Information Sheet & Consent Form



INFORMATION SHEET

Study Title: Online Survey on Recovery from COVID-19

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Project Ethics ID: 16159/002

Study Investigators:

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Invitation to Participate

You are being invited to participate in this research study because you previously experienced or you are currently experiencing symptoms consistent with COVID-19 as a result of suspected or confirmed SARS-CoV-2 infection.

1. Why is this study being done?

The aim of this research study is to better describe and understand the patient experience and recovery of those with confirmed or suspected COVID-19, with a specific emphasis on the Long COVID experience. The focus of this study includes participants' backgrounds, testing, symptoms,

and psychological wellbeing. A secondary aim of this study is to publish patient-driven data in order to advocate for the Long COVID population within the medical community. The survey was created by a group of patients with COVID-19 symptoms who are members of the **Body Politic online COVID-19 support group**.

2. How long will you be in the study?

This survey will be live for at least **2** weeks, but no more than **4** weeks. As new information about COVID-19 infections is discovered, the team may decide to continue their investigation with follow-up surveys (up to 4 more surveys). The data that you enter in this survey may be linked to data you enter in future surveys.

3. What are the study procedures?

If you agree to participate after reading this message, you will be taken to the survey which is housed on the Qualtrics platform. You will be asked to answer the questions to the best of your ability. In the mental health section and any question marked as optional, you can choose whether or not you would like to respond. The information that you enter will be collected after each page. You can take breaks and return to finish the survey at any time within one week.

4. What type of questions will be asked?

The survey asks different questions on testing, diagnosis, symptoms, treatments, background information, coping methods, as well as health and mental health.

5. Who can fill the survey? (inclusion/exclusion criteria)

You are being invited to participate in this research study because you <u>have</u>

<u>had a COVID-19</u>, or suspected COVID-19 infection (still suffering or suffered

<u>symptoms</u>) for longer than 1 week, and you are 18 years of age or older.

<u>Even if your COVID-19 test result was negative</u>, or you were not tested at

<u>all, please participate in the survey</u>.

6. How long it will take to fill the survey?

The survey can take between sessions 45-75 minutes to complete. You can take breaks and return to finish the survey at any time within one week.

7. Are there any risks to participating in this study?

There are no known risks associated with this research study. In order to mitigate risks inherent in all online surveys, this survey will be conducted on the Qualtrics platform.

8. What are the benefits for participating in this study?

There are no known direct benefits associated with participating in this research study. Your experiences will help us to better define the recovery from the COVID19 and improve advocacy for Long COVID (long-hauler) population.

9. Can participants choose to leave the study?

Participation in this study is voluntary. You may refuse to participate or at any point during the survey, if you decide to opt out from our study, you can fill this form by providing the anonymous ID we generate for you. Once you submit the survey you will be unable to withdraw your data.

10. How will participants' information be kept confidential?

There will be no information collected that may in any way identify you based upon your responses.

Email addresses will only be used to send you a link to the survey, or to notify you of future surveys. A cryptographic algorithm will be used to generate a hash code from each email address. Hash codes will link survey responses to a unique participant without revealing the participant's email address or identity. Paired email addresses and hash codes will be stored in a GDPR-compliant email database managed by a secure hosting provider. Survey responses will be stored on a separate server in a secure, encrypted format. Email addresses will not be stored with survey responses and will remain

unknown to both the research team and the hosting company. <u>Any data</u> <u>exported will only be used by the above survey investigators, and exported data will be housed solely on secure servers.</u>

Your responses will be housed on a secure server for **10**_**years**, after which they will be destroyed. Anonymized data may be made public or shared with any other researchers.

11. Are participants paid to be in this study?

You will receive no monetary compensation or gifts for participating in this study.

12. Conflict of Interest

The questions in this survey were created by the investigators listed above. All investigators have no conflicts of interests to disclose.

13. Whom do participants contact for questions?

If you have any questions about the study, please contact <u>Athena Akrami</u>. Please note that email is not a secure form of communication. Please contact UCL ethics committee in case of complaint (ethics@ucl.ac.uk, the UCL Data Protection Officer, Alexandra Potts, a.potts@ucl.ac.uk)

14. Local Data Protection Privacy Notice

Notice: The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice: For participants in health and care research studies, click here (https://www.ucl.ac.uk/legal-services/privacy/ucl-general-privacy-notice-participants-and-researchers-health-and-care-research-studies). The information that is required to be provided to

participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data are: 'Public task' for personal data and' Research purposes' for special category data. Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible. If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

If you have any questions or concerns about the study, or about your rights as a research participant or the conduct of this study, you may contact Athena
Akrami. If you feel your concerns have not been handled satisfactorily, you can contact the Chair of the UCL Research Ethics Committee at ethics@ucl.ac.uk. This office oversees the ethical conduct of research studies and is not part of the study team. Everything that you discuss will be kept confidential. Download Here

CONSENT FORM

This study has been approved by the UCL Research Ethics Committee: Project ID number: 16159/002

Thank you for considering taking part in this research.

This survey is voluntary. You may decline to answer any of the questions. By checking the box below you are acknowledging that you are voluntarily participating in this survey, have read and understood the Information Sheet, and consent to the following:

I understand that my participation is voluntary and that I am free to withdraw at

- any time without giving a reason.
- I understand I will need to provide an email address so that I can be sent the
 future surveys to answer. However, this email address will not be passed to any
 third parties and will be removed from my answers before any analysis takes
 place, so the information I provide will be anonymised.
- I understand that due to this anonymisation it will not be possible to withdraw my answers after they have been submitted, but I can withdraw from future surveys at any point.
- I understand that the data gathered in this study will be stored securely and it will not be possible to identify me in any outputs from this research.
- I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.
- I understand the direct/indirect benefits of participating.
- I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.
- I agree that my anonymized research data may be used by others for future research. No one will be able to identify me when this data is shared.
- I understand that the information I have submitted will be published as a report.
- I hereby confirm that I understand the inclusion criteria as detailed in the Information Sheet
- I understand the exclusion criteria as detailed in the Information Sheet
- I do not fall under the exclusion criteria.
- I am aware of who I should contact if I wish to log a complaint.
- I voluntarily agree to take part in this study.
- I would be happy for the data I provide to be securely archived at UCL until project completion
- I understand that other authenticated researchers working on this study at UCL will have access to my anonymized data
- O I consent
- O I do not consent

Please enter your email address. We will generate an anonymous ID and redirect you to the survey. Your responses cannot be linked to your email address. At any point during the survey, if you decide to opt out from our study, you can fill <u>this form</u> and provide the anonymous ID.

Your email address will be saved on a **GDPR-compliant email database** managed by a secure hosting provider.

We may send you occasional emails about this current survey, our research results and future surveys.

O Sure

O No, don't send me emails

[No Consent] Thank you page

You have not provided consent to the terms of this study, therefore you cannot participate in our study.

If you would like to participate, please press the back bottom, read the Information Sheet and click the "I consent" button.

For more information, please visit our Patient-Led Research Group for COVID-19

Powered by Qualtrics

Information needed

You may find it helpful to have the below items ready as you complete the survey. If you do not have these items, please still fill in the information as best you can.

Testing results	Dates, type (PCR, antibody) and result of tests <u>If you do not</u> remember the exact date, the estimated date is enough. <u>If you have had</u> antibody tests, we will ask about the manufacturer, but this information is not required.
Symptom time and severity	Your symptom log You will be asked to pick symptoms you had during the first 4 weeks, and the subsequent months after that, up to month 7.
Other diagnostic tests	Your medical test results You will be asked several questions about medical testing for your COVID-19 physical symptoms (blood tests, MRI/CT scans/X-rays, ultrasounds, ECGs). If you don't have these tests, that is fine.

Take a Break

Please remember that at any point, you may stop and resume this survey at a later time. We recommend taking breaks especially if you are currently experiencing

symptoms in order to limit mental exertion.

To return to the survey:

- Save the link that is in your browser to continue with the survey later.
- Do not complete the survey in private/incognito mode.
- Do not clear your browser cookies.

Your progress will be saved for one week.

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In which country do you currently reside? *
\$
What city do you live in? Please include state if applicable. (i.e. New York, NY) *
What type of area do you live in? *
SuburbanUrbanRural

What age group do you fall into? *
 ○ 18-29 ○ 30-39 ○ 40-49 ○ 50-59 ○ 60-69 ○ 70-79 ○ 80+
What is your gender? *
 Female/Woman Male/Man Non-binary/Genderqueer/Gender non-conforming Prefer not to say Other
Does your gender match your gender assigned at birth? *
○ Yes○ No
If applicable, are you pregnant? *
○ Yes○ No

0	N/A
If a	pplicable, are you 6 months or less postpartum? *
_	Yes No N/A
If a	pplicable, do you have periods/a menstrual cycle? *
000	Yes No, post-menopausal No, other reason N/A
	nich of the following best describes your ancestry? Select all that oly. *
	Asian, South Asian, South East Asian (Chinese, Asian Indian, Vietnamese, Filipino)
	Black (African American, Jamaican, Nigerian, Haitian)
	White (German, Italian, English, Polish, French)
	Hispanic, Latino, or Spanish Origin (Mexican, Mexican American, Puerto Rican, Cuban)
	Indigenous Peoples (Navajo Nation, Blackfeet Tribe, Mayan, Inupiat)
	Pacific Islander (Native Hawaiian, Samoan, Fujian, Chamorro)
	Middle Eastern, North African (Lebanese, Iranian, Egyptian, Moroccan)
	Prefer not to answer

Other
What was your household annual income immediately BEFORE COVID-19 ? *
 \$0 - \$10,000 USD \$10,001 - \$40,000 USD \$40,001 - \$85,000 USD \$85,001 - \$150,000 USD >\$150,000 USD Prefer not to answer
What is your household annual income now, AFTER COVID-19?
 \$0 - \$10,000 USD \$10,001 - \$40,000 USD \$40,001 - \$85,000 USD \$85,001 - \$150,000 USD >\$150,000 USD Prefer not to answer
What was your household annual income immediately BEFORE COVID-19? *
○ \$0 - \$10,000 CAD○ \$10,001 - \$40,000 CAD○ \$40,001 - \$85,000 CAD

\$85,001 - \$150,000 CAD>\$150,000 CADPrefer not to answer
C Freier not to answer
What is your household annual income now, AFTER COVID-19? *
 \$0 - \$10,000 CAD \$10,001 - \$40,000 CAD \$40,001 - \$85,000 CAD \$85,001 - \$150,000 CAD >\$150,000 CAD Prefer not to answer
What is your household annual income, BEFORE COVID-19 ? *
 €0 - £20,000 GBP £20,000 - £40,000 GBP £40,000 - £60,000 GBP £60,000 - £80,000 GBP >£80,000 GBP Prefer not to answer
What is your household annual income, AFTER COVID-19? *
 €0 - £20,000 GBP £20,000 - £40,000 GBP £40,000 - £60,000 GBP £60,000 - £80,000 GBP

○ >£80,000 GBP	
O Prefer not to answer	
What is your household annual income, BEFORE COVID-19 ? *	
O €0 - €20,000 EUR	
O €20,000 - €40,000 EUR	
O €40,000 - €60,000 EUR	
O €60,000 - €80,000 EUR	
O >€80,000 EUR	
O Prefer not to answer	
What is your household annual income, AFTER COVID-19 ? *	
O €0 - €20,000 EUR	
O €40,000 - €60,000 EUR	
O €60,000 - €80,000 EUR	
O >€80,000 EUR	
O Prefer not to answer	
What is your highest educational level achieved? *	
O Some high school or less	
O High school graduate	
O Baccalaureate/undergraduate degree	
O Graduate degree	

Are you a healthcare professional? *				
O Yes O No				
How did you	find this survey? *			
☐ Body Polit	ic Slack Group		Instagram	
Long Haul on Facebo	COVID Fighters Group		Friend/Family s	hared it with me
Long Covi Facebook	d Support Group on		Patient Led Res	search mailing list
Other supp	port group		Media (article, r	newspaper, blog)
Facebook			Other	
		Ш		
☐ Twitter				
Background	Section			
When did you	ur symptoms begin? *			
	Month		Day	Year

Are you still experiencing symptoms? *

Please

Select:

2020 🕏

○ Yes○ No
Recovered - Total Days
How many days total did you experience symptoms? *
Lifestyle & Pre-existing Conditions
Did you have any of these pre-existing conditions/diagnoses or did you experience any of the following pre-COVID?
 ☐ Food Allergies ☐ Environmental Allergies (dust, mold) ☐ Chemical Allergies ☐ Seasonal Allergies ☐ Allergies of unknown origin ☐ Other allergies ☐ Insomnia
 Lucid dreams (dreams where you are aware you are dreaming or have some control over what you dream) Nightmares Vivid dreams Night sweats
☐ Sleep apnea ☐ Acid Reflux Disease ☐ Celiac Disease

17/09/2020, 16:32 **Qualtrics Survey Software** Crohn's Disease Ulcerative Colitis Irritable Bowel Syndrome (IBS) Other GI issues Asthma COPD **Tuberculosis** Eczema Viral skin conditions (cold sores, herpes, warts, molluscum) Dementia Seizures/epilepsy Migraine ALS Parkinson's disease

Multiple Sclerosis Peripheral neuropathy Coronary Heart Disease THeart failure Hypertension (high blood pressure) Hypotension (low blood pressure) History of clotting History of strokes High cholesterol / hyperlipidemia Mitral valve prolapse Anemia Autism Auto-immune/rheumatological conditions Cancer (all types) Chronic kidney disease Diabetes Type 1 Diabetes Type 2

Ehlers-Danlos Syndrome (EDS) Endometriosis Fibromyalgia IgA deficiency Interstitial Cystitis (Bladder Pain Syndrome) Hepatitis (A/B/C) HIV Mast Cell Activation Syndrome (MCAS) Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) Obesity Postural Orthostatic Tachycardia Syndrome (POTS) Recurrent bacterial infections Recurrent viral infections Restless leg syndrome TMJ (temporomandibular joint dysfunction) Vertigo Vision: near-sighted/far-sighted Vitamin D deficiency None of the above Please indicate other pre-existing conditions/diagnoses not listed here. If multiple, please separate them with a comma. Please only list the conditions, no descriptions or explanations.

Qualtrics Survey Software

Did any of your pre-existing conditions change during the course of

your COVID19 symptoms?
Yes, they got worse.
Yes, they got better.
O Some got better, some stayed the same, some got worse (please add an explanation in the text boxes in the following page).
No, they stayed the same.
N/A (I did not have any pre-existing condition)
If any of your pre-existing conditions got worse, please describe here.
(optional)
If any of your pre-existing conditions got better, please describe here. (optional)
What is your blood type? If you don't know, please select 'Don't know'. * Don't know \$

Hospitalization

Hospitalization

Did you consult with a physician(s) for your COVID symptoms? Select all that apply. This can include both in-person appointments and telemedicine, like phone calls. *
☐ Alternative Medicine doctor
☐ Cardiologist
☐ Dermatologist
Gastroenterologist
☐ Hematologist
☐ Hospitalist
☐ Immunologist/Allergist
☐ Infectious disease specialist
□ Neurologist/Neuroimmunologist
☐ Obstetrician-Gynecologist (OB-GYN)
☐ Psychiatrist
☐ Pulmonologist
Rheumatologist
Other
☐ I have not seen any physician

Were you hospitalized? *

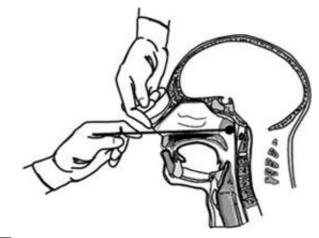
 Yes No I visited ER/Urgent care but was not admitted/did not stay overnight at a hospital
If yes: how long were you hospitalized for? [Number of days] *
Did you receive oxygen support in the hospital? *
 Yes, nasal cannula Yes, I was intubated No I was not hospitalized Other
(Optional) If you'd like, please describe your experience with medical care.

COVID-19 Testing

Were you tested for COVID-19 using a Swab test? (This is not asking about antibody tests, which are covered in a separate section of the survey.) *				
Yes, I was tested at least once.No, I tried to get tested but was unable.No, I did not try to get tested.				
How many times wer	re you tested (Swab test	:) *		
○ 1○ 2○ 3○ Other				
On what date did you first get tested? (if you don't remember the exact date, enter an estimate) *				
	Month	Day	Year	
Please Select:	\$	(2020 🕏	
Was this an estimated date?				
☐ This was an estimate				

What was the type of your first COVID-19 test?

Nasal (nasal secretions from nostrils, without moving forward into the back of the nose and throat)
Nasopharyngeal (nasal secretions from end of the nostrils, by moving to the cavity in back of the nose and throat)



☐ Throat

Other

What was the status of your test? *

Positive

O Negative

O Inconclusive/Awaiting results

On what date were your tested the second time? (if you don't remember the exact date, enter an estimate) *

	Month	Day	Year
Please Select:	*	÷	2020 💠

Was this an estimated date?
☐ This was an estimate
What was the type of your second COVID-19 test?
□ Nasal (nasal secretions from nostrils, without moving forward into the back of the nose and throat)
Nasopharyngeal (nasal secretions from end of the nostrils, by moving to the cavity in back of the nose and throat)
Throat Other
What was the status of your test? *
PositiveNegativeInconclusive/Awaiting results

On what date were you tested the third time? (if you don't remember the exact date, enter an estimate) *

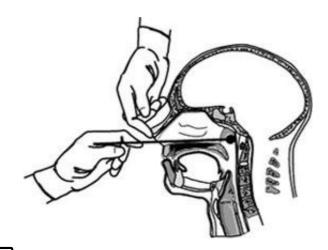
	Month	Day	Year
Please Select:	\$	+	2020 💠

Was this an estimated date?

This was an estimate

What was the type of your third COVID19 test?

- Nasal (nasal secretions from nostrils, without moving forward into the back of the nose and throat)
- Nasopharyngeal (nasal secretions from end of the nostrils, by moving to the cavity in back of the nose and throat)



Throat

Other

What was the status of your test? *

O Positive
O Negative
O Inconclusive/Awaiting results
If you had any other tests, please list them here. Please put each test on a new line with the type, date, and status separated by a comma. For example: Nasopharyngeal, 4-1-20, Positive. If you do not
remember the exact date, please enter the closest date possible
Antibody Testing
Did you receive an antibody test? *
Yes, I was tested at least once for antibodies
O No, I was NOT tested at all for antibodies
How many times were you tested for antibodies? *

What was your antibody test result? *
 I tested positive for both (IgG and IgM) antibodies I only tested positive for IgM antibodies I only tested positive for IgG antibodies I don't know the antibodies type but I tested positive. I tested negative for antibodies
If you tested positive and your test included a titer value, what was the value for IgM?
If you tested positive and your test included a titer value, what was the value for IgG?
What type of test was it? *
O Blood Draw O Blood Finger Prick
Enter the date of the antibody test (if you don't remember the exact date, enter an estimate). *
1

	Month	Day	Year
Please Select:	, A	+	2020 💠

Was this an estimated date?	
☐ This was an estimated date	
	the test? (Please only select the specific . Otherwise select "I don't know.") *
AbbottRocheMt. SinaiEurolmmun	Ortho-Clinical Diagnostics VitrosDiaSorinI don't know
Do you have another antibody O Yes O No	test to report? *
What was your antibody test re	esult? *
 I tested positive for both (IgG at Only tested positive for IgM at Only tested positive for IgG at Only tested positive for IgG at Only tested positive for IgG at Only tested positive for antibodies I tested negative for antibodies 	ntibodies ntibodies be but I tested positive.

If you tested positive and your test included a titer value, what was the value (in $_{\mbox{\scriptsize mg/dL})}$ for IgM? *				
If you tested positive value (in mg/dL) for IgO	and your test included a	a titer value	, what was the	
What type of test wa	s it? *			
O Blood Draw O Blood Finger Prick				
Enter the date of the antibody test (if you don't remember the exact date, enter an estimate). *				
	Month	Day	Year	
Please Select:			2020 💠	
Was this an estimated date?				
☐ This was an estimated date				

	o was the manufacturer of the to nufacturer if you are certain. Oth		` .
000	Abbott Roche Mt. Sinai Eurolmmun	000	Ortho-Clinical Diagnostics Vitros DiaSorin I don't know
Doy	you have another antibody test	to re	eport? *
_	Yes No		
Wha	at was your antibody test result	? *	
 I tested positive for both (IgG and IgM) antibodies I only tested positive for IgM antibodies I only tested positive for IgG antibodies I don't know the antibodies type but I tested positive. I tested negative for antibodies 			
•	ou tested positive and your test ue for IgM? *	inclı	uded a titer value, what was the

If you tested positive and your test included a titer value, what was the value for IgG? *						
What type of test wa	s it? *					
O Blood Draw O Blood Finger Prick						
Enter the date of the date, enter an estima	antibody test (if you dorate). *	n't remembe	er the exact			
	Month	Day	Year			
Please Select:	+	+	2020 🕏			
Was this an estimate	ed date?					
☐ This was an estima	ted date					
Who was the manufacturer of the test? (Please only select specific manufacturer if you are certain. Otherwise select "I don't know.") *						
O Abbott	Ortho	o-Clinical Dia	gnostics Vitros			
Roche	O DiaSo	O DiaSorin				

0	Mt. Sinai Eurolmmun	O I don't know
Sy	mptoms	
Me	emory Symptoms	
	ve you experienced any MEMO le start of your COVID-19 illness?	RY RELATED SYMPTOMS since
_	Yes No	
	nich of the following memory synestart of your COVID-19 illness?	nptoms have you experienced since
	Short-term memory loss (memory tremembering a phone number before you're in the middle of a task)	•
	Long-term memory loss (long-term remembering yesterday, forgetting recently learned information, or forgetting terms).	, ,
	Not being able to make new memo	ries
	Forgetting how to do routine tasks your hands)	(tying your shoe laces, washing
	None of the above	
	Other	

When did you experience these symptoms? *

Please mark symptoms for the first 4 weeks, then months (if applicable). Even if you have only experienced these symptoms for part of a week or month, please select it.

	Week 1		Month 2		Month 6
Memory symptoms					

Cognitive Function/Brain Fog Symptoms

Have you experienced issues with **BRAIN FOG** (inability to focus, think clearly, plan, process, understand, and maintain a coherent stream of thought; abnormally slow or fast thoughts) since the start of your COVID-19 illness? *

\bigcirc	Yes
\bigcap	No

Which of the following brain fog/cognitive functioning symptoms have you experienced since the start of your COVID-19 illness? *

Ш	the sequence of actions, abstracting)
	Agnosia (failure to recognize or identify objects despite intact sensory functioning)
	Difficulty problem-solving or decision-making

Qualtrics	Survey Softv	vare									17/09/2020,
	Diffi	culty t	hinking								
	_ Tho	ughts	moving	too qu	ickly						
	Slov	ved th	oughts								
] Poo	r atter	ntion or	concer	ntration						
	l did	NOT	have a	ny Brai	n Fog s	sympto	ms				
					Other						
١	When o	did vo	ou expe	erience	these	e svmp	toms? *				
•		ara y c				, c)p					
F	Please	mark	c symnt	oms fo	or the	first 4 v	weeks, t	hen m	onths (if vou	
							ease lea		· ·		VOLL
									•		-
		•	•	cea in	ese sy	mptor	ns for pa	ait Oi a	WEEK	OI IIIOII	uı,
1	olease	Selec	Ji II.								
			Week	Week	\\\a_a\r	Wools	Month	Month	Month	Month	Month
			1	vveek 2	Week 3	Week 4	2	Month 3	Month 4	Month 5	6
	Brain										
	fog/cogn functioni										
	sympton	•									
(Chang	es to	Daily/	Funct	ional	Abiliti	es due	to mer	nory lo	oss or	brain
						fog					
ŀ	Have y	ou fe	It signif	cantly	/ limite	d or u	nable to	do any	of the	follow	ing
C	due to	MEM	ORY L	oss (OR BF	RAIN F	OG (inc	luding	issues	with	
á	attentic	n, co	gnitive	functi	oning,	and a	warenes	ss) spe	cifically	/? *	
		•	•		σ,			, ,	•		
							Severely	Modera	tely Mi	ldly	
							unable	unabl	-	able Ab	ole apı

16:32

Drive	0	0	0	0	
Watch children	0	0	0	0	
Cook or use hot items	0	0	0	0	
Feed yourself	0	0	0	0	
Shower or bathe regularly	0	0	0	0	
	Severely unable	Moderately unable	Mildly unable	Able	apı
Make serious decisions	0	0	0	0	
Leave the house and return without getting lost	0	0	0	0	
Remember the correct month or year	0	0	0	0	
Have conversations with others	0	\circ	0	0	
Maintain your medication schedule (forgetting to take medication or forgetting you've taken medication)	0	0	0	0	
	Severely unable	Moderately unable	Mildly unable	Able	apı
Work	0	0	0	0	
Follow simple instructions	0	0	0	0	
Communicate your thoughts and needs	0	0	0	0	
Other					
	0	0	0	0	
	Severely	Moderately	Mildly	Ahle	anı

Optional: If you have other areas of your life that were affected by

memory loss or brain fog, please include them here. Please note whether they were mildly, moderately, or severely limiting.

Optional: Please use this space to describe examples of your brain fog, memory loss, and attention span.

Please do not include any identifying information (such as name or location).

Emotional/Behavioral Changes

Emotional and Behavioral Changes

Compared to how you felt before COVID, have you experienced an increase in any of the following? *

		Difficulty	controlling y	our emotions
ı	_			O 0 O O

Lack of inhibition (difficulty controlling your behavior)

Irritability Anger Impulsivity (acting on a whim without self-control) Aggression Euphoria (a feeling or state of intense excitement and happiness) Delusions Depression Apathy (lack of feeling, emotion, interest, or concern) Suicidality Mood swings Anxiety Mania (abnormally elevated/excited mood, decreased need for sleep, occasionally with delusions) Hypomania (a milder form of mania) Tearfulness Sense of doom None of the above Other Optional: Please use this space to describe examples of your emotional changes during your illness. Please do not include any identifying information (name, location, etc.).

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Optional: If you had any of these emotional experiences **pre**-COVID,

please describe how they differed post -COVID.
Please do not include any identifying information (name, location, etc.).
Speech and Other Language Issues
Speech and Language Issues
Have you experienced any issues with SPEECH AND LANGUAGE since the start of your COVID-19 illness? *
○ Yes○ No
Which of the following speech and language symptoms have you experienced since the start of your COVID-19 illness? *
 Difficulty finding the right words while speaking/writing Difficulty communicating verbally Difficulting speaking in complete sentences Speaking unrecognizable words Difficulty communicating in writing
☐ Difficulty processing/understanding what others say

Qualtrics Su	urvey Software								17/09	/2020,		
	Difficulty read	ling/prod	cessing	writter	n text							
	(If applicable) changes to your non-primary (second/third) language skills											
	■ None of the above											
) [Oth	ner								
W	'hen did you e	xperier	nce the	ese sy	mptom	ıs? *						
PI	ease mark sy	mptom	s for th	ne first	4 wee	ks, ther	n montl	ns (if				
ap	oplicable). Eve	en if you	u have	only e	experie	enced th	iese sy	mptom	s for			
pa	art of a week o	or mont	h, plea	ase se	lect it.							
		Week 1	Week 2	Week 3	Week 4	Month 2	Month 3	Month 4	Month 5	M		
S	Speech/language											
	ssues											
D	o you speak n	nultiple	langu	ages?	*							
) Yes											
) No											
	,											
0	ntional· Pleas	ا مورر م	hie en:	ace to	dascri	he evan	nnlae n	f vour				

Optional: Please use this space to describe examples of your language issues, including speech, writing, reading, and listening to words. Please include any changes to your speech/language that are not mentioned above. For instance, if you speak multiple languages and have noticed different problems with your primary and non-primary

16:32

language.
Headaches
Headaches
Have you experienced any new HEADACHES OR RELATED ISSUES since the start of your COVID-19 illness? *
O Yes
○ No
Which of the following symptoms have you experienced since the start of your COVID-19 illness? *
Headaches, at the base of the skull
Headaches, in the temples
Headaches, behind the eyes
Headaches, diffuse (entire brain)
Headaches/pain after mental exertion
Headaches, other
Sensation of brain warmth/"on fire"

 □ Sensation of brain pressure □ Migraines □ Stiff neck □ None of the above 									
When did y	When did you experience these symptoms? *								
Please mark symptoms for the first 4 weeks, then months (if applicable). Even if you have only experienced these symptoms for part of a week or month, please select it.									
	Week 1	Week 2	Week 3	Week 4	Month 2	Month 3	Month 4	Month 5	Month 6
Headaches and related symptoms									
Sense of S	mell a	nd Tas	ste						
Sense of S	Smell a	nd Tas	ste						
Have you experienced any changes to your SENSE OF SMELL OR TASTE since the start of your COVID-19 illness? *									
O Yes O No									

Which of the following symptoms have you experienced since the start									
of your COVID-19 illness? *									
Loss of smell Phantom smells (imagining/hallucinating smells - smelling things that aren't there) Heightened sense of smell Altered sense of smell Loss of taste Phantom taste (imagining/hallucinating tastes - tasting things when there's nothing in your mouth) Heightened sense of taste Altered sense of taste None of the above									
When did you experience these symptoms? * Please mark symptoms for the first 4 weeks, then months (if applicable). Even if you have only experienced these symptoms for part of a week or month, please select it.									
Week Week Week Month Mon									
Changes to sense of smell and taste									
If you had phantom tastes, please describe them:									

If you had phantom smells, please describe them:
Tremors and Vibrating Sensations
Tremors and Vibrating Sensations
Have you experienced any TREMOR OR VIBRATION SENTATIONS since the start of your COVID-19 illness? *
Tremor: Involuntary, rhythmic muscle contraction leading to shaking movements in one or more parts of the body Vibration sensation: A buzzing feeling, when you feel like your muscles, fingers, or legs are vibrating or shaking inside, but you don't see the movement
○ Yes○ No

Which of the following symptoms have you experienced since the start of your COVID-19 illness? *

Please specify the location on your body in the text box. If multiple locations, please separate them with a comma (i.e. leg, torso, hand).

	Tremors
	Vibrating sensations

When did you experience these symptoms? *

Please mark symptoms for the first 4 weeks, then months (if applicable). Even if you have only experienced these symptoms for part of a week or month, please select it.

	N/A	Week 1	Week 2	Week 3	Week 4	Month 2	Month 3	Month 4	Month 5	٨
Tremors										
Vibrating Sensations										

Please use this space to describe examples of your tremors or body vibration/shaking during your illness.

Please do not include any identifying information (such as name or location).

Sleeping issues Sleeping issues
Have you experienced any SLEEPING ISSUES since the start of your COVID-19 illness? * O Yes O No
Which of the following sleeping issues have you experienced since the start of your COVID-19 illness? *
Lucid dreams (dreams where you are aware you are dreaming or have some control over what you dream about) Vivid dreams Nightmares Insomnia Night sweats Restless leg syndrome Awakened by feeling like you couldn't breathe Sleep apnea

Other											
When did you experience these symptoms? *											
Please mark symptoms for the first 4 weeks, then months (if applicable). Even if you have only experienced these symptoms for part of a week or month, please select it.											
	N/A	Week 1	Week 2	Week 3	Week 4	Month 2	Month 3	Month 4	Month 5	М	
Insomnia										1	
Sleep apnea										[
All the other sleeping symptoms										[
If you have/had insomnia, which best describes the type of insomnia? * Difficulty falling asleep Waking up early in the morning Waking up several times during the night None of the above											
What is ca	ausing	g/cause	ed you	r inson	nnia? *						

 ☐ Sensitivity to outside light/noise ☐ Other physical discomfort ☐ Anxiety/depression/racing thoughts ☐ Difficulty breathing ☐ A sensation of adrenaline/energy ☐ A sensation like the virus was keeping me awake ☐ Other
Hallucinations
Hallucinations
Have you experienced any HALLUCINATIONS (visual, hearing, or touch) since the start of your COVID-19 illness? *
○ Yes
O No
Which of the following hallucinations have you experienced since the start of your COVID-19 illness? *
Visual (seeing) Hallucinations
Auditory (hearing) Hallucinations
Tactile (touch) Hallucinations
Hallucinations, other

When did you experience these symptoms? *

Please mark symptoms for the first 4 weeks, then months (if you haven't yet reached a week/month, please leave it blank). Even if you have only experienced these symptoms for part of a week or month, please select it.

			Month 2		
Hallucinations					

Weakness, numbness, tingling, coldness, and other sensations

Weakness, numbness, tingling, coldness, and other sensations

Which of the following **NEUROLOGICAL SENSATION SYMPTOMS** have you experienced since the start of your COVID-19 illness, if any? *

Please specify the location on your body in the text box. If multiple locations, please separate them with a comma (i.e. hand, leg, foot).

Skin sensations: burning, tingling, or itchiness without rash
Numbness/loss of sensation
Numbness/weakness on one side of the body only

Qualtrics Survey Software 17/09/2020, 16:32 Coldness Tingling/prickling/pins and needles sensation Electrical zaps/electrical shock sensation Facial paralysis (please indicate where on face was paralyzed) Sensation of facial pressure/numbness, left side Sensation of facial pressure/numbness, right side Sensation of facial pressure/numbness, other: Weakness None of the above When did you experience these symptoms? * Please mark symptoms for the first 4 weeks, then months (if applicable). Even if you have only experienced these symptoms for part of a week or month, please select it. Week Month Week Month Week Week Month Month N/A ΑII

Temperature Issues

neurological sensations

Temperature Issues

If you experienced any of the following temperature issues, when did you experience the following symptoms? *

Please mark symptoms for the first 4 weeks, then months (if you haven't yet reached a week/month, please leave it blank). Even if you have only experienced these symptoms for part of a week or month, please select it.

	N/A	Week 1	Week 2	Week 3	Week 4	Month 2	Month 3	Month 4
Elevated temperature (98.8- 100.4 degrees Fahrenheit, 37.1- 37.9 Celsius)								
Fever (100.4 degrees Fahrenheit / 38 degrees Celsius or above)								
Low temperature								
Chills/flushing/sweats								
All other temperature issues								
If you had a low to Please input numl	-		what v	vas yo	ur lowe	est temp	oeratur	e?
If you had a high t Please input numl	•	· ·	, what	was yo	our hig	hest ter	nperatı	ure?

Cardiovascular Symptoms

Cardiovascular Symptoms

When did you experience these symptoms? *

Please mark symptoms for the first 4 weeks, then months (if applicable), even if you have only experienced these symptoms for part of a week or month.

	N/A	Week 1	Week 2	Week 3	Week 4	Month 2	Month 3	Month 4	Mont 5
Tachycardia (high heart rate, >90 beats per minute)									
Bradycardia (low heart rate, <60 beats per minute)									
Heart palpitations (sensation or awareness of your heart beating. Feeling like your heart is racing, thumping or skipping beats)									
Abnormally high blood pressure									
Abnormally low blood pressure									
Visibly inflamed/bulging veins									
Fainting									
Blood clots (Thrombosis)									

If you had tachycardia and were able to measure it, what was the maximum heart rate (in bpm) that you measured, at rest?
If you had tachycardia and were able to measure it, what was the maximum heart rate (in bpm) that you measured, at exertion (during physical activity)?
If you had tachycardia and were able to measure it, was your heart rate higher when standing compared to sitting?
Yes, it was higher when I was standingNo, it was higher when I was sitting
O It was about the same while standing or sitting
If you had tachycardia and were able to measure it, how much did your heart rate generally change from lying position to standing, last time you measured? (In BPM, beats per minute)

All Other Symptoms - Timecourse

This section has multiple groups of questions about multiple symptoms/issues organized by body area (Generic Issues, Gastrointestinal issues, Respiratory and sinus symptoms, ear/hearing symptoms, eye symptoms, Reproductive and urinary symptoms, skin and allergy symptoms, and muscle and joint issues)

Did you experience these symptoms, and when did you experience them? *

Please mark symptoms for the first 4 weeks, then months (if applicable). Even if you have only experienced these symptoms for part of a week or month, please select it. If you experienced none of the symptoms in a set, select the checkbox (None of the below issues apply to me) above the grouped set.

Generic Issues

None of the below generic symptoms apply to me

When did you experience these symptoms? *

Please mark symptoms for the first 4 weeks, then months (if applicable). Even if you have only experienced these symptoms for part of a week or month, please select it.

	N/A	Week 1	Week 2	Week 3	Week 4	Month 2	Month 3	Month 4
Dizziness / vertigo / unsteadiness or balance issues								
Neuralgia (nerve pain)								
Seizures (confirmed)								
Seizures (suspected)								
Episodes of breathing difficulty/gasping for air when your oxygen saturation is normal								
Low oxygen levels (<94%)								
New/unexpected anaphylaxis reaction								
Acute (sudden) confusion/disorientation								
Slurring words/speech								
High blood sugar (if measured)								
Low blood sugar (if measured)								

Gastrointestinal Issues

Gastrointestinal Issues

	Week	Week	Week	Week	Month	Month	Month	Mor
N/A	1	2	3	4	2	3	4	5

Constipation Diarrhea Vomiting Nausea Loss of Appetite Abdominal pain Lower Esophagus Burning / gastroesophageal									
Respiratory ar		_	-		svmpto	ms apr	olv to m	e	
None of the b					<i>5</i> ,	то арр	,, .c		
					Week 2	Week 3	Week 4	Month 2	Mont 3
			ptoms	Week	Week	Week	Week	Month	
Respiratory and	d Sinu	s Sym	ptoms	Week	Week	Week	Week	Month	
Respiratory and	d Sinu	s Sym	ptoms	Week	Week	Week	Week	Month	
Respiratory and Dry cough Cough with mucus p	d Sinu	s Sym	ptoms	Week	Week	Week	Week	Month	
Dry cough Cough with mucus p	d Sinu	s Sym	ptoms	Week	Week	Week	Week	Month	
Dry cough Cough with mucus p Coughing up Blood Shortness of Breath	d Sinu	s Sym	ptoms	Week	Week	Week	Week	Month	
Dry cough Cough with mucus p Coughing up Blood Shortness of Breath Tightness of Chest	d Sinu	s Sym	ptoms	Week	Week	Week	Week	Month	

Rattling of bre	ath									
Sore Throat										
Other										
Ear and H	earin	ıg Sym	ptoms	8						
■ None of	the b	elow ea	r and h	earina	sympto	oms apr	olv to m	ıe		
		0.011 00.			сур. .		, to			
Ear and He	earin	g Symp	toms							
		Week	M / I	NA /1	M/s sl	Month		la N. A. a. a. a. l. L.		
	N/A	1	Week 2	Week 3	Week 4	2	Mont 3	h Month 4	n Month 5	ľ
Hearing loss										
Tinnitus										
Other ear/hearing issues										
iocuco										
Eye and V	ision	Symp	toms							
■ None of	the b	elow ey	e and v	ision s	symptor	ns apply	y to me	ļ		
		•								
Eye and Vi	sion	Sympto	oms							
	N/A	Week 1	Week	Week 3	Week 4	Month 2	Month 3	Month	Month 5	М

Vision symptoms										[
Other eye symptoms										1
Reproduc	ctive	and	Urinar	y Sym	ptoms	;				
☐ None o	f the b	elow	reprodu	uctive a	ınd urin	ary syn	nptoms	apply to	me	
Reproduc	tive a	nd U	rinary (Sympto	oms					
		N/A	Week 1	Week 2	Week 3	Week 4	Month 2	Month 3	Month 4	Mont 5
All menstrual/pe issues	eriod									
Bladder cont issues	trol									
Skin and	Aller	gy S	ympto	ms						
☐ None o	f the b	elow	skin an	d allerg	gy symp	otoms a	ipply to i	me		
Skin and A	Allerg	y Syı	mptom	S						
				N/A	Week 1	Week 2	Week 3	Week 4	Month 2	Mont 3
Peeling skin										

Survey Softwa	re								1.	7/09/2020,
brown spo arms, legs	ots on th s, stoma	urple, red, one skin, usualch, buttoche mouth of	ually on ks, and							
COVID too		oloration, or blisterin	g toes)							
	es red li	writing on nes where								
New allerç environme		od, chemic c)	al,							
Skin rashe	es									
Other										
Muscle None	of the	e below I	muscle	and jo	int sym	nptoms a	pply to	me		
	N/A	Week 1	Week 2	Week 3	Week 4	Month 2	Month 3	Month 4	Month 5	Mon 6
Muscle spasms										
Muscle aches										
Joint pain										
Bone ache or burning										

All Other Symptoms - Checkbox

All Other Symptoms

Hav	ve you experienced any of these symptoms since the start of your
CO	VID-19 illness? *
(Pl€	ease choose all options that apply)
	Inability to cry
	Inability to yawn
	Lump in throat/difficulty swallowing
	Changes in the voice
	Coughing up Blood
	Feeling like you aren't real/like you're observing yourself from outside your body (depersonalization)
	Feeling like the world isn't real (derealization)
	Extreme thirst
	None of the above
Ear	and Hearing
	Ear pain
	Changes to the ear canal (such as pressure, blockage, burning, swelling)
	Numbness/loss of sensation
	Sensitivity to noise
	Other ear/hearing symptoms
	None of the above

Eye and Vision

	Vision symptoms - Blurred vision
	Vision symptoms - Double vision
	Vision symptoms - Sensitivity to light
	Vision symptoms - Tunnel vision
$\overline{\Box}$	Vision symptoms - Total loss of vision
$\overline{\Box}$	Eye pressure or pain
$\overline{\Box}$	Pink eye (conjunctivitis)
$\overline{\Box}$	Bloodshot eyes
$\overline{\Box}$	Dry eyes
\Box	Redness on the outside of eyes
\Box	Floaters
\Box	Seeing things in your peripheral vision
$\overline{\Box}$	Other eye issues:
	None of the above
_	
Da	nuodustivo and Urinami
ne	productive and Urinary
	Early Menopause
$\overline{\Box}$	Post-Menopausal bleeding/spotting
$\overline{\Box}$	Abnormally heavy periods/clotting
\Box	Abnormally irregular periods
\Box	Other menstrual issues
_	
	Decrease in size of testicles/penis
	Pain in testicles

Other semen/penis/testicles issues Sexual dysfunction (difficulty maintaining erection, vaginal dryness, difficulty orgasming) Urinary issues, other None of the above Gastrointestinal $oldsymbol{\square}$ Feeling full quickly when eating Abdominal pain Hyperactive bowel sensations None of the above Skin and Allergy New allergies (food, chemical, environmental, etc) Heightened reaction to old allergies Itchy skin Itchy eyes Itchy, other Brittle/discolored nail **Shingles** None of the above

Symptom Course

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How severe were/are your symptoms over the course of the weeks/months? *

If you experienced multiple severities for symptoms within the time period, select the most severe within that time period.

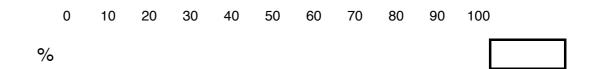
	No symptom	Very Mild	Mild	Moderate	Severe	Very Severe
Week 1	0	0	0	0	0	0
Week 2	\circ	0	0	0	0	0
Week 3	\circ	0	0	0	0	0
Week 4	\circ	0	0	0	0	0
Month 2	\circ	0	0	0	0	0
	No symptom	Very Mild	Mild	Moderate	Severe	Very Severe
Month 3	0	0	0	0	0	0
Month 4	\circ	0	0	0	0	0
Month 5	\circ	0	0	0	0	0
Month 6	\circ	0	0	0	0	0
Month 7+	\circ	0	0	0	0	0
	No symptom	Very Mild	Mild	Moderate	Severe	Very Severe

Which of these descriptions appropriately describes your experience with relapses, and your symptom course overall? Please select all that apply: *

My relapses happen in a regular pattern (monthly, daily, or weekly). My relapses happen in an irregular pattern (randomly). My relapses happen in response to a trigger (stress, alcohol, exercise/exertion, etc). My relapses are getting shorter/easier over time. My relapses are getting longer/harder over time. My relapse severity has stayed about the same over time. Overall, my symptoms have slowly gotten better over time. Overall, my symptoms have stayed about the same over time. Overall, my symptoms have slowly worsened over time. I got worse rapidly. I got better rapidly. Other Which of these trigger a relapse or worsening of symptoms? Please select all that apply: * Stress Alcohol Caffeine Heat Period/menstruation Week before period/menstruation Exercise Physical activity Mental activity Other

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How would you rate how you feel today, on a scale of 0-100% (with 100% being your pre-COVID baseline)?



Symptom Severity

List at least **three symptoms** that have been the most debilitating during recovery.

On a scale of 0-10, how severe have they been? (0 is completely fine, 10 is completely debilitating).

	0	1	2	3	4	5	6	7	8	9	10
Symptom 1 *											
Symptom 2 *											
Symptom 3 *											
Symptom 4											
Symptom 5											

Post-Exertional	Malaise	•	s of physi nptoms)	cal and	mental a	ctivity on
Post-Exertional Worsening or rela			ns after ph	ysical ar	nd/or ment	tal activity
During your COV or relapse of your			•	•	_	•
Yes No No						
How strongly have symptoms, on avergence this.	•	•		•	•	
	No post exertion malaise	nal	Some pos exertiona malaise	al	strong post- exersional malaise	
Physical	0 1	2 3	4 5	6 7	8 9	10
Cognitive						

If you have experienced worsening or a relapse after Physical Activity, when does the worsening/relapse of symptoms happen? *
 ☐ Immediately ☐ The same day, after a few hours ☐ The following day ☐ A couple of days later ☐ It varies ☐ I do not experience worsening/relapse of symptoms after Physical Activity
If you have experienced worsening or a relapse after Mental Activity, when does the worsening/relapse of symptoms happen? *
 ☐ Immediately ☐ The same day, after a few hours ☐ The following day ☐ A couple of days later ☐ ☐ It varies ☐ I do not experience worsening/relapse of symptoms after Mental Activity
How long does the worsening/relapse of symptoms usually last following Physical or Mental Activity? *
☐ Few hours ☐ Few days

Qualtrics Survey Software 17/09/2020, 16:32 Few weeks Other (Optional) Please explain anything else you'd like to share about your experience with Post-Exertional Malaise. For instance, you can list the type of activities that worsens your symptoms strongest (walking, strenuous exercise, reading, watching movies, etc). When did you experience these symptoms? * Please mark symptoms for the first 4 weeks, then months (if applicable). Even if you have only experienced these symptoms for part of a week or month, please select it. Week Month Week Month Week Week Month Month Worsening/relapses of symptoms from physical and mental exertion **Fatigue Assessment Scale Fatigue**

The following ten statements refer to how you feel at the **current** stage of your COVID-19 recovery (over the past week). **Please give an answer to each question, even if you do not have any complaints at the moment.** *

	Never	Sometimes	Regularly	Often	Always
I am bothered by fatigue	0	0	0	0	0
I get tired very quickly	0	0	0	0	0
I don't do much during the day	0	0	0	0	0
I have enough energy for everyday life	0	0	0	0	0
Physically, I feel exhausted	0	0	0	0	0
	Never	Sometimes	Regularly	Often	Always
I have problems starting things	0	0	0	0	0
I have problems thinking clearly	0	0	0	0	0
I feel no desire to do anything	0	0	0	0	0
Mentally, I feel exhausted	0	0	0	0	0
When I am doing something, I can concentrate quite well	0	0	0	0	0

Compared to how you felt before contracting COVID-19, how would you describe your level of fatigue during COVID recovery? *								
 Significantly more than pre-COVID Moderately more than pre-COVID Slightly more than pre-COVID Same as pre-COVID Less than pre-COVID 								
How much DAILY rest are/were you able to get on average, DURING your COVID-19 recovery? (Rest means time recovering/relaxing without work, childcare, or other obligations). Please do not include your daily sleep, or naps. *								
 less than 2hrs per day 2-4hrs 4-6hrs 6-8hrs more than 8 hours per day 								
If you experienced fatigue, when did you feel fatigue? *								
Please mark symptoms for the first 4 weeks, then months (if applicable). Even if you have only experienced these symptoms for part of a week or month, please select it.								
Week N/A 1	Week Week 2 3	Week 4	Month 2	Month 3	Month 4	Month 5	Moni 6	
Fatigue								

Changes in Sensitivity to Medication or Other Substances

Changes in Sensitivity to Medication or Other Substances

Did you experience issues with changes in sensitivity to medication or other substances? *
○ Yes○ No
What medication(s) or substance(s)? If multiple, please separate with a comma.
If medication, what do you take this for?

Please describe the changes you noticed:

General Functioning
In general, would you say your health BEFORE the onset of COVID was: *
ExcellentVery goodGoodFairPoor
In general, would you say your health CURRENTLY is: *
ExcellentVery goodGoodFairPoor
Does your health currently limit your ability to climb several flights of stairs? *
Yes, limited a lotYes, limited a little

O No, not limited at all
Does your health currently limit your ability to walk one block? *
Yes, limited a lotYes, limited a littleNo, not limited at all
Does your health currently limit your ability to bathe or dress yourself? *
Yes, limited a lotYes, limited a littleNo, not limited at all
During the last 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? (check all that apply) *
 ☐ Accomplished less than you would like ☐ Were limited in the kind of work or other activities ☐ Not limited
During the last 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your

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emotional health? (check all that apply) *

Accomplished less than you would like Were limited in the kind of work or other activities Not limited	
Not limited	
ental Health	
ental Health Symptoms	
nu may choose not to answer any of questions.	
you are having suicidal thoughts, these free helplines are available 24/7 to offer support:	
S: 1-800-273-8255 (Crisis Text Line: text TALK to 741741)	
K : 116 123	
etherlands: 0800 0113	
anada: 833-456-4566	
nd <u>additional crisis lines</u> for your country	

○ Yes○ No						
If you answered yes to eit have you experienced? (c	•		ŕ	hich of the	e following)
Depression Bipolar Disorder Anxiety Disorder Substance Use Disorder Eating Disorder Personality Disorder Psychotic Disorder Delirium Post-traumatic stress dis	Other	·	ise sne	rifv.		
	N/A	No change during COVID- 19	Onset during COVID- 19	Significant worsening during COVID-19	Moderate worsening during COVID- 19	N imr C
Depression	0	0	0	0	0	
Bipolar Disorder	0	0	0	0	0	
Anxiety Disorder	0	0	0	0	0	
Substance Use Disorder	\circ	0	\circ	0	\circ	

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Eating Disorder

Personality Disorder	(C	0	0	0	0	
Psychotic Disorder	(C	0	0	0	0	
Delirium	(\supset	0	0	0	0	
Post-traumatic stress disorde (PTSD)	er (C	0	0	0	0	
Other		O	0	0	0	0	
Optionally describe how the conditions felt or affected you during COVID-19.							
Depressive Symptoms							
Over the last 2 weeks, how often have you been bothered by any of the following problems?							
	Not at all	S	everal Days		e Than N ne Days	learly Every day	
Little interest or pleasure in doing things	0		0	(C	0	
Feeling down, depressed, or hopeless	0		0	(O	0	

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Trouble falling/staying asleep, sleeping too much	0	0	0 0	
Feeling tired or having little energy	0	0	0	0
	Not at all	Several Days	More Than Half the Days	Nearly Every day
Feeling bad about yourself or that you are a failure or have let yourself or your family down	0	0	0	0
Moving or speaking so slowly that other people could have noticed. Or the opposite; being so fidgety or restless that you have been moving around a lot more than usual.	0	0	0	0
Thoughts that you would be better off dead or of hurting yourself in some way.	0	0 0		0
	Not at all	Several Days	More Than Half the Days	Nearly Every day

If you checked off any of the above problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

\bigcirc	Not difficult at all
0	Somewhat difficul
0	Very difficult

O Extremely difficult

(Optional) If desired, please share more about your expe	rience.

Anxiety Symptoms

Over the last 2 weeks, how often have you been bothered by any of the following problems?

	Not at all	Several Days	More Than Half the Days	Nearly Every day
Feeling nervous, anxious, or on edge	0	0	0	0
Not being able to stop or control worrying	0	0	0	0
Worrying too much about different things	0	0	0	0
Trouble relaxing	0	0	0	0
	Not at all	Several Days	More Than Half the Days	Nearly Every day
Being so restless that it is hard to sit still	0	0	0	0
Becoming easily annoyed or irritable	0	0	0	0
Feeling afraid as if something awful might happen	0	0	0	0
	Not at all	Several Days	More Than Half the Days	Nearly Every day

problems made it for you to do your work, take care of things at home, or get along with other people?
 Not difficult at all Somewhat difficult Very difficult Extremely difficult
(Optional) If desired, please share more about your experience.

Suicidal Thoughts

If you are having suicidal thoughts, these free helplines are available 24/7 to offer support:

US: 1-800-273-8255 (Crisis Text Line: text TALK to 741741)

UK: 116 123

Netherlands: 0800 0113

Canada: 833-456-4566

Find additional crisis lines for your country

At any time during the COVID-19 pandemic, have you ever:

Wished you were dead or wished you could go to sleep and not wake up Had thoughts of killing yourself Had thoughts of harming yourself Done anything to harm yourself I did not have any suicidal thoughts Other **Psychiatric Medication** Have you been taking prescribed psychiatric medication while in recovery? At any time during the COVID-19 pandemic, were there changes to your psychiatric medication? Yes, a dose adjustment was made to my prior medication Yes, new medications were prescribed to me No, I continued taking medication at the prior dose No, I have not required psychiatric medication

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If you were prescribed NEW medications, what were they?

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Antidepressant (Not Bupropion)
Melatonin for insomnia

Ш	Antidepressant (Not Bupropion)	Ш	Melatonin for insomnia
	Wellbutrin (Bupropion)		Mood stabilizer (e.g. lithium, valproic acid, topiramate, etc)
	Benzodiazepine (anti-anxiety medication)		Stimulant
	Antipsychotic		Other
	Z-drug for insomnia (e.g. zolpidem, zopiclone, zaleplon)		

Have you been taking any of these medications, please indicate how they affected your condition. (Answer any that apply)

	Much better	Moderately better	Slightly better	About the same	Slightly worse	Mode wor
Antidepressant (SSRI/SNRI/Wellbutrin, etc.)	0	0	0	0	0	C
Benzodiazepine (anti-anxiety medication)	0	0	0	0	0	C
Antipsychotic	0	0	0	0	0	C
Z-drug for insomnia (e.g. zolpidem, zopiclone, zaleplon)	0	0	0	0	0	C
	Much better	Moderately better	Slightly better	About the same	Slightly worse	Mode wor
Melatonin for insomnia	0	0	0	0	0	C
Mood stabilizer (e.g. lithium, valproic acid, topiramate, etc)	0	0	0	0	0	C
Stimulant	0	0	0	0	0	\subset

Qualtrics Survey Software 17/09/2020, 16:32 Other About the Much Moderately Slightly Slightly Mode better better better same worse 10W If you required psychiatric treatment during COVID-19, please check all that apply: lacksquare I received treatment from my primary care provider / ${\sf GP}$ I received treatment from my prior mental health practitioner I received treatment from a new mental health practitioner I was unable to obtain the treatment that I needed If you were not able to get psychiatric treatment, which of the following factored into the inability to receive care? Cost Access to a device compatible with tele-health

Coping

What wellbeing activities have you done/participated in to help you cope? (check all that apply)

Preferred provider does not take my insurance

Preferred provider does not see patients via telehealth

Other

Online COVID-19 specific support groups/communities Online non-COVID-19 specific support groups/communities Therapy Yoga Aerobic exercise Meditation None of the above If you have joined an online COVID-19 community, what is the effect of participation on your psychological wellbeing? Significantly improved my psychological wellbeing Moderately improved my psychological wellbeing Had no effect on my psychological wellbeing Moderately worsened my psychological wellbeing Significantly worsened my psychological wellbeing Do you agree with this statement? "I was not believed by one or more of my physicians") Strongly agree Agree Somewhat agree Neither agree nor disagree Somewhat disagree **)** Disagree Strongly disagree

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(Optional) Describ	oe how particip	ation in onlin	ie communiti	es affect your
D				
Being physically s	secluded from d	otners nas:		
O Had a negative O Had no impact of O Had a positive i O Had a strong po	egative impact or impact on my me on my mental we mpact on my me ositive impact on physically seclude below 28 sta	ental wellbein ellbeing ental wellbeing my mental we ded from othe	g ellbeing ers	of coping
	I haven't been doing this at all	A little bit	A medium amount	I've been doing this a lot
I've been turning to work or other activities to take my mind off things	0	0	0	0
I've been concentrating my efforts on doing something about the situation I'm in	0	0	0	0
I've been saying to myself "this isn't real"	0	0	0	0

l've been using alcohol or other drugs to make myself feel better	O	O	O	O
I've been getting emotional support from others	0	0	0	0
I've been giving up trying to deal with it	0	0	0	0
I've been taking action to try to make the situation better	0	0	0	0
	I haven't been doing this at all	A little bit	A medium amount	I've been doing this a lot
I've been refusing to believe that it has happened	0	0	0	0
l've been saying things to let my unpleasant feelings escape	0	0	0	0
l've been getting help and advice from other people	0	0	0	0
I've been trying to see it in a different light, to make it seem more positive	0	0	0	0
I've been criticizing myself	0	0	0	0
l've been trying to come up with a strategy about what to do	0	0	0	0
l've been getting comfort and understanding from someone	0	0	0	0
	I haven't been doing this at all	A little bit	A medium amount	I've been doing this a lot

I've been giving up the attempt to cope	O	O	O	O
l've been looking for something good in what is happening	0	0	0	0
I've been making jokes about it	0	0	0	0
I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping	0			0
I've been accepting the reality of the fact that it has happened	0	0	0	0
l've been expressing my negative feelings	0	0	0	0
I've been trying to find comfort in my religion or spiritual	0	0	0	0
beliefs				
	I haven't been doing this at all	A little bit	A medium amount	l've been doing this a lot
		A little bit		
l've been trying to get advice or help from other people about		A little bit		
l've been trying to get advice or help from other people about what to do I've been learning to	doing this at all	A little bit		
l've been trying to get advice or help from other people about what to do I've been learning to live with it I've been thinking hard about what	doing this at all	A little bit		
l've been trying to get advice or help from other people about what to do I've been learning to live with it I've been thinking hard about what steps to take I've been blaming myself for things that	doing this at all	A little bit		

I haven't be doing this a		little bit	A medium amount		een doing s a lot		
Anything else you'd like to share regarding coping.							
					4		
Structural Support							
How would you describe the following people during your			f support	from the			
	Harmful	Dismissive	Skeptical	Apathetic	Slightly concerne		
Medical Providers							
Friends							
Spouse / Partner							
Family (not Spouse/Partner)							
Employer							
Other							

(Optional) If you'd like, feel free to share your experience of the

support or lack of support of people during your illness.
While you have been ill, which of these scenarios matched your experience?
☐ I lived alone and felt well-equipped to take care of myself
☐ I lived alone and needed more help than I could get
☐ I lived with someone and they took care of me well
☐ I lived with someone and needed more help than I could get
Other
If you were isolating, either in a space within the same house or in a different house, which of these scenarios matched your experienced best?
Please consider 'reunited' to mean you began living with others again, not just visiting/socializing with others.
☐ I was not isolating/I have been living with others throughout my illness.
☐ I reunited with others at some point during weeks 1-3 and they got infected (most likely from me)
☐ I reunited with others at some point during weeks 1-3 and they did not get infected
☐ I reunited with others at some point during weeks 4-6 and they got infected

I reunited with others at some point during weeks 4-6 and they did not get infected I reunited with others at some point after week 6 and they got infected I reunited with others at some point after week 6 and they did not get infected I am still isolating/have not reunited with others N/A Do you have any animal pets at home? * If yes, please specify: * Cats Dogs Rodents Others Regarding the medical care you have received during the COVID-19 pandemic: * () I believe I received the appropriate amount of care I believe I received somewhat below the appropriate amount of care I believe I received significantly below the appropriate amount of care I did not require any medical care

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Regarding financial status during the COVID-19 pandemic (choose althat apply): *
 I lost my job or have been unable to work if self-employed I have been unable to afford basic necessities like food and rent I have been under financial pressure but have been able to make ends meet I have not felt any financial pressures
(Optional) I believe my federal government and national public health institutions did the best they possibly could in handling the COVID-19 pandemic.
 Strongly agree Agree Somewhat agree Neither agree nor disagree Somewhat disagree Disagree Strongly disagree
If you have children, have your children been sick with COVID (or suspected COVID) for over three weeks?
 I don't have children. My children did not get sick. My children got sick but recovered in less than 3 weeks. One or more of my children have been sick for over 3 weeks, and one or more of my children have recovered before 3 weeks.

All of my children have been sick for over 3 weeks.
Work
Were you employed pre-COVID?
 Yes, full-time Yes, part-time I was self-employed, full-time I was self-employed, part-time No
Did/do you need accommodation or reduced hours because of persistent issues/symptoms?
 Yes, I needed to reduce my hours (working in-person). Yes, I needed to reduce my hours (working remotely). Yes, I had to quit my job or was fired. No, I have been able to continue working as normal. Other, please describe

Other Medical Diagnostics

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Have you received any medical diagnostic testing for your COVID-19

physical symptoms? (Scans, ultrasounds, ECG	às)
✓ Yes✓ No	

Have you completed any of the following medical diagnostic testing? Note: If you have had any test done multiple times, please enter "Abnormal" if you received an abnormal result at any time.

	Not tested	Yes - normal	Yes - abnorma
MRI - brain	0	0	0
MRI - chest	0	0	0
CT scan - chest	0	0	0
CT scan - brain	0	0	0
CT scan - abdomen	0	0	0
	Not tested	Yes - normal	Yes - abnorma
CT scan - pulmonary angiogram	0	0	0
X-ray - chest	0	0	0
Spinal tap (lumbar puncture)	0	0	0
Ultrasound - leg	0	0	0
Ultrasound (echo) - heart	0	0	0
	Not tested	Yes - normal	Yes - abnorma
Ultrasound - abdomen	0	0	0
ECG/EKG (heart)	0	0	0
EEG (brain)	0	0	0
EMG (muscle/nerves)	0	0	0

Other	0	0	0
	Not tested	Yes - normal	Yes - abnormal
If the brain MRI, brain CT, or describe the results here.	brain EEG w	ere abnormal,	please
			<i>l</i> e
If the chest MRI, chest CT, or describe the results here.	⁻ chest X-ray	were abnorma	I, please
			<i>(</i> ,
If the spinal tap was abnorma	al, please des	scribe the resul	lts here.
If the EMG was abnormal, ple	ease describe	e the results he	ere.

If any of the other tests listed above were abnormal, please describe the results here.
If you had any abnormal tests that were not listed here, please describe the results here.
Diagnostics Blood Tests
Have you received diagnostic blood tests for your COVID-19 symptoms? (e.g. CBC)
○ Yes○ No
What was the result of your blood tests for the following? If these were abnormal at one point but then resolved, please include the abnormal

result.

	Not tested	Normal	Abnormal, high	Abnormal, low	Unsure/Can find it
Creatinine (usually part of the basic metabolic panel)	0	0	0	0	0
Lymphocyte count (usually part of the CBC, complete blood count)	0	0	0	0	0
Eosinophils count (usually part of the CBC)	0	0	0	0	0
Eosinophils % (usually part of the CBC)	0	0	0	0	0
Hepatic Panel/Liver function test	0	0	0	0	0
	Not tested	Normal	Abnormal, high	Abnormal, low	Unsure/Can
D-dimer	0	0	0	0	0
C-Reactive Protein	0	0	0	0	0
ESR (sedimentation rate)	0	0	0	0	0
Fibrinogen	0	0	0	0	0
Other	0	0	0	0	0
For any abnormal blood test	s, plea	se desc	cribe the r	esult furth	ner

a new line).	ormai blood te	ests. (Please	put each abh	ormai test on
Have you been tes	sted for these	conditions s	ince COVID?	
	Not tested	Negative	Current/recent infection (since COVID)	Past infection
Epstein-Barr (mono)	0	0	0	0
Lyme disease	0	0	0	0
Cytomegalovirus (CMV)	0	0	0	0
Were you given an		agnoses for a	any of your syr	nptoms?
☐ Guillain-Barre Sy☐ Small fiber neuro ☐ Autonomic neuro ☐ Polyneuropathy	opathy opathy			
Neuralgia (pleas	e include type o	of neuralgia ir	text box)	
Antiphospholipid	Syndrome, vira	al induced or	autoimmune	
Sarcoidosis				

Stroke (please include type of stroke in text box)
Demyelinating lesions
POTS
Encephalopathy
Encephalitis (please include type of encephalitis in text box)
Mengingoencephalitis
Meningitis
Acute Disseminated Encephalomyelitis
Acute myelitis
Ophthalmoparesis
Psychiatric Diagnosis
Migraine
Motor Peripheral or Cranial Neuropathies
Posterior reversible encephalopathy syndrome
Myasthenia
Thrombotic microangiopathy
Tapia Syndrome
Epilepsy
Traumatic Brain Injury (TBI) or TBI-like symptoms
Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS)
Cranial nerve involvement
Macular hole
Costochondritis
Blood clot
Myocarditis

Please describe any other diagnosis you	u were given (if multiple, please
put each diagnosis on a new line and pr	ess "enter" between each of
them.)	

Treatments

Have you tried any of the following treatments for your COVID19 symptoms, if yes, how helpful it was? (choose all that apply)

This includes Prescription or off-the-counter Medications, or Alternative Treatments.

	Did not try this	Slightly helpful	Significantly helpful	Not Helpful	Unsure
Non-medication treatment options Electrolytes	0	0	0	0	0
Pacing programs (regulating the amount of activity)	0	0	0	0	0
Adding salt to food and drinks	0	0	0	0	0
Compression garments (socks, leggings)	0	0	0	0	0
Acupuncture	0	0	0	0	0
Lymphatic massage	0	\circ	\circ	\circ	0

Anti-histamines H1 type Anti- histamines (diphenhydramine, acrivastine and cetirizine, like benadryl, zyrtec, claritin)	0	0	0	0	0
H2 type Anti- histamines (cimetidine, famotidine, like Pepcid)	0	0	0	0	0
Cannabis CBD/THC products	0	0	0	0	0
CBD-only products	0	0	0	0	0
Steroids Prednisone and Dexamethasone	0	0	0	0	0
Blood-thinners Baby aspirin (75- 81mg)	0	0	0	0	0
Direct oral anticoagulants, Rivaroxaban (Xarelto)	0	0	0	0	0
Warfarin (Coumadin)	0	0	0	0	0
Anti-inflammatories Curcumin (tumeric)	0	0	0	0	0
Omega 3 / DHA / EPA (Fish oil)	0	0	0	0	0
Immune system treatments Intravenous gamma globulin	0	0	0	0	0
Convalescent plasma	0	0	0	0	0
Anti-viral medication Remsdesevir (Veklury)	0	0	0	0	0

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Antibiotics Azithromycin	0	0	0	0	0
Malaria treatments Chloroquine	0	0	0	0	0
Hydroxychloroquine	0	0	0	0	0
Anti-oxidants Oxaloacetate	0	0	0	0	0
Over the counter painkillers Non-NSAIDs (Tylenol, Paracetamol)	0	0	0	0	0
NSAIDs (Ibuprofen, Naproxen, Adult aspirin (full dose))	0	0	0	0	0
Please describe ar anything else that seach on a new line	significantl	y improved	d your sym	ptoms. (Pl	

Overall COVID Experience Text Write In

Optional: Please use this space to describe anything you particularly want others to know about the COVID experience, or that haven't been captured here. Please do not include any identifying information (such as name or location).

s Survey Software	17/09/20
You ha	ve reached the end of the survey!
	ke a moment to review anything you may have missed. Once ure of your responses, hit next to submit.
	omitted, you cannot go back to make modifications. Thank you energy and time!
return to th	nis survey later, bookmark the link that is in your browser.
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