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Clinical characteristics, activity levels and mental health problems in children with Long COVID: a survey of 510 children

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Abstract

Background

The World Health Organization has recently recognized Long COVID, calling the international medical community to strengthen research and comprehensive care of patients with this condition. However, if Long COVID pertains to children as well is not yet clear.

Methods

An anonymous, online survey was developed by an organization of parents of children suffering from persisting symptoms since initial infection. Parents were asked to report signs

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and symptoms, physical activity and mental health issues. Only children with symptoms persisting for more than four weeks were included.

Results

510 children were included (56.3% females) infected between January 2020 and January 2021. At their initial COVID-19 infection, 22 (4.3%) children were hospitalized. Overall, children had persisting COVID-19 for a mean of 8.2 months (SD 3.9). Most frequent symptoms were: Tiredness and weakness (444 patients, 87.1% of sample), Fatigue (410, 80.4%), Headache (401, 78.6%), Abdominal pain (387, 75.9%), Muscle and joint pain (309, 60.6%), Post-exertional malaise (274, 53.7%), rash (267, 52.4%). 484 (94.9%) children had had at least four symptoms. 129 (25.3%) children have suffered constant COVID-19 infection symptoms, 252 (49.4%) have had periods of apparent recovery and then symptoms returning, and 97 (19.0%) had a prolonged period of wellness followed by symptoms. Only 51 (10.0%) children have returned to previous levels of physical activity. Parents reported a significant prevalence of Neuropsychiatric symptoms.

Conclusions

Our study provides further evidence on Long COVID in children. Symptoms like fatigue, headache, muscle and joint pain, rashes and heart palpitations, and mental health issues like lack of concentration and short memory problems, were particularly frequent and confirm previous observations, suggesting that they may characterize this condition. A better comprehension of Long COVID is urgently needed.

Keywords: long covid; children; SARS-CoV-2

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Background

One year after the first description of SARS-COV-2 in China, several results have been achieved in the understanding of epidemiology and physio-pathological bases of COVID-19 (1) and its treatment (2), and a number of effective vaccines have been developed and marketed (3). However, unexplained issues still remain. Among them, a particularly debated issue, by both patients and researchers, has been the recognition that a relevant percentage of patients with COVID-19 experience persisting symptoms after the resolution of acute disease. While patients relatively quickly highlighted their persisting symptoms and change in quality of life, Italian researchers first documented this on an International peer-reviewed journal (4). Carfì et al found that in patients who had recovered from COVID-19, 87.4% reported persistence of at least one symptom, particularly fatigue and dyspnoea. Later, several other papers confirmed these data in adults and a recent large cohort of 1,733 patients from Wuhan found persistent symptoms in 76% of patients 6 months after initial diagnosis (5).

Since this condition is still not completely understood, a definite official name was not initially recognized. Nevertheless, patient organizations started complex discussions and movements on social media with various kinds of evidence and advocacy to demonstrate a longer, more complex course of illness than laid out in initial reports from Wuhan and, eventually, coined the term Long COVID (6) which was, later, also recognized by the World Health Organization (7). Long COVID is probably the first illness named directly from patients.

Researchers have only recently began to study why people develop these symptoms. According to the WHO, several explanations can be considered (7): persistence of the virus in some parts of the body that are sheltered from the immune system, such as the brain; direct damage to organs, such as the heart and lungs, and also the pancreas, causing some new cases of diabetes; and blood clotting, which can cause heart attacks and strokes. However, there is a huge variety in both the pattern of symptoms and their severity, with gender and, possibly, age differences.

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While at the beginning children were considered relatively spared by the pandemic, around December parent movements began highlighting that most children never recovered from acute COVID-19. Parents developed social media movements aiming to highlight that children were also suffering from Long COVID. The Long COVID Kids UK (https://www.longCOVIDkids.org/) began initially with the launch of an online message on YouTube on October 31st 2020 (https://www.youtube.com/watch?v=RiIambG8vs0) and with Facebook and Twitter channels. Since its start, 197,000 people have been reached on Facebook and 1.8 million interactions on Twitter. So far, the group includes over 1,800 children from 1,332 families (Appendix figures). Later, a case series from Sweden described a group of five children with Long COVID (8). A larger study from Italy confirmed that about one out of three children with acute COVID-19 experienced persisting symptoms months after initial diagnosis (9).

Considering the importance of patient-driven data in this pandemic and for the understanding of Long COVID in particular, and aiming to provide more insights in the burden of Long COVID in children, one of the largest parent movements (Long COVID Kids UK) performed an online follow-up survey of a large cohort of children that experienced COVID-19 and had persisting symptoms.

Methods

Long COVID Kids Rapid Survey 2

In order to assess the presence of persisting symptoms in children with previous COVID-19, the parents non-profit association LongCOVIDKids developed an online platform where parents from all over the world can access and anonymously report their child's experience. The 'Long COVID Kids Rapid Survey 2' was designed as a follow-up to a pilot survey (that established quantity and type of symptoms) as a means to establish clusters of symptoms rather than the full breadth of symptoms as well as the effects on the mental and physical health of the child as a result of Long COVID. Certain symptoms were deliberately excluded as they were not considered relevant to the clusters under consideration. Links to the survey site on JotForm were disseminated on the closed Facebook group LongCOVIDKids. Parents'

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consent was required before answering questions on their children with COVID-19 persistent symptoms.

In the 'Long COVID Kids Rapid Survey 2', participants were asked to self-declare the following main information on their children: how COVID-19 was confirmed and details at infection, including need of hospitalization, age, sex and ethnicity; month of initial infection; course of symptoms, if any, from initial infection; activity before after infection; mental health status and comorbidities before COVID-19; displayed symptoms since COVID-19; behavioural/activity/habits changes after COVID-19; need of medical care after COVID-19; parents' perspectives of need of medical care for their children and type of care; parents' perspective on child's need of support to be readmitted at school after COVID-19. The full version of the survey is available at https://form.jotform.com/210431051528039?fbclid=IwAR3uYxbqO-AFcOO8o73Dhc5kolP8aaTx0wY_ba7MvIQ83UxHEy6eBLpH720

For the purpose of this study, we used data from the 'Long COVID Kids Rapid Survey 2' collected between 13 February 2021 and 06 March 2021. Only those children with symptoms lasting longer than 4 weeks were included. Given the nature of the survey, an Ethic Committee was not necessary for this study.

Data Analysis

The Confirmation status of COVID-19 infection was asked about as "Has your child had confirmed or suspected COVID-19 infection?". The possible answers to that question were: "Clinical Diagnosis", "Lateral Flow", "Positive PCR Swab", and "Unconfirmed by a test or medical professional but we think we had it." We will initially report the counts for the original possible answers, and then in tables we will use a simplified version by merging "Positive PCR Swab" and "Lateral Flow" as "Positive Test". Time from infection was estimated (with a 15-day uncertainty) by subtracting the 15th day of the reported month of (confirmed or suspected) infection from the date of response to the survey. Children with an estimated time from infection below 1.5 months were excluded to ensure that all included children had had symptoms for longer than 4 weeks. In practice this implied excluding all children

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infected on February 2021 and those infected on January 2021 and reported on February 2021.

We produced summary tables and graphs aiming at the description of the study sample, the symptoms and changes in Long-COVID children, looking further at changes in their physical activity levels and mental health. We cross-tabulated variables by confirmation status of COVID-19 infection and by the pre-existence of comorbidities.

Results

Study Sample

Data on 510 children who had had COVID-19 for more than 4 weeks were reported by their parents. 351 (68.8%) of them live in the UK and 94 (18.4%) in the USA. They got COVID-19 between January 2020 and January 2021 at a mean age of 10.3 years (standard deviation 3.8) (Figure 1, left). 287 (56.3%) were female. For 297 (58.2%) children COVID-19 has been confirmed by a positive PCR test (N=141), a positive (antibody) lateral flow test (N= 4) or clinical diagnosis (N=156). For 209 (41%) children, COVID-19 was suspected but has not been confirmed by a test or medical professional; most of those children are from UK and were infected around March 2020, at a time when access to tests, particularly for non-severe cases, was difficult in most countries (Table 1).

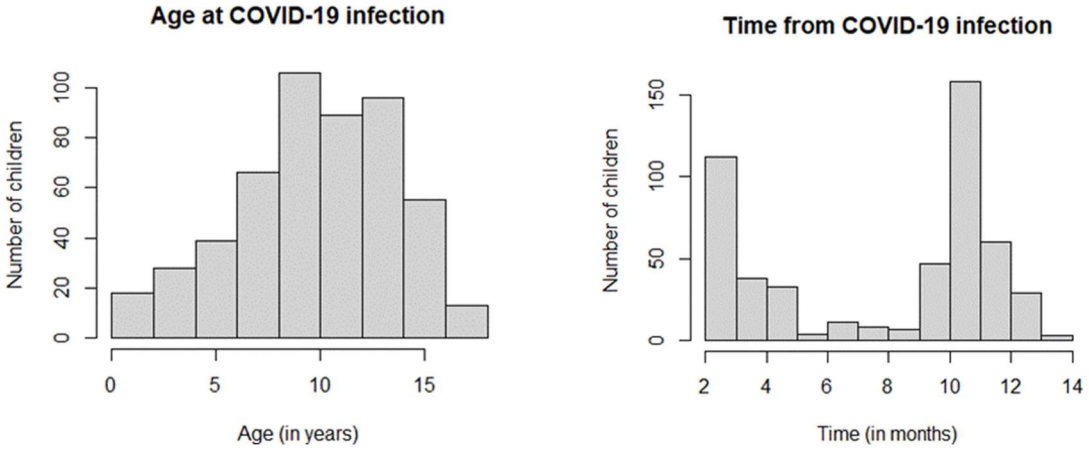

Figure 1. Age of respondents at COVID-19 infection (left) and time from infection at date of response to the 'Long COVID Kids Rapid Survey 2' questionnaire (right).

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Table 1. Confirmation status of COVID-19 infection, by country of residence and by time from infection

Confirmation status	Country of Residence			Time from infection		
	UK *N=351*	**USA** *N=94*	**Other** *N=65*	**1-2 months** *N=82*	**3-6 months** *N=108*	**7+ months** *N=320*
Clinical Diagnosis	100 (28.5%)	39 (41.5%)	17 (26.2%)	13 (15.9%)	21 (19.4%)	122 (38.1%)
Positive Test	83 (23.6%)	37 (39.4%)	25 (38.5%)	64 (78%)	60 (55.6%)	21 (6.6%)
Unconfirmed but suspected	168 (47.9%)	18 (19.1%)	23 (35.4%)	5 (6.1%)	27 (25%)	177 (55.3%)

At their initial COVID-19 infection, only 22 (4.3%) children were hospitalized; 62 (12.2%) were asymptomatic, 378 (74.1%) were managed at home, and 48 (9.4%) went to hospital but were not admitted. 223 (43.7%) children had no pre-existing condition. Detailed information on pre-COVID conditions of children is available in the Appendix Table A1. 411 (80.6%) children had no pre-COVID mental health concern or diagnosis.

Persistence of symptoms in children since COVID-19

Overall, children had persisting COVID-19 for a mean of 8.2 months (standard deviation 3.9) (Figure 1, right). Details of reported symptoms are described in Table 2. Most frequent symptoms were: Tiredness and weakness (444 patients, 87.1% of sample), Fatigue (410, 80.4%), Headache (401, 78.6%), Tummy pain or cramps (387, 75.9%), Muscle aches and pains (349, 68.4%), Muscle and joint pain (309, 60.6%), Post-exertional malaise (274, 53.7%), A rash (267, 52.4%), Unexplained irritability (262, 51.4%), and Dizziness (245, 48%). 484 (94.9%) children had at least four symptoms. Appendix Table A2 reports symptoms according to disease diagnosis and pre-existence of comorbidities.

129 (25.3%) children have suffered constant COVID-19 infection symptoms, 252 (49.4%) have had periods of apparent recovery and then symptoms returning, and 97 (19%) had a prolonged period of wellness followed by symptoms. Among those who had no pre-COVID condition it was slightly less frequent to have constant COVID-19 (23.8% versus 26.5%) or alternating recovery/symptom episodes (48.4% versus 50.2%) (Table 3).

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Table 2. Symptoms present since COVID-19 infection (multiple choices allowed), by the pre-existence of comorbidity conditions, by sex, by age group, and by time from infection

Symptom	All	Had Pre-conditions	No Pre-conditions	Female	Male	Age less than 10 yrs	Age 10 yrs or older	1-2 months	3- 6 months	7+ months
	N=510	*N=287*	*N=223*	*N=287*	*N=222*	*N=196*	*N=314*	*N=82*	*N=108*	*N=320*
Cardio-respiratory										
Heart palpitations	205 (40.2%)	112 (39%)	93 (41.7%)	121 (42.2%)	83 (37.4%)	71 (36.2%)	134 (42.7%)	29 (35.4%)	45 (41.7%)	131 (40.9%)
Coughing	151 (29.6%)	81 (28.2%)	70 (31.4%)	79 (27.5%)	71 (32%)	66 (33.7%)	85 (27.1%)	25 (30.5%)	30 (27.8%)	96 (30%)
Throat clearing	107 (21%)	59 (20.6%)	48 (21.5%)	59 (20.6%)	47 (21.2%)	55 (28.1%)	52 (16.6%)	21 (25.6%)	16 (14.8%)	70 (21.9%)
Dermatologic										
A rash	267 (52.4%)	149 (51.9%)	118 (52.9%)	143 (49.8%)	123 (55.4%)	118 (60.2%)	149 (47.5%)	35 (42.7%)	54 (50%)	178 (55.6%)
Red and cracked lips	201 (39.4%)	112 (39%)	89 (39.9%)	124 (43.2%)	77 (34.7%)	89 (45.4%)	112 (35.7%)	33 (40.2%)	37 (34.3%)	131 (40.9%)
Peeling skin on your hands and feet	143 (28%)	83 (28.9%)	60 (26.9%)	78 (27.2%)	65 (29.3%)	63 (32.1%)	80 (25.5%)	20 (24.4%)	26 (24.1%)	97 (30.3%)
Swollen hands and feet	107 (21%)	56 (19.5%)	51 (22.9%)	62 (21.6%)	45 (20.3%)	42 (21.4%)	65 (20.7%)	10 (12.2%)	14 (13%)	83 (25.9%)
Ulcers	79 (15.5%)	43 (15%)	36 (16.1%)	51 (17.8%)	28 (12.6%)	47 (24%)	32 (10.2%)	10 (12.2%)	11 (10.2%)	58 (18.1%)
Gastrointestinal										
Tummy pain or cramps	387 (75.9%)	218 (76%)	169 (75.8%)	225 (78.4%)	161 (72.5%)	157 (80.1%)	230 (73.2%)	58 (70.7%)	78 (72.2%)	251 (78.4%)
Nausea	233 (45.7%)	134 (46.7%)	99 (44.4%)	135 (47%)	97 (43.7%)	78 (39.8%)	155 (49.4%)	35 (42.7%)	52 (48.1%)	146 (45.6%)
Diarrhoea and vomiting	216 (42.4%)	128 (44.6%)	88 (39.5%)	115 (40.1%)	100 (45%)	92 (46.9%)	124 (39.5%)	34 (41.5%)	44 (40.7%)	138 (43.1%)
HEENT (Head, Ears, Eyes, Nose, Throat)										
Red eyes	206 (40.4%)	113 (39.4%)	93 (41.7%)	102 (35.5%)	104 (46.8%)	87 (44.4%)	119 (37.9%)	30 (36.6%)	41 (38%)	135 (42.2%)
Sore throat	230 (45.1%)	132 (46%)	98 (43.9%)	131 (45.6%)	99 (44.6%)	87 (44.4%)	143 (45.5%)	36 (43.9%)	43 (39.8%)	151 (47.2%)
Swollen neck glands	128 (25.1%)	74 (25.8%)	54 (24.2%)	81 (28.2%)	47 (21.2%)	46 (23.5%)	82 (26.1%)	19 (23.2%)	21 (19.4%)	88 (27.5%)
Musculoskeletal										

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Muscle aches and pains	349 (68.4%)	204 (71.1%)	145 (65%)	201 (70%)	147 (66.2%)	111 (56.6%)	238 (75.8%)	60 (73.2%)	70 (64.8%)	219 (68.4%)
Muscle and joint pain	309 (60.6%)	179 (62.4%)	130 (58.3%)	180 (62.7%)	129 (58.1%)	102 (52%)	207 (65.9%)	51 (62.2%)	69 (63.9%)	189 (59.1%)
Neurological										
Headache	401 (78.6%)	239 (83.3%)	162 (72.6%)	231 (80.5%)	169 (76.1%)	138 (70.4%)	263 (83.8%)	63 (76.8%)	86 (79.6%)	252 (78.8%)
Unexplained irritability	262 (51.4%)	149 (51.9%)	113 (50.7%)	150 (52.3%)	112 (50.5%)	117 (59.7%)	145 (46.2%)	41 (50%)	56 (51.9%)	165 (51.6%)
Dizziness	245 (48%)	148 (51.6%)	97 (43.5%)	150 (52.3%)	94 (42.3%)	60 (30.6%)	185 (58.9%)	39 (47.6%)	55 (50.9%)	151 (47.2%)
Twitches	55 (10.8%)	34 (11.8%)	21 (9.4%)	35 (12.2%)	20 (9%)	16 (8.2%)	39 (12.4%)	9 (11%)	10 (9.3%)	36 (11.2%)
Word repetition	52 (10.2%)	25 (8.7%)	27 (12.1%)	29 (10.1%)	22 (9.9%)	21 (10.7%)	31 (9.9%)	7 (8.5%)	14 (13%)	31 (9.7%)
Tics	47 (9.2%)	25 (8.7%)	22 (9.9%)	26 (9.1%)	21 (9.5%)	18 (9.2%)	29 (9.2%)	5 (6.1%)	8 (7.4%)	34 (10.6%)
Stuttering	40 (7.8%)	17 (5.9%)	23 (10.3%)	23 (8%)	17 (7.7%)	15 (7.7%)	25 (8%)	4 (4.9%)	7 (6.5%)	29 (9.1%)
Swearing	26 (5.1%)	15 (5.2%)	11 (4.9%)	9 (3.1%)	17 (7.7%)	10 (5.1%)	16 (5.1%)	2 (2.4%)	5 (4.6%)	19 (5.9%)
Growling	24 (4.7%)	12 (4.2%)	12 (5.4%)	11 (3.8%)	12 (5.4%)	15 (7.7%)	9 (2.9%)	5 (6.1%)	4 (3.7%)	15 (4.7%)
General										
Tiredness and weakness	444 (87.1%)	249 (86.8%)	195 (87.4%)	248 (86.4%)	195 (87.8%)	168 (85.7%)	276 (87.9%)	70 (85.4%)	98 (90.7%)	276 (86.2%)
Fatigue	410 (80.4%)	235 (81.9%)	175 (78.5%)	236 (82.2%)	173 (77.9%)	142 (72.4%)	268 (85.4%)	64 (78%)	93 (86.1%)	253 (79.1%)
Post-exertional malaise	274 (53.7%)	161 (56.1%)	113 (50.7%)	158 (55.1%)	116 (52.3%)	95 (48.5%)	179 (57%)	44 (53.7%)	57 (52.8%)	173 (54.1%)
Fever	151 (29.6%)	81 (28.2%)	70 (31.4%)	94 (32.8%)	56 (25.2%)	68 (34.7%)	83 (26.4%)	22 (26.8%)	29 (26.9%)	100 (31.2%)
Flu-like symptoms	121 (23.7%)	69 (24%)	52 (23.3%)	78 (27.2%)	42 (18.9%)	47 (24%)	74 (23.6%)	20 (24.4%)	20 (18.5%)	81 (25.3%)
Other										
Sepsis	7 (1.4%)	5 (1.7%)	2 (0.9%)	4 (1.4%)	3 (1.4%)	3 (1.5%)	4 (1.3%)	0 (0%)	1 (0.9%)	6 (1.9%)
Appendicitis	7 (1.4%)	6 (2.1%)	1 (0.4%)	5 (1.7%)	2 (0.9%)	4 (2%)	3 (1%)	0 (0%)	0 (0%)	7 (2.2%)
Peritonitis	1 (0.2%)	0 (0%)	1 (0.4%)	0 (0%)	1 (0.5%)	0 (0%)	1 (0.3%)	0 (0%)	0 (0%)	1 (0.3%)

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Table 3. Children experience of COVID-19 by confirmation status of COVID-19 infection, and by the pre-existence of comorbidity conditions

	All	Clinical Diagnosis	Positive Test	Unconfirmed but suspected	Had Pre-Conditions	No Pre-Conditions
	N=510	*N=156*	*N=145*	*N-209*	*N=287*	*N=223*
Constant COVID-19	129 (25.3%)	45 (28.8%)	50 (34.5%)	34 (16.3%)	76 (26.5%)	53 (23.8%)
Alternance recovery/symptoms	252 (49.4%)	78 (50%)	66 (45.5%)	108 (51.7%)	144 (50.2%)	108 (48.4%)
Long wellness followed by symptoms	97 (19%)	21 (13.5%)	24 (16.6%)	52 (24.9%)	46 (16%)	51 (22.9%)
Undetermined	32 (6.3%)	12 (7.7%)	5 (3.4%)	15 (7.2%)	21 (7.3%)	11 (4.9%)

Changes in children since COVID-19 infection

Long-COVID children have suffered complex changes since COVID-19 infection (Figure 2 and Appendix Table A3). The most frequently reported changes are in: Energy levels (425 patients, 83.3% of sample), Mood (300, 58.8%), Sleep (287, 56.3%), and Appetite (253, 49.6%). The latter changes were significant on children with confirmed/unconfirmed COVID-19 and occurred similarly on those with or without pre-existing conditions (Figure 2 and Appendix Table A3). Overall, all children have had at least 1 change and 325 (63.7%) children have had at least 4 changes from those in Table 4 since their COVID-19 infection. The proportion of those with at least 4 changes is above 60% independently of whether they had had pre-COVID conditions (Appendix Table A4).

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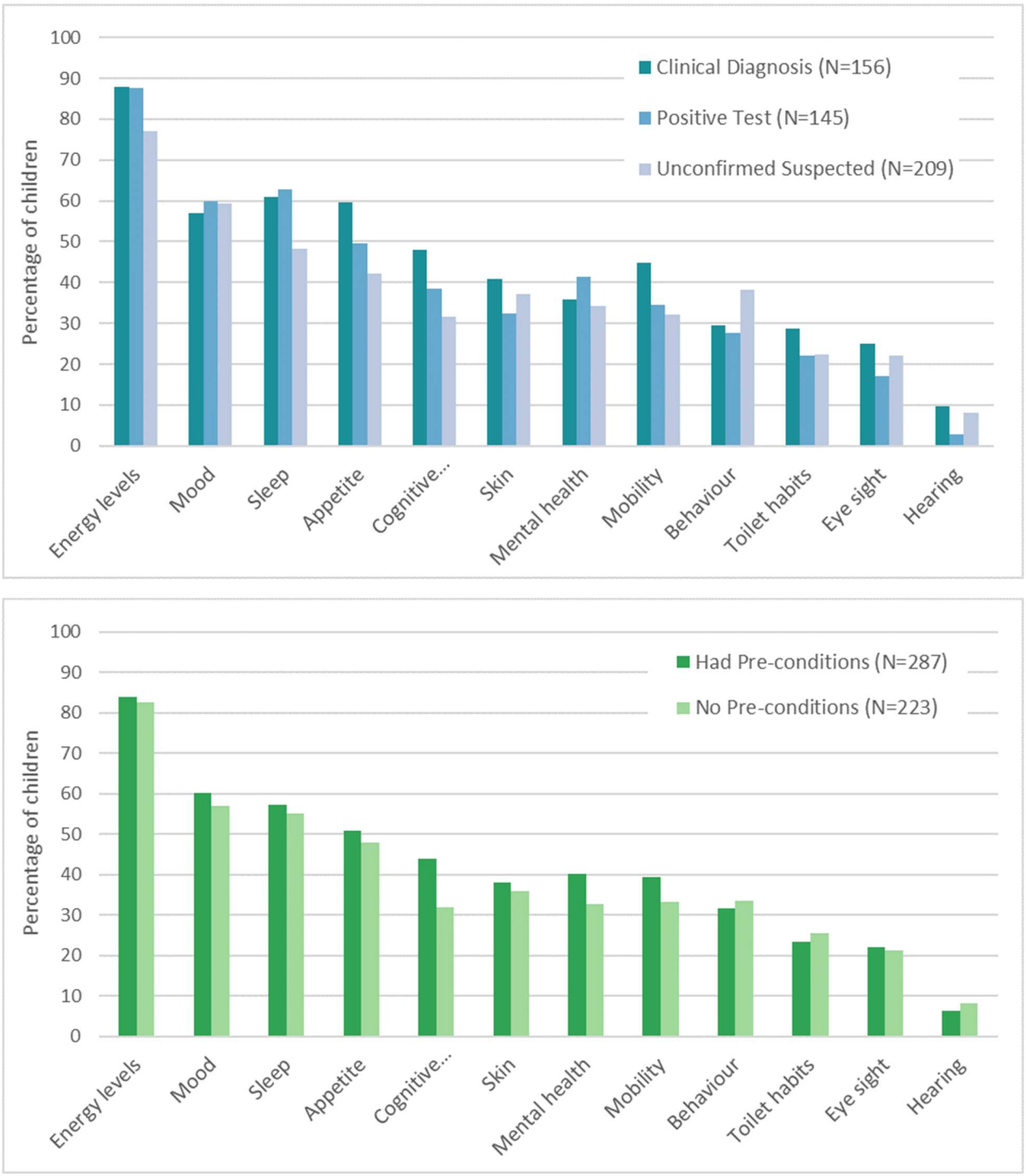

Figure 2. Changes reported since COVID-19 infection by confirmation status of infection (left), and by the pre-existence of comorbidity conditions (right).

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Changes in Physical Activity Levels

Most children were physically active before their COVID-19 infection. During the first 6 weeks after infection, 262 (51.4%) children did participate in some level of activity, 217 (42.5%) did not, and for 31 (6.1%) children their parents were unsure.

Families reported that their children activity levels were worse than before infection (Appendix tables A5 and A6). Only 51 (10%) children have returned to previous levels of activity. 108 (21.2%) are currently unable to enjoy any activity, and 154 (30.2%) enjoy occasional activity but usually have an increase of symptoms after. Overall, the more physically active they were before COVID-19, the higher the proportion of them who returned to previous activity levels, although these rates are very low: only 17 (11.8%) of those who practiced daily sports before COVID-19 returned to previous levels.

Changes in Mental Health

Parents reported a significant prevalence of Neuropsychiatric symptoms among their children with persisting symptoms (Figure 3 and Appendix Table A7). In more detail, several parents reported Lack of concentration (309 children, 60.6% of sample), Difficulty remembering information (234, 45.9%), Difficulty in doing everyday tasks (204, 40%), Difficulty processing information (167, 32.7%), and Short term memory issues (167, 32.7%). 279 (54.7%) children have had at least 3 mental health issues (excluding “None of the above” and “Other”), 45 (8.8%) children have had 2 issues, 54 (10.6%) children have had 1 issue, and 132 (25.9%) children have had no issues (excluding “None of the above” and “Other”). Only 64 (28.7%) of those with no pre-COVID conditions haven’t had any mental health/cognitive issues since their COVID infection (Appendix Table A8).

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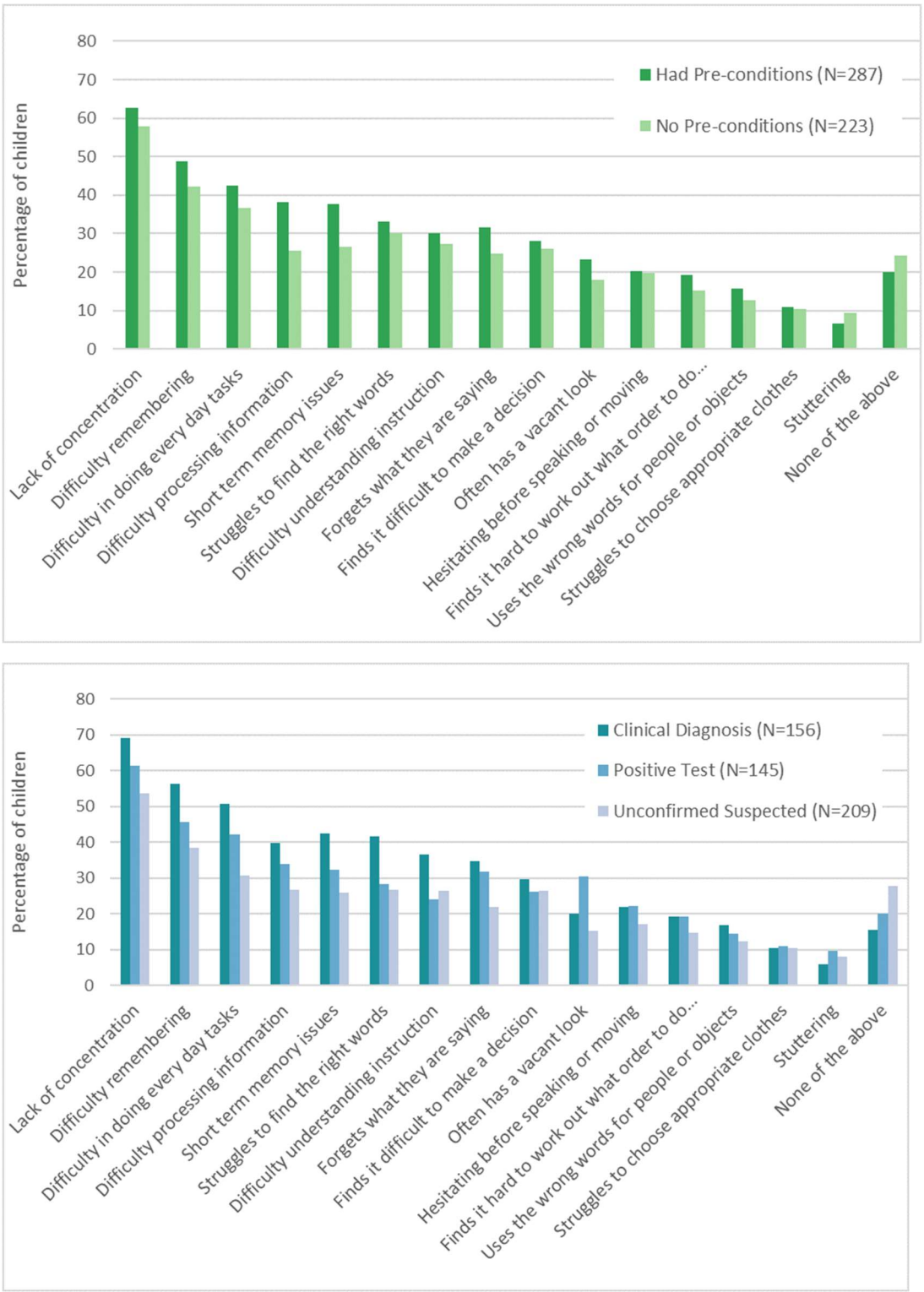

Figure 3. Mental health / cognitive issues since COVID-19 infection (multiple issues per child are usual) by confirmation status of infection (top), and by the pre-existence of comorbidity conditions (bottom)

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Discussion

In this study, we performed a comprehensive assessment of parents' perspectives about long-term physical and mental health outcomes of a large cohort of children with persisting symptoms after initial COVID-19 infection, providing details about reported symptoms, their dynamics and the overall changes in children activities and mental health.

We found that fatigue, headache, muscle and joint pain, post-exertional malaise, rashes, heart palpitations were commonly reported by parents. This cluster of symptoms were frequently reported in another paediatric Long COVID study from Italy, where insomnia (18.6%), respiratory symptoms (including pain and chest tightness) (14.7%), nasal congestion (12.4%), fatigue (10.8%), muscle (10.1%) and joint pain (6.9%), and concentration difficulties (10.1), were the most frequently reported symptoms (9). In the Italian study, 35 children (27.1%) had at least one symptom 120 days or more after diagnosis, and 29 out of the 68 (42.6%) children assessed ≥120 days from diagnosis were still distressed by these symptoms. A similar pattern of symptoms was reported in a small case series published in Sweden by Ludvigsson (8), which reported five children having fatigue, dyspnoea, heart palpitations or chest pain, headaches, difficulties concentrating, muscle weakness, dizziness and sore throats months from initial diagnosis. While some had improved after 6–8 months, none had fully returned to school. Interestingly, the UK, Italian and Swedish patients had similar age patterns. Of note, adults' studies on Long COVID report a very similar pattern of symptoms as well (4, 5). The similarity of the reported symptoms in different cohorts of adult and paediatric studies suggest that those may be the defining symptoms of Long COVID in general, including in children.

In this survey, we assessed symptom dynamics. This is an important aspect of Long COVID according to descriptions of patient organizations and adults' studies, while it was not assessed in children before. Interestingly, we found that 25.3% of children have suffered constant COVID-19 infection symptoms, 49.4% have had periods of apparent recovery and then symptoms returning, 19.0% had a prolonged period of wellness followed by symptoms. Importantly, a similar pattern was reported independently in those with and without pre-existing conditions. To date, we did not find any paediatric study to compare our data.

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Since physical activity plays an important role in child health, growth, development and socialization, we assessed how it changed after the infection of COVID-19. Overall, we found that most children had worse activity levels than before infection, since, at the time of the survey, 21.2% were currently unable to enjoy any activity and 30.2% enjoyed occasional activity but usually had an increase of symptoms after. Although lockdown and school closure may have contributed to this change (10), from our survey it seems that physical conditions were the main limiting factor for not enjoying physical activity.

We also assessed mental health issues in this cohort of children with previous COVID-19. During the last months of the pandemic, healthcare professionals seeing an increase in suicide attempts and other issues related with mental health in children and adolescents have raised several warnings (11, 12). Parents reported a wide range of neuro-cognitive symptoms, including lack of concentration, difficulty processing/remembering information or understanding instruction, short term memory issues and struggles to find the right words. Similar problems have been reported in the only paediatric study performed so far (9) and in several adult studies (4, 5).

This study has several limitations to address. First, it is an online survey that was only shared through an online platform and not systematically proposed to consecutively diagnosed children within specific settings, therefore determining a selection bias. Also, this survey has been launched on the page of Long COVID Kids UK, which was created with the purpose to provide awareness and support to families with children with Long COVID. Therefore, parents of children with persisting symptoms may have had more interest in participating in this survey, and this can explain the large number of children with persisting symptoms in this cohort, when compared with other cohorts. Therefore, we were not able to define the incidence of Long COVID in children. Another limitation is that not all children received a microbiologically confirmed diagnosis. This is mainly due to unpreparedness of health systems (13) and difficulties in access to test, particularly during the first months of the pandemic, and because of different decision-rules practices in different settings. Also, the small number of children requiring hospitalization did not allow us to determine how initial severity affected long COVID in children. Last, the lack of a control group cannot allow us to determine a cause-effect link between COVID-19 and these symptoms.

In conclusion, we described a cluster of the most frequent symptoms and its dynamics in children with Long COVID in a large cohort of children. Symptoms like fatigue, headache, muscle and joint pain, rashes and heart palpitations, and mental health issues like lack of concentration and short memory problems, were particularly frequent and confirm previous observations, suggesting that they may characterize this condition. A better comprehension of Long COVID is urgently needed, considering that at the moment there are no therapeutic options for these children that, months after COVID-19, still struggle to come back to a normal life.

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Data availability statement: Dataset available upon reasonable request to the corresponding author.

Conflict of Interests: SM and FKS are co-founders of Long COVID Kids UK. While they developed the survey and were responsible to share the page online, they had no role in the data analysis, which was performed independently by DB and FEP.

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Appendix

Table A1. Pre-existing conditions before COVID-19 infection (multiple choices and free text allowed). Conditions found only in 1 Long-COVID child were grouped into Other

Precondition	Freq	%
Abdominal migraines	2	0.4%
ADHD/ADS	28	5.5%
Allergies	81	15.9%
Anxiety	38	7.5%
Asthma	74	14.5%
Autism	29	5.7%
Cerebral Palsy	2	0.4%
Coeliac	8	1.6%
Downs Syndrome	3	0.6%
Dyspraxia	6	1.2%
Eczema	63	12.4%
EDS	6	1.2%
Epilepsy	9	1.8%
Epstein Bar	6	1.2%
Gluten sensitivity	2	0.4%
Hayfever	2	0.4%
Headaches	36	7.1%
Heart disease	2	0.4%
Heart murmur	2	0.4%
HPV Virus	2	0.4%
HSV virus	2	0.4%
Hyper-mobility	51	10%
Hypertonia	5	1%
IBS	4	0.8%
Lyme Disease	3	0.6%
OCD/Depression/Anxiety	36	7.1%
Pandas	2	0.4%
POT's	6	1.2%
Sensory Processing Disorder	4	0.8%
Stomach pain	2	0.4%
TICS/Tourettes	3	0.6%
Urticaria	2	0.4%
Other	48	9.4%
None	223	43.7%

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Table A2. Symptoms present since COVID-19 infection (multiple choices allowed), by confirmation status of COVID-19 infection.

Symptom	All	Clinical Diagnosis	Positive Test	Unconfirmed but Suspected
Cardio-respiratory				
Heart palpitations	205 (40.2%)	71 (45.5%)	61 (42.1%)	73 (34.9%)
Coughing	151 (29.6%)	52 (33.3%)	43 (29.7%)	56 (26.8%)
Throat clearing	107 (21%)	30 (19.2%)	30 (20.7%)	47 (22.5%)
Dermatologic				
A rash	267 (52.4%)	83 (53.2%)	73 (50.3%)	111 (53.1%)
Red and cracked lips	201 (39.4%)	69 (44.2%)	53 (36.6%)	79 (37.8%)
Peeling skin on your hands and feet	143 (28%)	52 (33.3%)	37 (25.5%)	54 (25.8%)
Swollen hands and feet	107 (21%)	43 (27.6%)	24 (16.6%)	40 (19.1%)
Ulcers	79 (15.5%)	24 (15.4%)	17 (11.7%)	38 (18.2%)
Gastrointestinal				
Tummy pain or cramps	387 (75.9%)	124 (79.5%)	111 (76.6%)	152 (72.7%)
Nausea	233 (45.7%)	80 (51.3%)	67 (46.2%)	86 (41.1%)
Diarrhea and vomiting	216 (42.4%)	78 (50%)	67 (46.2%)	71 (34%)
HEENT (Head, ears, eyes, nose, throat)				
Red eyes	206 (40.4%)	74 (47.4%)	55 (37.9%)	77 (36.8%)
Sore throat	230 (45.1%)	80 (51.3%)	60 (41.4%)	90 (43.1%)
Swollen neck glands	128 (25.1%)	49 (31.4%)	36 (24.8%)	43 (20.6%)
Musculoskeletal				
Muscle aches and pains	349 (68.4%)	117 (75%)	102 (70.3%)	130 (62.2%)
Muscle and joint pain	309 (60.6%)	103 (66%)	92 (63.4%)	114 (54.5%)
Neurological				
Headache	401 (78.6%)	131 (84%)	116 (80%)	154 (73.7%)
Unexplained irritability	262 (51.4%)	90 (57.7%)	70 (48.3%)	102 (48.8%)
Dizzyness	245 (48%)	82 (52.6%)	77 (53.1%)	86 (41.1%)
Twitches	55 (10.8%)	17 (10.9%)	16 (11%)	22 (10.5%)
Word repetition	52 (10.2%)	20 (12.8%)	16 (11%)	16 (7.7%)
Tics	47 (9.2%)	18 (11.5%)	8 (5.5%)	21 (10%)

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Stuttering	40 (7.8%)	11 (7.1%)	10 (6.9%)	19 (9.1%)
Swearing	26 (5.1%)	11 (7.1%)	4 (2.8%)	11 (5.3%)
Growling	24 (4.7%)	9 (5.8%)	6 (4.1%)	9 (4.3%)
General				
Tiredness and weakness	444 (87.1%)	139 (89.1%)	131 (90.3%)	174 (83.3%)
Fatigue	410 (80.4%)	139 (89.1%)	116 (80%)	155 (74.2%)
Post-exertional malaise	274 (53.7%)	110 (70.5%)	71 (49%)	93 (44.5%)
Fever	151 (29.6%)	63 (40.4%)	45 (31%)	43 (20.6%)
Flu-like symptoms	121 (23.7%)	49 (31.4%)	37 (25.5%)	35 (16.7%)
Other				
Sepsis	7 (1.4%)	2 (1.3%)	1 (0.7%)	4 (1.9%)
Appendicitis	7 (1.4%)	2 (1.3%)	1 (0.7%)	4 (1.9%)
Peritonitis	1 (0.2%)	1 (0.6%)	0 (0%)	0 (0%)

Table A3. Changes reported since COVID infection, by confirmation status of COVID-19 infection, and by the pre-existence of comorbidity conditions

Changed since COVID	All	Clinical Diagnosis	Positive Test	Unconfirmed but Suspected	Had Pre-conditions	No Pre-conditions
Appetite	253 (49.6%)	93 (59.6%)	72 (49.7%)	88 (42.1%)	146 (50.9%)	107 (48%)
Behaviour	166 (32.5%)	46 (29.5%)	40 (27.6%)	80 (38.3%)	91 (31.7%)	75 (33.6%)
Cognitive function	197 (38.6%)	75 (48.1%)	56 (38.6%)	66 (31.6%)	126 (43.9%)	71 (31.8%)
Energy levels	425 (83.3%)	137 (87.8%)	127 (87.6%)	161 (77%)	241 (84%)	184 (82.5%)
Eye sight	110 (21.6%)	39 (25%)	25 (17.2%)	46 (22%)	63 (22%)	47 (21.1%)
Hearing	36 (7.1%)	15 (9.6%)	4 (2.8%)	17 (8.1%)	18 (6.3%)	18 (8.1%)
Mental health	188 (36.9%)	56 (35.9%)	60 (41.4%)	72 (34.4%)	115 (40.1%)	73 (32.7%)
Mobility	187 (36.7%)	70 (44.9%)	50 (34.5%)	67 (32.1%)	113 (39.4%)	74 (33.2%)
Mood	300 (58.8%)	89 (57.1%)	87 (60%)	124 (59.3%)	173 (60.3%)	127 (57%)
Skin	189 (37.1%)	64 (41%)	47 (32.4%)	78 (37.3%)	109 (38%)	80 (35.9%)
Sleep	287 (56.3%)	95 (60.9%)	91 (62.8%)	101 (48.3%)	164 (57.1%)	123 (55.2%)
Toilet habits	124 (24.3%)	45 (28.8%)	32 (22.1%)	47 (22.5%)	67 (23.3%)	57 (25.6%)

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Table A4. *Number of changes since COVID-19 infection, by confirmation status of infection, and by the pre-existence of comorbidity conditions*

Number of changes since COVID-19	All	Clinical Diagnosis	Positive Test	Unconfirmed but suspected	Had Pre-Conditions	No Pre-Conditions
1	63 (12.4%)	16 (10.3%)	15 (10.3%)	32 (15.3%)	31 (10.8%)	32 (14.3%)
2	59 (11.6%)	15 (9.6%)	17 (11.7%)	27 (12.9%)	31 (10.8%)	28 (12.6%)
3	63 (12.4%)	20 (12.8%)	17 (11.7%)	26 (12.4%)	38 (13.2%)	25 (11.2%)
4 or more	325 (63.7%)	105 (67.3%)	96 (66.2%)	124 (59.3%)	187 (65.2%)	138 (61.9%)

Table A5. Activity level before infection by Participation in Any level of activity in the first 6 weeks of COVID-19 infection

Activity before infection	Activity first 6 weeks			
	No	**Unsure**	**Yes**	**Total**
Daily Sports/Dance	44	4	96	144
Weekly Sports/Dance	77	10	92	179
Weekly Moderate Activity	76	13	71	160
Very Occasional Activity	13	4	1	18
Rare Activity	7	0	2	9

Table A6. *Child's current activity level by Activity level before infection*

Current Activity	Activity before infection					
	Daily Sports/Dance	**Weekly Sports/Dance**	**Weekly Moderate**	**Very Occasional**	**Rare Activity**	**Total**
Returned to previous	17	15	18	1	0	51
Level varies by day	38	59	58	6	4	165
Occasional, same symptoms	10	9	9	4	0	32
Occasional, worst symptoms	44	59	46	2	3	154
Unable to enjoy	35	37	29	5	2	108

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Table A7. Mental health / cognitive issues since COVID-19 infection (multiple issues per child are usual), by confirmation status of infection, and by the pre-existence of comorbidity conditions

Mental Health / Cognitive Issues	All	Clinical Diagnosis	Positive Test	Unconfirmed but Suspected	Had Pre-conditions	No Pre-conditions
Difficulty in doing everyday tasks	204 (40%)	79 (50.6%)	61 (42.1%)	64 (30.6%)	122 (42.5%)	82 (36.8%)
Difficulty processing information	167 (32.7%)	62 (39.7%)	49 (33.8%)	56 (26.8%)	110 (38.3%)	57 (25.6%)
Difficulty remembering information	234 (45.9%)	88 (56.4%)	66 (45.5%)	80 (38.3%)	140 (48.8%)	94 (42.2%)
Difficulty understanding instruction	147 (28.8%)	57 (36.5%)	35 (24.1%)	55 (26.3%)	86 (30%)	61 (27.4%)
Finds it difficult to make a decision	139 (27.3%)	46 (29.5%)	38 (26.2%)	55 (26.3%)	81 (28.2%)	58 (26%)
Finds it hard to work out what order to do things in	89 (17.5%)	30 (19.2%)	28 (19.3%)	31 (14.8%)	55 (19.2%)	34 (15.2%)
Forgets what they are saying	146 (28.6%)	54 (34.6%)	46 (31.7%)	46 (22%)	91 (31.7%)	55 (24.7%)
Hesitating before speaking or moving	102 (20%)	34 (21.8%)	32 (22.1%)	36 (17.2%)	58 (20.2%)	44 (19.7%)
Lack of concentration	309 (60.6%)	108 (69.2%)	89 (61.4%)	112 (53.6%)	180 (62.7%)	129 (57.8%)
Often has a vacant look	107 (21%)	31 (19.9%)	44 (30.3%)	32 (15.3%)	67 (23.3%)	40 (17.9%)
Short term memory issues	167 (32.7%)	66 (42.3%)	47 (32.4%)	54 (25.8%)	108 (37.6%)	59 (26.5%)
Struggles to choose appropriate clothes	54 (10.6%)	16 (10.3%)	16 (11%)	22 (10.5%)	31 (10.8%)	23 (10.3%)
Struggles to find the right words	162 (31.8%)	65 (41.7%)	41 (28.3%)	56 (26.8%)	95 (33.1%)	67 (30%)
Stuttering	40 (7.8%)	9 (5.8%)	14 (9.7%)	17 (8.1%)	19 (6.6%)	21 (9.4%)
Uses the wrong words for people or objects	73 (14.3%)	26 (16.7%)	21 (14.5%)	26 (12.4%)	45 (15.7%)	28 (12.6%)
None of the above	111 (21.8%)	24 (15.4%)	29 (20%)	58 (27.8%)	57 (19.9%)	54 (24.2%)
Other	53 (10.4%)	18 (11.5%)	11 (7.6%)	24 (11.5%)	33 (11.5%)	20 (9%)

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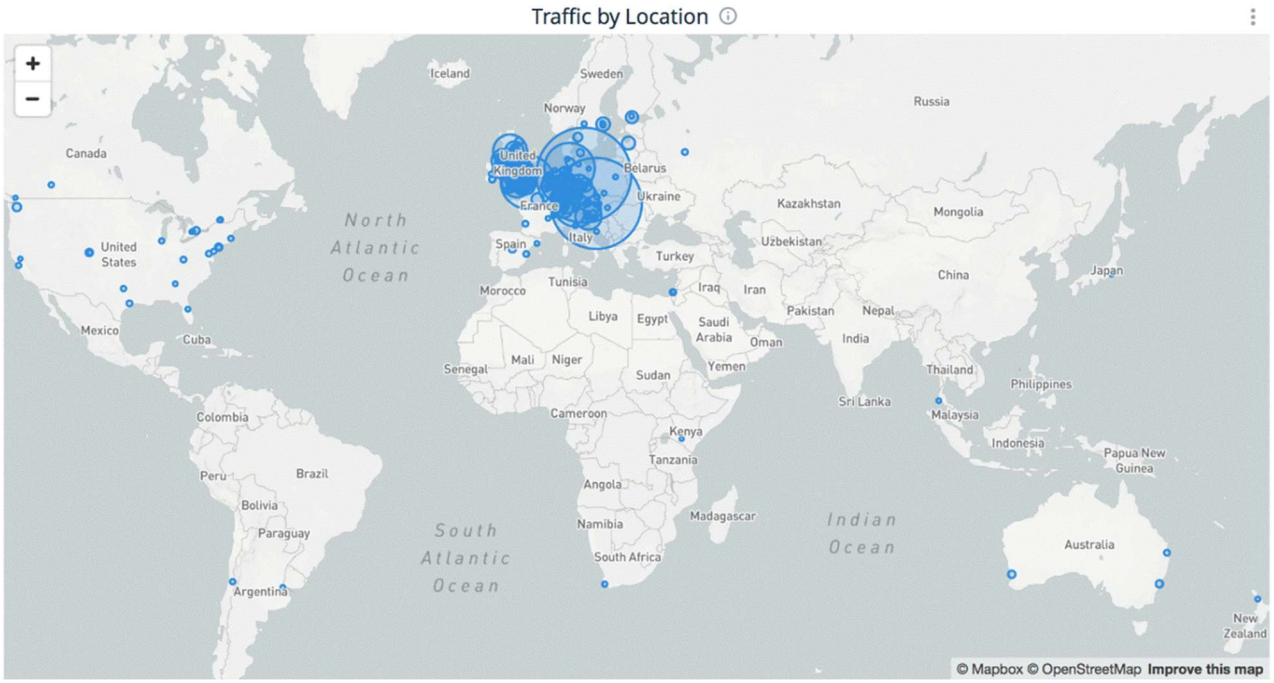
Table A8. Number of mental health / cognitive issues since COVID-19 infection (from those in Table 5, excluding "None of the above" and "Other"), by confirmation status of infection, and by the pre-existence of comorbidity conditions

Number of issues since COVID-19	All	Clinical Diagnosis	Positive Test	Unconfirmed but suspected	Had Pre-Conditions	No Pre-Conditions
0	132 (25.9%)	28 (17.9%)	32 (22.1%)	72 (34.4%)	68 (23.7%)	64 (28.7%)
1	54 (10.6%)	17 (10.9%)	18 (12.4%)	19 (9.1%)	29 (10.1%)	25 (11.2%)
2	45 (8.8%)	9 (5.8%)	12 (8.3%)	24 (11.5%)	18 (6.3%)	27 (12.1%)
3 or more	279 (54.7%)	102 (65.4%)	83 (57.2%)	94 (45%)	172 (59.9%)	107 (48%)



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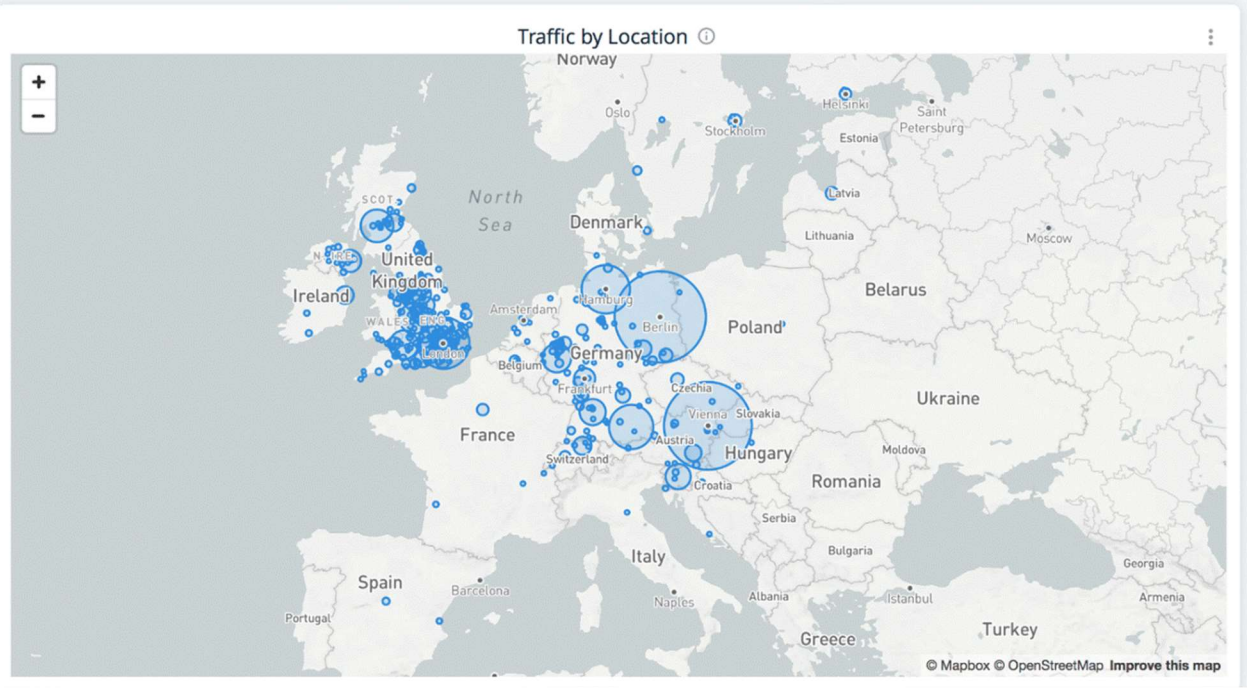

Appendix Figure A1. Social media traffic of the Long Covid Kids UK platform.