DATA NOTE

TwinsUK COVID-19 personal experience questionnaire (CoPE): wave 1 data capture April-May 2020 [version 1; peer review: awaiting peer review]

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Any reports and responses or comments on the article can be found at the end of the article.

Abstract

TwinsUK is a population-based study which consists of 14,575 adult twins at present (55% monozygotic and 43% dizygotic) who are between 18 to 101 years of age from around the United Kingdom (UK). In response to the coronavirus disease 2019 (COVID-19) pandemic and the resulting UK 'lockdown' restrictions, our team developed the TwinsUK COVID-19 personal experience (CoPE) questionnaire. To date the CoPE questionnaire has been implemented three times, once during the first lockdown (April-May 2020), once as the restrictions eased (July-August 2020) and another when we entered the second wave of the pandemic and stricter restrictions were put into place (October-November 2020). This data note details the sample characteristics, and response rates of the data collected during the initial lockdown phase (wave 1) using the CoPE questionnaire. This questionnaire was designed to capture a variety of social, behavioural, psychological, environmental and health factors. It includes both measures that have been collected previously in TwinsUK as well as new measures. This data can be combined with pre-pandemic TwinsUK data and biological and genetic data. TwinsUK will also soon be complemented with the availability of linked health records. All TwinsUK data is available upon request and details are provided on how to access the data below.

Keywords

COVID-19, Population health, longitudinal, data, Twin research

This article is included in the [Coronavirus \(COVID-19\)](#) collection.

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Introduction

The global coronavirus disease 2019 (COVID-19) pandemic resulting from the spread of severe acute respiratory syndrome coronavirus 2 has triggered differing responses from governments around the world in attempts to safeguard their populations. In the United Kingdom (UK), a national 'lockdown' was instigated ordering all citizens to 'stay at home', with regulations coming into effect on 23rd March 2020. Whilst negative impacts of social isolation and loneliness on health and wellbeing are well-documented¹⁻⁵, little is known about the impacts in the context of health policy promoting widespread isolation as a mitigation to the outbreak.

As the largest adult twin registry in the UK, with extensive biological and baseline phenotypic measures, TwinsUK⁶ are well placed to collect data that capture the experiences of individuals during this time and importantly present analytical opportunities to utilise the powerful twin design to understand the influence of lockdown regulations without genetic confounding⁷. The 'COVID-19 personal experience study (CoPE)' collected questionnaire data on a number of measures that focused on capturing mental health, social isolation, loneliness and key risk factors. The CoPE study collected data at three waves throughout 2020, with many measures repeated at each time point to allow longitudinal assessment.

Here, we present the questions asked as part of the first round of CoPE (April 2020), and highlight key measures of interest to researchers. All data is available upon request (see 'data availability' section below) and can be linked to other cohort data (including biological and genetic) and soon health records data. Furthermore, as members of the [Wellcome Trust's Covid-19 Questionnaire](#) steering group we have where possible harmonised our data collection with other cohorts.

Methods

Sample

The UK Adult Twin Registry (or [TwinsUK](#)) is a cohort of volunteer adult twins which consists of 14,575 adult twins at present (55% monozygotic and 43% dizygotic) who are between 18 to 101 years of age from around the United Kingdom. The registry was set up in 1992 via media campaigns which aimed to recruit middle-aged women to study osteoporosis and osteoarthritis. The success of these studies drove the growth of the registry, with the scope broadening to include both male, female and mixed twins with a spectrum of clinical and behavioural phenotypes in addition to genotyping data.

The Department of Twin Research and Genetic Epidemiology at St. Thomas' Hospital, King's College London accommodates the registry. The leading focus of the TwinsUK study is the genetic foundation of complex diseases (cardiovascular, metabolic, musculoskeletal, and ophthalmologic diseases) and healthy ageing processes. Data in the registry, which include longitudinal measures, are collected on a rolling basis through clinical visits, yearly questionnaires, and various project-led studies.

Study design

The COVID-19 personal experience study (CoPE) commenced data collection in April 2020. The questionnaire was around 100 questions long and took around 30 minutes for the twins to complete online, or about 20 minutes over the phone by TwinsUK administrative staff. This questionnaire was implemented three times. The first questionnaire was sent out in April 2020 (at the beginning of the first UK lockdown), the second was sent out in July 2020 (towards the end of the COVID-19 outbreak when the government eased isolation and distancing measures), and the third was sent out in October 2020 (further detail can be found here: <https://time.graphics/line/4c88cc0482538f247bcb58b299463ca2>)

For the subsequent two rounds of data collection, questions viewed as time variant were repeated. Additional questions capturing COVID-19 symptoms and long-term fatigue were added as part of a synergistic study outside the scope of this data presentation. Round 2 was collected during a period of broadly lighter restrictions in the UK (July–August 2020), although local lockdowns remained in force. Round 3 was collected during fluctuating restrictions as the pandemic approached a 'second wave'.

Participants and questionnaire methods

For the first wave of data collection, a total of 3901 twins completed the questionnaire. [Figure 1](#) presents a flow diagram of the selection process. Twins were eligible to take part in the study if they were over the age of 18 years, lived in the UK, were members of the TwinsUK registry, and had previously taken part in at least one prior questionnaire (indicating them as engaged participants).

Based on this eligibility criteria, 5666 twins were contacted via email and 404 twins were contacted via post and telephone.

To aid recruitment, a follow up e-mail was sent to those completing the questionnaire online, encouraging them to take part or thanking them for their participation.

For those completing the questionnaire via the telephone, priority twins were contacted first via telephone to ensure representation in case resource limitations meant the whole call list could not be contacted by the administrative team. Priority twins were flagged as those who live in more deprived areas (captured by Index of Multiple Deprivation), were from Black, Asian or minority ethnic backgrounds, or those who had lower educational attainment (no formal education beyond age 16).

Questionnaire content

The questions included were designed to capture a number of social, behavioural psychological, environmental and health factors. This questionnaire included both measures that had been previously collected in the TwinsUK cohort as well as new measures. Efforts were also made to utilize measures from the Longitudinal Population Studies (LPS) [Wellcome Trust's Covid-19 Questionnaire](#), in order to harmonize with other UK national cohorts.

Figure 1. Consort flow diagram of responses to wave 1 of TwinsUK COVID-19 personal experience (CoPE) study questionnaire.

The questionnaire included 5 sections, and captured information on the following:

- Section A: Questions about whether participants have contracted COVID-19, the pandemic's immediate effect on a participant's behaviour (e.g., changes in habits and social contact) and psychological questions about trust in institutions in relation to COVID-19
- Section B: Questions about participants' responsibilities and social network including changes to their caring responsibilities
- Section C: Questions about participants' mental health incorporating key validated questionnaires (see below)
- Section D: Questions about the household location and environment, including nature relatedness and

environmental health of the home, and financial challenges due to COVID-19.

- Section E: Demographic questions, including capture of key worker status.

All questions listed in full (supplementary [Table 2⁸](#)), and a detailed breakdown of the responses by question can be found as extended data⁸.

Results

Overall response rate (waves 1–3)

[Table 1](#) presents the number of twins who took part in each data collection wave and the number of twins who took part in all data collection waves.

Response rate by measure (wave 1)

Supplementary Table 2 presents the counts and percentages of valid and missing data for each measure included in wave 1⁸.

Table 1a. Recruitment and response rates of waves 1–3 of the TwinsUK COVID-19 personal experience questionnaire (CoPE).

	Recruited online	Responded online	Recruited by post	Responded by post	Recruited by telephone	Responded by telephone	Total Recruited	Total Responded
Wave 1 CoPE April / May	N = 5666	N = 3643	na	na	N = 404	N = 258	6070 (100)	N = 3901
Wave 2 CoPE July / August	N = 6020	N = 4661	N = 582	N = 317	N = 240	N = 191	6842 (100)	N = 5169
Wave 3 CoPE October / November	N = 6014	N = 4545	N = 381	N = 315	N = 238	N = 188	6633 (100)	N = 4545

Table 1b. Overall Response Rate for those who took part in waves 1–3 of the TwinsUK COVID-19 personal experience questionnaire (CoPE).

	Wave 1 CoPE April / May	Wave 2 CoPE July / August	Wave 3 CoPE October / November
Wave 1 CoPE April / May	N = 3901	-	-
Wave 2 CoPE July / August	N = 3355	N = 5169	-
Wave 3 CoPE October / November	N = 3446	N = 3973	N = 4545

Summary of key characteristics for those who responded (wave 1)

Table 2. Summary of key characteristics (wave 1).

	Female (N=3501)	Male (N=400)	Total (N=3901)
Sex			
Female	3501 (100%)	0 (0%)	3501 (89.7%)
Male	0 (0%)	400 (100%)	400 (10.3%)
Age Group			
18–24	44 (1.3%)	11 (2.8%)	55 (1.4%)
25–34	196 (5.6%)	25 (6.2%)	221 (5.7%)
35–44	295 (8.4%)	32 (8.0%)	327 (8.4%)
45–54	448 (12.8%)	63 (15.8%)	511 (13.1%)
55–69	1353 (38.6%)	146 (36.5%)	1499 (38.4%)
70–79	941 (26.9%)	94 (23.5%)	1035 (26.5%)
80+	224 (6.4%)	29 (7.2%)	253 (6.5%)
Ethnicity			
Black	43 (1.2%)	1 (0.2%)	44 (1.1%)
East Asian	3 (0.1%)	0 (0%)	3 (0.1%)
Mixed	26 (0.7%)	2 (0.5%)	28 (0.7%)

	Female (N=3501)	Male (N=400)	Total (N=3901)
Other	6 (0.2%)	1 (0.2%)	7 (0.2%)
Other Asian background	6 (0.2%)	0 (0%)	6 (0.2%)
South Asian	26 (0.7%)	2 (0.5%)	28 (0.7%)
White	3388 (96.8%)	393 (98.2%)	3781 (96.9%)
Missing	3 (0.1%)	1 (0.2%)	4 (0.1%)
Education			
A-level, Scottish Advanced Higher	210 (6.0%)	21 (5.2%)	231 (5.9%)
Higher vocational training (e.g. Diploma, NVQ4, SVQ4)	611 (17.5%)	80 (20.0%)	691 (17.7%)
No qualification	334 (9.5%)	24 (6.0%)	358 (9.2%)
NVQ1/SVQ1	104 (3.0%)	7 (1.8%)	111 (2.8%)
O-level/GCSE/NVQ2/SVQ2/Scottish intermediate	734 (21.0%)	53 (13.2%)	787 (20.2%)
Postgraduate degree (e.g. Masters or PhD), NVQ5, SVQ5	471 (13.5%)	81 (20.2%)	552 (14.2%)
Scottish Higher, NVQ3, City and Guilds, Pitman	189 (5.4%)	29 (7.2%)	218 (5.6%)
Undergraduate degree	839 (24.0%)	104 (26.0%)	943 (24.2%)
Missing	9 (0.3%)	1 (0.2%)	10 (0.3%)
Index Multiple Deprivation			
1	55 (1.6%)	10 (2.5%)	65 (1.7%)
2	132 (3.8%)	15 (3.8%)	147 (3.8%)
3	201 (5.7%)	23 (5.8%)	224 (5.7%)
4	266 (7.6%)	37 (9.2%)	303 (7.8%)
5	346 (9.9%)	30 (7.5%)	376 (9.6%)
6	379 (10.8%)	37 (9.2%)	416 (10.7%)
7	452 (12.9%)	51 (12.8%)	503 (12.9%)
8	459 (13.1%)	52 (13.0%)	511 (13.1%)
9	552 (15.8%)	59 (14.8%)	611 (15.7%)
10	651 (18.6%)	85 (21.2%)	736 (18.9%)
Missing	8 (0.2%)	1 (0.2%)	9 (0.2%)
Country			
Channel Islands	1 (0.0%)	0 (0%)	1 (0.0%)
England	3282 (93.7%)	377 (94.2%)	3659 (93.8%)
Isle of Man	1 (0.0%)	0 (0%)	1 (0.0%)
Northern Ireland	17 (0.5%)	0 (0%)	17 (0.4%)
Scotland	109 (3.1%)	13 (3.2%)	122 (3.1%)
Wales	85 (2.4%)	9 (2.2%)	94 (2.4%)
Missing	6 (0.2%)	1 (0.2%)	7 (0.2%)

Selected responses (wave 1)

Tables 3 to Table 10 highlight key measures from wave 1 of COPE. Presented measures were selected following consultation with members of the calling team, as a qualitative assessment of questions of interest (gauged by perceived interest of participants, and potential interest to researchers); we additionally present the validated questionnaires. The remaining response summaries can be viewed in Supplementary File S1.

Measures of understanding, knowledge and trust

Table 3 presents the responses to question 6–8 of COPE. These measures aimed to assess participants' understanding, knowledge and institutional trust in the context of COVID-19. These measures may be of interest to researchers in particular who are interested in understanding individuals' psychology in relation to health behaviour.

Behaviour change

Table 4 presents the responses to: In the past week, have any of the following aspects of your life changed? For this measure (and affiliated section of the questionnaire), behavioural change was assessed over the first UK 'lockdown' period.

Self-reported loneliness in TwinsUK during the COVID-19 pandemic

Loneliness was assessed using four items from the UCLA Loneliness Scale. A very similar short form of the UCLA Loneliness Scale has previously been developed for use in large-scale surveys and correlates strongly with the full 20-item version⁹. Participants were asked to fill out the UCLA loneliness scale twice; once in relation to how they felt prior to the COVID-19 pandemic and once in relation to how they feel at time of response. Table 5–Table 6 present responses to the UCLA Loneliness Scale (4 item version).

Table 3. Participants responses to confidence in government questions.

		N (%)							
		Completely unconfident	Fairly unconfident	Somewhat unconfident	Neither confident nor unconfident	Somewhat confident	Fairly confident	Completely confident	Total
8	How much confidence do you have in the GOVERNMENT that they can handle COVID-19 well?	174 (4.5)	284 (7.3)	505 (13)	446 (11.4)	938 (24.1)	1233 (31.6)	316 (8.1)	3896 (100)

Table 4. Participants responses to: In the past week, have any of the following aspects of your life changed?

		N (%)				
		Decreased	Stayed the same	Increased	I don't do this	Total
26a	Amount you sleep	857 (21.97)	2264 (58.04)	748 (19.17)	5 (0.13)	3874 (100)
26b	Amount of physical activity/exercise you do	1633 (41.86)	1185 (30.38)	1019 (26.12)	36 (0.92)	3873 (100)
26c	Time spent in green spaces such as parks or gardens	1141 (29.25)	1186 (30.4)	1409 (36.12)	135 (3.46)	3871 (100)
26d	Amount you smoke/vape	54 (1.38)	145 (3.72)	89 (2.28)	3585 (91.9)	3873 (100)
26e	Amount of alcohol you drink	351 (9)	1578 (40.45)	812 (20.82)	1133 (29.04)	3874 (100)
26f	Amount of time you spend on public transport	1390 (35.63)	94 (2.41)	13 (0.33)	2376 (60.91)	3873 (100)
26g	Amount of time you spend in a car	3148 (80.7)	272 (6.97)	57 (1.46)	396 (10.15)	3873 (100)
26h	Number of hours you work in usual workplace	1362 (34.91)	352 (9.02)	111 (2.85)	2048 (52.5)	3873 (100)
26i	Number of hours you work at home	306 (7.84)	488 (12.51)	1051 (26.94)	2027 (51.96)	3872 (100)
26j	Time spent talking to family/friends who I live with	163 (4.18)	1658 (42.5)	1515 (38.84)	536 (13.74)	3873 (100)

		N (%)				
		Decreased	Stayed the same	Increased	I don't do this	Total
26k	Time spent talking to family/friends via phone or technology	116 (2.97)	721 (18.48)	3009 (77.13)	26 (0.67)	3872 (100)
26l	Time spent digitally socialising (e.g. group chats, watching movies in groups online)	100 (2.56)	527 (13.51)	2103 (53.91)	1142 (29.27)	3872 (100)
26m	Time spent talking to work colleagues	936 (23.99)	571 (14.64)	339 (8.69)	2026 (51.94)	3872 (100)
26n	Practising relaxation/mindfulness/meditation	205 (5.26)	960 (24.61)	510 (13.07)	2197 (56.32)	3872 (100)
26o	Time spent listening to the news	560 (14.36)	1082 (27.74)	2163 (55.45)	67 (1.72)	3872 (100)
26p	Time spent using devices with a screen	97 (2.49)	1192 (30.56)	2426 (62.19)	157 (4.02)	3872 (100)
26q	Time spent doing hobbies/things I enjoy	782 (20.05)	1363 (34.94)	1636 (41.94)	90 (2.31)	3871 (100)
26r	Amount of fruit you eat	405 (10.38)	2854 (73.16)	568 (14.56)	46 (1.18)	3873 (100)
26s	Amount of vegetables you eat	267 (6.84)	2968 (76.08)	625 (16.02)	12 (0.31)	3872 (100)

Table 5. Participants responses to UCLA Loneliness Scale: How often you felt like this BEFORE the COVID-19 pandemic?

		N (%)			
		Hardly ever	Some of the time	Often	Total
58a	How often do you feel you lack companionship?	2740 (71.1)	940 (24.4)	173 (4.5)	3853 (100)
58b	How often do you feel left out?	2698 (70)	1004 (26.1)	151 (3.9)	3853 (100)
58c	How often do you feel isolated from others?	2913 (75.6)	781 (20.3)	158 (4.1)	3853 (100)
58d	How often do you feel alone?	2784 (72.3)	874 (22.7)	194 (5)	3853 (100)

Table 6. Participants responses to UCLA Loneliness Scale: How often do you feel like this NOW?

		N (%)			
		Hardly ever	Some of the time	Often	Total
57a	How often do you feel you lack companionship?	2100 (54.5)	1328 (34.5)	425 (11)	3853 (100)
57b	How often do you feel left out?	2504 (65)	1099 (28.5)	249 (6.5)	3853 (100)
57c	How often do you feel isolated from others?	1720 (44.7)	1533 (39.8)	599 (15.6)	3853 (100)
57d	How often do you feel alone?	2456 (63.8)	1063 (27.6)	331 (8.6)	3853 (100)

Common mental health in TwinsUK during the COVID-19 pandemic

Anxiety and depressive symptoms were measured using the Hospital Anxiety and Depression Scale (HADS)¹⁰, the Patient Health Questionnaire (PHQ-2)¹¹ and the Generalised Anxiety Disorder (GAD-2). [Table 7](#) presents responses to the PHQ-2 and the GAD-2.

Self-reported resilience in TwinsUK during the COVID-19 pandemic

Resilience was measured using the Brief Resilience Scale (BRS-R). [Table 8](#) presents responses to the BRS.

Self-reported general health in TwinsUK during the COVID-19 pandemic

General health was measured through asking twins 'In general would you say your health is': poor (0), fair (1), good (2), very good (3), excellent (4). [Table 9](#) and [Table 10](#) present responses to general health.

Ethical approval and consent

The data which has been generated and provided in the report have been collected via questionnaires that had received ethical approval associated with TwinsUK Biobank (19/NW/0187), Twins UK (EC04/015) or Healthy Ageing Twin

Table 7. Participants responses Patient Health Questionnaire-2 and the Generalized Anxiety Questionnaire-2: Over the last 2 weeks HOW OFTEN have you been bothered by the following problems?

		N (%)				
		Not at all	Several days	More than half the days	Nearly everyday	Total
59a	Little interest or pleasure in doing things	2552 (66.2)	969 (25.1)	223 (5.8)	110 (2.9)	3854 (100)
59b	Feeling down, depressed or hopeless	2598 (67.4)	983 (25.5)	178 (4.6)	94 (2.4)	3854 (100)
59c	Feeling nervous, anxious or on edge	2398 (62.2)	1150 (29.8)	200 (5.2)	106 (2.8)	3854 (100)
59d	Not being able to stop or control worrying	2850 (74)	760 (19.7)	152 (4)		3854 (100)

Table 8. Participants responses to the Brief Resilience Scale: For the next set of statements, please respond to each item by indicating the extent you agree with the statement.

		N (%)					
		Strongly disagree	Disagree	Neutral	Agree	Strongly agree	Total
60a	I tend to bounce back quickly after hard times	43 (1.1)	259 (6.7)	753 (19.6)	2020 (52.5)	773 (19.8)	3848 (100)
60b	I have a hard time making it through stressful events	675 (17.3)	1603 (41.1)	910 (23.3)	584 (14.9)	74 (1.9)	3846 (100)
60c	It does not take me long to recover from a stressful event	91 (2.3)	540 (13.8)	934 (23.9)	1784 (45.7)	497 (12.7)	3846 (100)
60d	It is hard for me to snap back when something bad happens	662 (16.9)	1589 (40.7)	909 (23.3)	622 (15.9)	64 (1.6)	3846 (100)
60e	I usually come through difficult times with little trouble	88 (2.3)	581 (14.9)	1108 (28.4)	1630 (41.8)	440 (11.3)	3846 (100)
60f	I tend to take a long time to get over set-backs in my life	746 (19.1)	1652 (42.3)	908 (23.3)	464 (11.9)	77 (1.9)	3846 (100)

Table 9. Participants responses to: In general, would you say your health was:

		N (%)					
		Poor	Fair	Good	Very good	Excellent	Total
90a	In general, would you say your health <i>was</i>	49 (1.3)	359 (9.4)	1072 (28)	1542 (40.2)	814 (21.2)	3836 (100)

Table 10. Participants responses to: In general, would you say your health is:

		N%					
		Poor	Fair	Good	Very good	Excellent	Total
96	In general, would you say your health <i>is</i>	55 (1.4)	398 (10.4)	1106 (28.9)	1488 (38.8)	787 (20.5)	3834 (100)

Study (H.A.T.S) (07/H0802/84) studies from NHS Research Ethics Committees at the Department of Twin Research and Genetic Epidemiology, King's College London. All members part of the study hold the right to withdraw their consent partially or entirely upon their request. The TwinsUK volunteers all provided us with written/verbal informed consent when they registered and when completing the questionnaires. The TwinsUK volunteer advisory panel reviewed and provided vital input to the questions and design of the study.

Data availability

Underlying data

TwinsUK promotes and encourages data to be shared within the scientific community to help assist and generate further scientific research. Researchers who would like access to the datasets which have been presented in this data note in addition to other TwinsUK data can follow the steps provided below.

1. Please use the [TwinsUK Phenotype spreadsheet](#) containing a list of all TwinsUK phenotypes to search for the specific phenotype required. If requesting data from this study, if phenotypes are not listed in the above spreadsheet, please submit the question numbers in Table 2 and refer to the study as the 'CoPE study'.
2. Please read through the [TwinsUK Data Access Policy document](#) which explains how to access the data and samples in addition to the costs. There are a limited number of grants available to waive any costs to any researcher whose research scope can be considered 'social science'.
3. Please send your [Proposal Form](#) to the TwinsUK Resource Executive Committee (TREC) for it to be considered. You will receive a notification about the conclusion of the review within three weeks of

submitting and then be advised on the next step of the process.

The data and/or samples required including individual variables should be specified on the proposal form with an appropriate reason outlining the aims/hypothesis of the project for which the data is needed. If further information is required, it can be found on the TwinsUK website (www.twinsuk.ac.uk/data-access). If there are any other enquires linked to data access please email Collaborations and Data Access Manager, Victoria Vazquez (victoria.vazquez@kcl.ac.uk).

Extended data

Open Science Framework: The TwinsUK Covid Personal Experience (CoPE) Study. <https://doi.org/10.17605/OSF.IO/3BS4P>⁸

This project contains the following extended data:

- Cope_wave1_06.01.21.html (Summary of survey responses)
- Datanote Table 2_17.12.20.xlsx (supplementary Table 2)

Data are available under the terms of the [Creative Commons Zero "No rights reserved" data waiver](#) (CC0 1.0 Public domain dedication).

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