day DA=Prefer not to answer		
PHQ-4 1b	28736	Not being able to stop or control worrying	Field ID 20509 (Mental health questionnaire)	Select one from the following for each of the statements] 01=Not at all 02=Several days 03=More than half the days 04=Nearly every day DA=Prefer not to answer		
PHQ-4 1c	28737	Little interest or pleasure doing things	Field ID 20514 (Mental health questionnaire)  Field ID 120104 (Pain questionnaire)	[Select one from the following for each of the statements] 01=Not at all 02=Several days 03=More than half the days 04=Nearly every day DA=Prefer not to answer		
PHQ-4 1d	28738	Feeling down, depressed or hopeless	Field ID 20510 (Mental health questionnaire)  Field ID 120105 (Pain questionnaire)	[Select one from the following for each of the statements] 01=Not at all 02=Several days 03=More than half the days 04=Nearly every day DA=Prefer not to answer		
ELINTRO1	We would like to know if your current health is impacting on your everyday life.					
ELBLOCK1		How much difficulty do you have with the following activities?				
EL1	28739 28740 28741 28742 28743 28744 28745	<ul> <li>a. Standing for long periods, such as 30 minutes?</li> <li>b. Taking care of your household responsibilities?</li> <li>c. Learning a new task, e.g. learning how to get to a new place?</li> <li>d. Joining in community activities (e.g. festivities, religious, other)?</li> <li>e. Being emotionally affected by your health problems?</li> <li>f. Concentrating on doing something for ten minutes?</li> <li>g. Walking a long distance such as one kilometre or half a mile?</li> </ul>		[For each of questions EL1.a to EL1.n, select one from] 00=No difficulty 01=Mild difficulty 02=Moderate difficulty 03=Severe difficulty 04=Extreme difficulty / unable to do this DK(-1)=Do not know DA(-3)=Prefer not to answer		

	28746 28747 28748 28749 28750 28751 28752	h. Washing your whole body? i. Getting dressed? j. Dealing with people you do not know? k. Maintaining a friendship? l. Dealing with noisy environments (e.g. from TV, people's chattering, street noise)? m. Doing your day-to-day work (including unpaid work or studying)? n. Looking after your children/grandchildren? What additional help do you need because of the health issue(s) you have identified? Please select all that apply.						
EL2	28753	What additional help do you need because of the health issue(s) you have identified? Please select all that apply.			[Select one or more from 01-09. 00 is exclusive. If EL2=I do not need any additional help (00) no other selection can be made]  00=I have not needed any additional support 01=Getting essential shopping e.g. food or medication 02=Preparing food and/or drink 03=Washing and dressing 04=Doing housework e.g. laundry, cleaning or vacuuming 05=Managing household responsibilities e.g. finances or paying bills 06=Doing day-to-day work (including unpaid work or studying) 07=Doing childcare or other caring responsibilities 08=Letting other people know about my illness (e.g. employer, university, family) 09=Getting about (travel) e.g. driving			
Comments								
C1		Please tell us anything else relevant to this questionnaire here. (If you do not wish to add any extra information here, please click Save/continue).			Free text field, max. 1000 characters]			

<sup>\*</sup> Fields in common with items from other questionnaires can be mapped between respective field IDs using <u>Schema 21</u> on Showcase.