

Witness Name: LCG  
Statement No.: 1  
Exhibits: LC/1 -  
LC/141  
Dated: 28 November  
2023

## UK COVID-19 INQUIRY

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### WITNESS STATEMENT OF THE LONG COVID CORE PARTICIPANT GROUP

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We, the undersigned on behalf of the Long Covid Core Participant Group, will say as follows: -

#### INTRODUCTION

##### *Introduction to the Authors*

- 1.1. I, Sammie McFarland, am the Chief Executive Officer and co-founder of Long Covid Kids.
- 1.2. I, Dr Mark Faghy, am the co-vice chair of Long COVID Physio<sup>1</sup>.
- 1.3. I, Ondine Sherwood, am the co-founder of Long Covid SOS.
- 1.4. I, Natalie Rogers, am a founding trustee of Long Covid Support.

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<sup>1</sup> Dr Mark Fahy does not have Long Covid and provides this statement in his role on behalf of Long Covid Physio as the other board members are too unwell with Long Covid and/or are concerned about professional repercussions of providing oral evidence. The board has reviewed the statement and any member can speak to it.

- 1.5. Together we represent the Long Covid Core Participant Group (“LCG”). We make this composite statement in response to the Inquiry’s Request for Evidence under Rule 9 of the Inquiry Rules 2006 dated 19 April 2023.
- 1.6. We have provided a statement in accordance with the Inquiry’s request addressing the impact of Long Covid on patients and healthcare staff in the United Kingdom between 1 March 2020 and 28 June 2022 (“the relevant period”).
- 1.7. This statement is broken down as follows:
- Who we are: The Long Covid Core Participant Group
  - What is Long Covid
  - The impact of Long Covid on patients and healthcare staff, including:
    - The recognition of Long Covid
    - Treatment and rehabilitation provided to patients with Long Covid
    - Long Covid in children
    - Long Covid in healthcare settings
    - The effect of Long Covid on mental health
    - Research into Long Covid
    - Health inequalities
  - Suggested lessons to be learned and recommendations for future pandemics

**The Long Covid Core Participant Group**<sup>2</sup>

- 1.8. The LCG is comprised of the four above-named organisations. Together, our organisations represent tens of thousands of adults and children who are

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<sup>2</sup> All website and social media statistics in the following paragraphs correct as at 26 June 2023.

surviving victims of Covid-19 and who have suffered life-changing illness and/or disability following SARS-CoV-2 infection:

- 1.8.1. Long Covid Kids (“LCK”) was established in September 2020 by a group of families whose children became victims of Long Covid. LCK supports, represents and advocates for children and young people living with the ongoing symptoms of Covid-19/Long Covid. This includes the families/caregivers and education and health professionals working with them. LCK supports over 11,000 families and has 29,000 Twitter followers and almost 4,000 Instagram followers. In October 2021, LCK became the first registered charity advocating for families, children and young people living with Long Covid and related illness anywhere in the world.
- 1.8.2. Long COVID Physio (“LC Physio”) was formed in November 2020 to connect physiotherapists and allied healthcare professionals living with Long Covid through social media, provide free educational resources and advocate for safe rehabilitation. LC Physio has 25,400 Twitter followers, a website with more than 30,000 monthly page views, a peer support Facebook group with 488 members and an online video series watched more than 1 million times across all social media channels.
- 1.8.3. Long Covid SOS (“LC SOS”) was established in June 2020 as a volunteer-run patient advocacy and campaign group. LC SOS advocates for recognition, research and rehabilitation for people impacted by Long Covid. LC SOS has 26,000 Twitter followers; 12,100 Instagram followers and 6,468 individuals have signed up to the website. LC SOS became a registered charity in May 2022.
- 1.8.4. Long Covid Support (“LC Support”) began as a peer support Facebook group in May 2020, registering as a charitable company in May 2021. Membership of the Facebook group grew quickly and there are now 62,500 members globally. LC Support also has a following of 30,600 on Twitter and 13,700 on Instagram. LC Support provides support and information and campaigns for equitable access to high quality healthcare, employment and welfare rights and research into treatment for Long Covid.

- 1.9. The professional expertise of our volunteers spans all aspects of the health and education sectors, as well as occupational health and those involved in and leading Covid-19 and Long Covid research. We work closely with other organisations focused on specific employment sectors, such as Long Covid Nurses and Midwives.
- 1.10. Our organisations are mostly led by people with Long Covid or carers of those with Long Covid. We (Sammie McFarland, Natalie Rogers and Ondine Sherwood) have suffered long-term harm, chronic illness and, in some cases, disability from Covid-19. Most of us are not recovered when compared to our pre-infection health and continue to experience health impairment more than three years after infection. Our organisations were all formed in the first year of the pandemic and played a direct and significant role in the characterisation, identification, diagnosis and treatment of Long Covid.
- 1.11. We use the term “Long Covid” as an umbrella, patient-led term to encapsulate long-term illness caused by infection from Covid-19. We note that ‘Post Covid-19 Syndrome’ has been used by bodies such as the NHS to refer to the condition of Long Covid. We find this term inappropriate and harmful. The word ‘post’ implies that the Covid-19 illness is over, creating an artificial fracture between infection and what follows. Our experience of Long Covid is that for many people there is no clear delineation of symptoms between the acute phase and the period that follows; the initial illness has not resolved and Long Covid is not merely an after-effect of acute Covid-19. Similarly, use of the word ‘syndrome’ is suggestive of an illness of an uncertain aetiology rather than one rooted in infectious disease. We perceive this term as stigmatising and minimising. We urge that the patient-derived term Long Covid is used instead.
- 1.12. The LCG is a name used by the Covid-19 Inquiry to describe our organisations collectively. We provide here a brief summary of how the group came to be formed:

1.12.1. LC SOS instructed Ms Jane Ryan of Bhatt Murphy in May 2021, shortly after the Prime Minister's announcement of the establishment of the Inquiry on 12 May 2021. In June 2021, Bhatt Murphy wrote to the Prime Minister and Cabinet Office asking for confirmation of the process by which we would participate in the consultation on the Terms of Reference for the Inquiry.

1.12.2. LCK instructed Ms Ryan in September 2021 and wrote to the government on the same terms as LC SOS in respect of being consulted on the Terms of Reference.

1.12.3. In March and April 2022, LCK, LC SOS and LC Support participated in the consultation on the Terms of Reference.

1.12.4. In May 2022, LC Physio and LC Support instructed Ms Ryan.

1.12.5. The LCG was subsequently granted Core Participant status in Module 3 on 16 January 2023. LCK, LC SOS and LC Support were also granted CP status in Module 2.

1.13. Long Covid is a patient derived term; it was patient advocacy that was instrumental in the formal recognition of Long Covid as a clinical illness<sup>3</sup> as we explain further below. We annex with this statement at LC/1 - INQ000320227, LC/2 - INQ000320228 and LC/3 - INQ000320229 chronologies detailing all the advocacy to the government and the NHS by our organisations, and our collaboration with various bodies, but some of our key submissions are also included throughout this statement.

1.14. From our first-hand experience and the experience of our members, those who were suffering from Long Covid struggled for recognition; they struggled to access appropriate care, diagnosis, and treatment during the relevant period. Many people report that their physiological symptoms were routinely disbelieved and disregarded by health care professionals and instead, often

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<sup>3</sup> Perego and Callard, How and why patients made Long Covid, Social Science & Medicine Journal, published on 7 October 2020

attributed to a psychological cause. In our view, there was a damaging delay in the UK's healthcare system recognising and responding to Long Covid.

- 1.15. Our organisations were established to advocate on behalf of Long Covid sufferers for appropriate recognition by, and access to, healthcare systems across the United Kingdom. We did so by documenting the long-term harm and disability that people infected from Covid-19 continued to suffer and shared this information with decision-makers.
- 1.16. Through our advocacy and work supporting thousands of Long Covid sufferers, as well as our own personal experiences, we have identified a number of issues in relation to the impact of Long Covid on both patients and healthcare staff during the relevant period (although it should be noted that many of the issues are ongoing). We will set out the definition of Long Covid before making some general comments and then address specific points individually.

### **What is Long Covid?**

#### **Definition**

- 1.17. Long Covid in adults was formally defined by NICE in December 2020 as *“signs and symptoms that develop during or after an infection consistent with Covid-19, ... and are not explained by alternative diagnosis. It usually presents with clusters of symptoms, often overlapping which can fluctuate and change over time and can affect any system in the body”* [LC/4 – INQ000238545] Long Covid *“includes both ongoing symptomatic COVID-19 (from 4 to 12 weeks) and post-COVID-19 syndrome (12 weeks or more)”*.
- 1.18. The WHO designated emergency use ICD codes for *“post covid condition”* in September 2020 and developed an international clinical case definition for Long Covid in Adults via Delphi methodology in October 2021. A clinical case definition of Long Covid in children and adolescents was developed by WHO expert consensus and published on 16 February 2023 [LC/5 - INQ000320231].

## Symptoms

1.19. There are more than 200 known symptoms identified with Long Covid in adults, affecting every part of the body and notably the following systems. musculoskeletal, respiratory, neurocognitive, gastrointestinal, cardiovascular, and reproductive, as well as specific organs and tissues; ear, nose, throat, skin and hair. Mental health and wellbeing are also impacted.<sup>4</sup> Children are not little adults and have a different physiology to adults. The symptomology and nature of Long Covid in children is therefore distinct though it is now recognised in paediatric medicine that children and adolescents also present with a wide range of symptoms. These include chronic gastrointestinal symptoms, shortness of breath, behavioural changes and regression of developmental milestones.

1.20. Long Covid symptoms are often *“debilitating enough to leave patients unable to work and are overlap with those of Myalgic Encephalomyelitis/chronic fatigue syndrome, and those triggered after infections with poliovirus, and borrelia (Lyme Disease) which fall under the well-known concept of post-acute infection syndrome”*.<sup>5 6 7</sup> Organ damage (heart, liver, kidney, pancreas, lungs, spleen) has been found in 59% of Long Covid patients 12 months after initial diagnosis.<sup>8</sup> Other studies have identified neurological damage.<sup>9</sup>

## Recovery

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<sup>4</sup> Greenhalgh, Sivan, Delaney, Evans, Milne, *Long Covid – an update for primary care* BMJ 2022 (published 22 September 2022) *BMJ* 2022;378:e072117

<sup>5</sup> Walker S, Goodfellow H, Pookarnjanamorakot P, et al. 'Impact of fatigue as the primary determinant of functional limitations among patients with post-COVID-19 syndrome: a cross-sectional observational study'. *BMJ Open* 2023;13:e069217.

<sup>6</sup> The Lancet Regional Health – Europe (November 2022) 'Long COVID: An opportunity to focus on post-acute infection syndromes'. Volume 22, 100540

<sup>7</sup> Thomas C, Faghy MA, Owen R, et al. Lived experience of patients with Long COVID: a qualitative study in the UK *BMJ Open* 2023;13:e068481

<sup>8</sup> Multi-organ impairment and long COVID – a 1 year prospective longitudinal cohort study, *Journal of the Royal Society of Medicine*, 14 February 2023 Volume 116, Issue 3

<sup>9</sup> Douaud, G., Lee, S., Alfaro-Almagro, F. et al. SARS-CoV-2 is associated with changes in brain structure in UK Biobank. *Nature* 604, 697–707 (2022)

1.21. As with the range of reported symptoms, recovery rates for Long Covid sufferers vary widely. Symptoms tend to be relapsing and remitting, with some Long Covid sufferers unlikely to ever recover. The British Medical Journal (BMJ) reports that while some Long Covid sufferers may improve, many patients plateau in their recovery and their illness fluctuates with exacerbations triggered by physical, cognitive, emotional and mental stress.<sup>10</sup> The factors underlying lengths of recovery are not yet known so it is not possible to predict which patients will recover within weeks, and which will develop a long-term, or even life-long condition.<sup>11</sup> There is clear evidence of ongoing issues, including cardiovascular issues, resulting from Covid-19<sup>12</sup> but their precise longer-term ramifications are yet to be fully understood.

1.22. We also know that being reinfected with Covid-19 can worsen the symptoms of Long Covid and can even reverse recovery. A survey by LCK and LC Support [LC/6 - INQ000272233] assessed 484 adults and 112 children and adolescents. It found that, of those who still had Long Covid at the time of reinfection, 80% had a worsening of symptom severity. Of those who were in recovery or remission, reinfection caused a recurrence of Long Covid in 60%. Alarmingly, 46% of children and adolescents reported new additional symptoms on reinfection and 28% suffered a return of some old symptoms.

### Prevalence

1.23. Long Covid is an often-debilitating illness that has been found to occur in at least 10% of Covid-19 infections. It is estimated by ONS that 1.9 million people living in private households in the UK (2.9% of the population) were

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<sup>10</sup> Greenhalgh, Sivan, Delaney, Evans, Milne, Long Covid – an update for primary care BMJ 2022 (published 22 September 2022) BMJ 2022;378:e072117

<sup>11</sup> Ibid.

<sup>12</sup> Knight R, Walker V, Ip S, Cooper JA, Bolton T, Keene S, Denholm R, Akbari A, Abbasizanjani H, Torabi F, Omigie E, Hollings S, North TL, Toms R, Jiang X, Angelantonio ED, Denaxas S, Thygesen JH, Tomlinson C, Bray B, Smith CJ, Barber M, Khunti K, Davey Smith G, Chaturvedi N, Sudlow C, Whiteley WN, Wood AM, Sterne JAC; CVD-COVID-UK/COVID-IMPACT Consortium and the Longitudinal Health and Wellbeing COVID-19 National Core Study. Association of COVID-19 With Major Arterial and Venous Thrombotic Diseases: A Population-Wide Cohort Study of 48 Million Adults in England and Wales. *Circulation*. 2022 Sep 20;146(12):892-906.

experiencing Long Covid as of 5 March 2023.<sup>13</sup> The ONS March 2023 data set estimated 62,000 children aged 2-16 years old had Long Covid of any duration and 52,000 had Long Covid for at least 12 months [INQ000272181]. This is a substantial number of children and adults whose lives have been, and continue to be, directly harmed by Covid-19.

- 1.24. Many previously fit and healthy individuals have suffered profound changes to their lives as they experience the continuing effects of the disease.<sup>14</sup>

## **THE IMPACT OF LONG COVID ON PATIENTS AND HEALTHCARE STAFF**

### **2. The impact of Long Covid on the health and wellbeing of members of the LCGs**

- 2.1. Our personal experience, and that of the thousands of people who we represent and support, is that the healthcare systems in the United Kingdom did not pay anything like sufficient attention to the long-term health consequences of Covid-19. Healthcare professionals were unprepared for the possibility that large numbers of individuals might not recover within the initially prescribed two-week period and, as a result initially dismissed and disbelieved patients presenting with Long Covid. As a result, the recognition of, response to and treatment of those who did not recover from Covid-19 was inadequate.
- 2.2. We exhibit to this witness statement at LC/7A - INQ000356270 to LC/7D - INQ000356273 case studies of people suffering from Long Covid. These are case study summaries from our members and are provided to illustrate the range of problems people with Long Covid experience from severity of their symptoms to gaining access to adequate care and treatment. Below are examples extracted from the exhibited case studies:

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<sup>13</sup> Office for National Statistics (ONS), released 30 March 2023, ONS website, statistical bulletin, Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 30 March 2023

<sup>14</sup> Owen, R., Ashton, R.E., Skipper, L. et al. Long COVID quality of life and healthcare experiences in the UK: a mixed method online survey. Qual Life Res (2023).

- Case Study 5 [LC/7B - INQ000356271], a child, 15 years old who caught Covid in April 2020 and has been re-infected. She has experienced prolonged and distressing symptoms including *“severe headaches, body burning, itchiness, rashes, high fever, struggling to breathe, chest pains, eye pain, styes, muscle aches and pains, light sensitivity, skin disorders and extreme fatigue”*. She was admitted to hospital and paediatricians could not work out what was wrong with her. She was eventually referred to a Long Covid clinic. Her GP had no experience of Long Covid in children. The possibility of Long Covid was discussed with a doctor but he did not have any knowledge of a Long Covid clinic for children. She should be starting year 11 but has been stopped due to severe Post Exertional Malaise (PEM). She is 2 years behind her in education.
- Case Study 1 [LC/7C - INQ000356272] an adult, states: *“I was a Covid frontline Nurse in the first wave and at that point I went down with Covid “Long Covid” had not been mooted as a thing. As a result my ongoing symptoms were often met with scepticism and a degree of gaslighting.”* She states *“rehab and gaining access to services has been a real battle – I say that as a senior Nurse with many years’ experience of the system. LC patients have had to be their own advocates – at a time when many like me have been just struggling to survive and get through each day.”*
- Case Study 2 [LC/7A - INQ000356270] an adult states *“Most likely initially infected through work, although this is not confirmed due to no testing outside of hospital[...] As time has gone on some healthcare professionals know and understand more but others are still very dismissive and can’t understand symptoms they can’t see. On one A&E visit my stats were 90% and I was told ‘ahh but you had Covid so that’s fine’.”*
- Case Study 4 [LC/7D – INQ000356273], an adult states: *“My initial symptoms were ear pain, fever and fatigue. PCR testing wasn’t available to*

*the general public at that time so I did not have a confirmed diagnosis of Covid-19. I self-isolated in my flat by myself for 10 weeks ... During this time I was in contact with numerous doctors. As I did not have a positive test and I did not present with a cough, they were of the opinion that I did not have Covid. I was diagnosed with anxiety and depression and prescribed anti-depressants”.*

- Case Study 4 [LC/7C - INQ000356272] an adult states: *“Long Covid still dictates my life. I get post-exertional symptom exacerbation and fatigue, have difficulty in pretty much everything I do including work, and I can definitely do less around the house than I could in 2020 or 2021. I definitely feel like I am deteriorating and hugely exhausted from trying to keep going at work. I don’t think I could change jobs because no-one would employ me.”*
- Case Study 3 [LC/7C - INQ000356272], an adult states: *“I am still ill 3.5 years later. I was bed bound for the first 4-6 months and severely ill for the first year. I couldn’t walk any distance at all for 18 months and I am still not back to pre-Covid walking levels.”*

### **3. Recognition and diagnosis of Long Covid as a condition**

- 3.1. Many of our members contracted Covid-19 early on in the pandemic. We found ourselves not recovering and not understanding why, when all of the public health messaging at the time was that Covid-19 was a short and mild illness for those who were not clinically vulnerable.
- 3.2. Our organisations were all formed as a result of individuals developing Long Covid in the absence of any public information and reaching out to find support and acknowledgement from fellow sufferers:
  - 3.2.1. On 2 May 2020, the LC Support Facebook group was set up to share information and to provide support for people struggling to recover from

Covid-19. Members, who met online, began to advocate through the group for research, rehabilitation and recognition of the condition.

3.2.2. LC SOS was formed in June 2020 by a group of survivors of Covid-19 who had not recovered. The founders met in a support group for people who had not recovered from Covid-19 (Body Politic Covid-19 Support Group). It was clear from the posts in this group that there were large numbers of people worldwide, previously healthy, who were suffering ongoing symptoms after a Covid-19 infection and getting very little help. The founders of LC SOS felt strongly that something needed to be done to draw attention to the many thousand affected individuals in the UK who were unable to get care.

3.2.3. LCK was formed as a result of parents reaching out to each other on social media from pockets of isolation in August 2020. In October 2020, a Facebook group was created. The number of members exploded with large numbers of families joining daily for many months.

3.2.4. LC Physio was formed in November 2020 by a group of physiotherapists living with Long Covid who met on social media, sharing personal experience. A Facebook group was created to provide a safe place for peer support which soon evolved into a global organisation.

3.3. Long Covid sufferers experienced a significant delay in the UK's healthcare sector recognising and responding to Long Covid. During the early months of the pandemic, the majority of people contacting NHS 111 were advised to stay at home<sup>15</sup> and/or were turned away from A&E. This meant they were left to deal with symptoms at home, even serious ones which would have been red flags in pre-pandemic circumstances (for example chest pain, heart palpitations, low oxygen saturation, extreme shortness of breath). Several of these people went on to develop more severe Long Covid and were not able to access the same care as those who were hospitalised. For example, Natalie Rogers' of Long

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<sup>15</sup> *The USA and UK symptom checkers triaged 38% and 44% of cases to healthcare contact, respectively. Both the US and UK symptom checkers consistently failed to identify severe COVID-19, bacterial pneumonia and sepsis, triaging such cases to stay home.* Mansab F, Bhatti S, Goyal D Performance of national COVID-19 'symptom checkers': a comparative case simulation study. *BMJ Health & Care Informatics* 2021;28:e100187

Covid Support witness statement dated 25 September 2023 [INQ000280197] describes her experience at paragraph 102 of being hypercapnic during her acute illness in March 2020 and that she understands she would have been treated in hospital under non-pandemic protocols. Another example is a board member for Long Covid Physio at Case Study 3 of LC/7A – INQ000356270, who believes she contracted Covid-19 in a private hospital where she was working in April 2020, who suffered desaturation of below 93 with severe shortness of breath and chest pain but was still advised to stay home. She was told to remain at home until she was unable to talk. She has been disabled by Long Covid suffering myocarditis and other issues. Case Study 3 of LC/7C – INQ000356272 describes spending 9 weeks isolating at home with fevers and deteriorating health before NHS111 put them in contact with a Covid Hub. Case Study 1 of LC/7D - INQ000356273 describes being told their symptoms were "all in my head" at A&E. Case Study 4 of LC/7D - INQ000356273 describes self-isolating for 10 weeks and contacting doctors who did not believe they had Covid due to the lack of a positive test. These experiences are familiar and common for our members and supporters. They, along with others in the community with acute illness not considered to warrant hospitalisation, found it extremely difficult to receive care. They were often not believed to have had Covid-19 because of the inaccurate pervasive view that those who were not hospitalised, would recover in two weeks. This dismissive approach by healthcare workers was exacerbated by the Government's decision to restrict access to community testing for Covid-19 on 12 March 2020 [LC/8 – INQ000320233]. This meant that a large number of people who developed Long Covid had no access to testing in the community and had no positive test result on their records to link their symptoms to infection with Covid 19. The lack of community testing created obstacles for people seeking care from the healthcare system.

- 3.4. Our organisations received many reports of patients' physiological symptoms being disbelieved and minimised by healthcare providers.

- 3.5. A survey conducted by LC SOS in September 2020, exhibited at LC/9 - INQ000320234, highlights the difficulties encountered by adult patients when contacting their GPs reporting symptoms of Long Covid, including:
- 3.5.1. 33.3% of respondents stated that their GP was willing to accept that long-term symptoms were a feature of Covid-19 but was unaware of any steps that could be taken to alleviate them
  - 3.5.2. 22.0% of respondents were told by their GP that they had post-viral fatigue
  - 3.5.3. 10.7% of respondents reported their GP suggested they may be suffering from anxiety due to having had Covid-19 or experiencing lockdown
  - 3.5.4. 3.2% of respondents stated that their GP told them Covid-19 only lasts two weeks and so it must be some other virus or illness that was causing their symptoms
  - 3.5.5. More than two thirds of GPs (69.7%) did not follow up this initial contact by phone or other means
  - 3.5.6. 37.0% of respondents reported that their GP did not discuss referral to any specialist services
  - 3.5.7. Respondents also provided comments, some of which are extracted here:
    - *“I had one GP tell me I should seek counselling, another that post Covid doesn’t exist, a couple that were sympathetic but not offering anything else, finally I spoke to one end of July that believes in post Covid and referred me.”*
    - *“I had different responses from different GP’s. The majority dismissed my symptoms as mere anxiety. Eventually a Locum GP & then one of the practice GPs diagnosed long Covid. I was then referred to a respiratory Consultant.”*
    - *“One GP suggested anxiety and said that symptoms varying in intensity (i.e. peaks and troughs) meant it couldn’t be viral and told me off for requesting a chest x-ray after symptoms persisted for*

*two months. A second GP believed me and sought a cardiology referral.”*

- *“Absolutely horrendous, they refused to admit it was covid, then didn't know how to treat it, then refused to treat it, then blamed in on anxiety (it definitely wasn't), then accepted there were physical symptoms, still didn't know how to treat it. Were so reluctant to make referrals. Referrals took 6 months to come through. I'm still waiting. The whole process has been a total nightmare.”*
- *“At first it was suggested I had anxiety. When I was positive for antibodies their attitude changed considerably and I felt like i was taken seriously. One of the GPs admitted however that they only really have the resources to deal with each symptom rather than treat the illness as a whole.”*

3.6. Our organisations also received reports of unwell patients being 'met with shrugs' in A&E, unable and unwilling to investigate their health concerns any further. A frequent problem documented by our organisations is of people who presented with abnormally high heart rates of over 100 bpm and persistent fevers greater than 38°C being dismissed and being told it would 'settle' rather than being investigated further.

3.7. For example, LC Support conducted a survey of Patient Experience of Assessment Services between 5 January 2021 and 19 April 2021 [LC/10 - INQ000272247] which showed that 75% of responses up to 2 February 2021 were refused an onward referral to the Long Covid Service by GPs, and that this changed to 48% by April 2021. Among 373 respondents, key issues mentioned were that GPs were not aware of a clinic or service or lacked information about referral pathways, first wave patients were refused because they had not had Covid-19 recently enough or until they had been sick for 12 weeks or more. Extracts from the survey include:

- *“Next appt with Respiratory Team. After being taken by the paramedics to A&E in August 2020 the GP was advised by the hospital to organise a 24*

hour heart monitor. Despite chasing this, it still hasn't happened and we are in January 2021. Symptoms worsened during this time and it was only after requesting this yet again, that there was an admission that they had dropped the ball. Requested to be sent to Imperial and I finally got to have a 9 minute telephone appointment with a cardiologist. Still awaiting next tests!"

- *"It has been 4 and half weeks now and so far I have had no contact. I understand that the NHS must treat those whose lives are at risk first but I was hoping for investigations into heart rate and breathing when exercising. I was hoping for investigation into the headaches other than don't do anything during the day because activity triggers them. I was hoping to be referred for scans of my heart, lungs and brain if the initial investigations warranted it."*
- *"I requested referral to UCLH long covid clinic in October. I sent my then-GP's practice the referral criteria. I had at that point, already had a chest X-ray taken 6 weeks after positive test result. It showed significant fibrosis and read of ground glass opacity. GP said this would "clear up". My then-GP said I was not ill, despite fatigue, difficulty breathing, loss of feeling in fingers and toes etc. Rather, he said, I had anxiety and depression. I pressed for a referral to UCLH and asked for an appointment for a stand-sit test. My then-GP claimed no such examination existed and refused to help. I switched practices and am now going through referral process, 6 months after contracting covid. As a result of my initial experiences with old GP practice I am worried that I will not be believed, and do not deserve help because I am a "depressed and anxious" middle aged woman."*
- *"I get the impression my GP doesn't think my referral is important in the grand scheme of everything else going on. I am made to feel like a time waster for asking to see multiple specialists for my multi system issues, even though as a previously healthy 40 yr old I now faint every day, have chronic fatigue, breathing difficulties, and rashes all over my body. I am on the verge of giving up my career as a scientist because my symptoms seem to be getting worse not better 10 months on."*

- *“I continue to have so called brain fog which is more like a cognitive impairment. This has only happened since I had the COVID symptoms in March 2020. I am unwilling to go back to the Doctor because I feel I will either be told “It’s in your head/ it’s anxiety/ it’s stress”, none of which is true, or I will be told as I was last time ‘Learn to live with it.’”*
- 3.8. Other Long Covid sufferers reported in the survey that they were given alternative, incorrect diagnoses such as Functional Neurological Disorder, anxiety, fibromyalgia, or ME/CFS when there was a clear onset of symptoms following a Covid-19 infection.
- 3.9. Disbelief from healthcare providers was compounded by the fact that most standard tests, e.g. X-rays and ECGs, were generally unable to identify any abnormalities and determine a reason for presenting symptoms.<sup>16</sup> As noted above, patients were therefore often dismissed and sent home with a cursory diagnosis of anxiety or depression. Several of these individuals have reported going through this process only to be diagnosed with myocarditis, pulmonary embolism and micro clots in their lungs much later which may have been detectable earlier had they been referred for specialist diagnostics.
- 3.10. Patient advocacy led to medical and scientific advisors beginning to recognise the long-term effects of Covid-19 in the early summer of 2020:
- 3.10.1. On 5 April 2020, Elaine Maxwell, (subsequently a member of LC Support) who worked for NIHR, spoke to Irrelevant & Sensitive General Manager of the NIHR Office for Clinical Research Infrastructure about the importance of post-covid sequelae.
- 3.10.2. On 7 May 2020, at its 34th meeting [LC/11 - INQ000120513] SAGE noted:

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<sup>16</sup> *“On the basis of the tests that are offered as standard care, the results for patients with long COVID are often normal; many providers are unaware of the symptom-specific testing and diagnostic recommendations from the ME/CFS community.”* Davis, H.E., McCorkell, L., Vogel, J.M. et al. Long COVID: major findings, mechanisms and recommendations. *Nat Rev Microbiol* 21, 133–146 (2023)

*“some rare symptoms or complications which are emerging including cerebrovascular events, renal disease and systemic endothelial and organ dysfunction. SAGE also noted the existence of longer-term health sequelae (such as persistence of extreme tiredness and shortness of breath for several months) and the importance of monitoring these impacts through longer term-health cohort studies (as agreed previously and being taken forward by funders).”*

3.10.3. On 15 May 2020, at its first bird table meeting [LC/12 - INQ000120143] NERVTAG discussed *“ongoing clinical issues post-COVID and the potential need for a clinical forum”*.

3.10.4. On 5 July 2020 the NHS announced Your Covid Recovery Platform

3.10.5. On 14 July 2020 the Academy of Medical Science published a report *“Preparing for a Challenging Winter”* [INQ000203604] (which was endorsed by SAGE) which stated that the NHS will need to provide ongoing care for those who have had COVID-19 infection and who are suffering from post-viral sequelae.

3.10.6. On 23 July 2020, at its 48th meeting [LC/13 - INQ000119954] SAGE referred to the longer term effects of Covid-19.

3.10.7. On 21 August 2020 the WHO convened a meeting about Long Covid. [INQ000238544]

3.11. Before Summer 2020, it would appear that healthcare professionals were unprepared for the possibility that large numbers of patients – including those who were not hospitalised or in ICU – would not recover within two weeks. The healthcare system was not ready for the possibility of long-term morbidity. This delayed the healthcare sector’s recognition and understanding of Long Covid, despite early recognition of the long-term sequelae of Covid-19 amongst scientific advisors.

3.12. It unfortunately took a very long time, and only after persistent advocacy, for healthcare professionals to accept that patients could have persistent symptoms of Covid-19 or develop and suffer from consequences afterwards.

We would note that post-acute sequelae and long term morbidity from viruses was well known and established (see for example Chief Medical Officer Chris Whitty note on Long Covid to the Prime Minister dated 31 May 2021 [INQ000073417]; Brightling and Evans expert report Module 2 Long Covid paragraph 7.1-7.5 [INQ000280198]) but the experience of our organisation's members and supporters was that those suffering prolonged symptoms were often disbelieved.

- 3.13. By July 2020, the long-term health consequences of Covid-19 were formally recognised as a Category A direct health impact [LC/14 - INQ000220213] and in December 2020, the UK Government departments specifically recognised Long Covid as a Category A direct health impact [LC/15 - INQ000074959], noting:

*“There are likely to be health impacts for those surviving COVID-19, particularly for those who are admitted to hospital and spend time in critical care. This may include cognitive, mental and physical health impairments”.*

- 3.14. However, any mention of the risk and likely prevalence of long-term sequelae continued to be absent from government advice and public health messaging.

- 3.15. We consider that the contributing factors to people accessing healthcare for prolonged Covid-19 were:

3.15.1. The failure to update the list of symptoms associated with Covid-19 until April 2022 [LC/16 – INQ000320241] despite developing evidence that the official guidance was out of date.<sup>17</sup> This failure to recognise the wide range of symptoms caused by Covid-19 adversely affected people accessing treatment and care as they were not believed to have Covid-19 if they did not have one of the three officially recognised symptoms. This in turn made it even more difficult to convince medical professionals that the

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<sup>17</sup> Mahase E. Covid-19: GPs urge government to clear up confusion over symptoms BMJ 2021; 373 :n1654

long-term symptoms people were suffering were as a result of a SARS-CoV-2 infection.

3.15.2. There was an over-reliance on the twin metrics of deaths and hospitalisations throughout the pandemic and these formed the basis for public health and government messaging. As a result, most of the population – unless personally affected – could not have been aware that a Covid-19 infection could lead to long-term illness.

3.16. It was left to advocacy groups such as ours to raise awareness, via social media, the press and broadcast media, to seek recognition by policy makers, in the healthcare sector and amongst the general public. For example:

3.16.1. On 18 May 2020, two founding members of LC Support started a placard campaign on **I&S** listing symptoms and the number of days of being ill.

3.16.2. On 8 July 2020, LC SOS shared a film we created called “*Message in a Bottle*” [LC/17 - INQ000272234] highlighting the stories of more than 100 people, most of whom had been unwell for around 3 months. This was part of a campaign in conjunction with an open letter sent to the then Prime Minister Boris Johnson and members of government (see below).

3.16.3. Following this campaign, LC SOS were contacted by Maria Van Kerkhove (Covid-19 Technical Lead at the World Health Organisation) and invited to convene a meeting about Long Covid. The meeting took place on 21 August 2020 and was attended by WHO members including Director General Tedros Adhanom Ghebreyesus.

3.16.4. Subsequently, several meetings took place between LC SOS and WHO to inform them of the development of clinical guidelines for Long Covid.

3.16.5. Over the Summer of 2020, members of LC SOS and LC Support featured in news articles, television and radio, thereby raising awareness of Long Covid.

3.17. Before any formal recognition of Long Covid, we wrote to and met with key members of Government. For example:

- 3.17.1. On 16 June 2020, Natalie Bennett MP tabled a written question about Long Covid in the UK House of Commons [LC/18 - INQ000320243].
- 3.17.2. The next day, on 17 June 2020, Steve McCabe MP tabled a written question about Long Covid in the House of Commons in response to a letter written to him by a constituent, who was also a founding member of LC Support [LC/19 - INQ000320244]. She wrote that she was suffering diverse and alarming prolonged symptoms, that she had been admitted to A&E four times and raised concerns about the public “unwittingly transmitting” the virus as the WHO listed more than a dozen symptoms of Covid-19. He asked the Secretary of State for Health and Social Care whether he planned to commission research into the long-term effects of Covid-19 on people whose symptoms last longer than three weeks [LC/20 – INQ000320245].
- 3.17.3. On 17 June 2020, LC Support members met with Shadow Public Health minister Alex Norris.
- 3.17.4. On 3 July 2020, LC SOS sent a letter to then Prime Minister, copied to all sitting members of Parliament and Chief Medical Officer Professor Chris Whitty and UK Government Chief Scientific Advisor Patrick Vallance [LC/21 – INQ000238582]. The letter was on behalf of the “*thousands of forgotten victims of Covid-19 who have been sick since the early days of the outbreak.*” It raised concerns that the government and public health sources had assured the public that most “*mild or moderate cases not requiring hospital admission resolve within two weeks.*” It referred to the COVID Symptom Study suggesting 1 in 10 people were sick for three weeks or more and that there was a “*pattern of illness experienced by many which is completely at odds with the prevailing view about this virus.*” It referred to many people suffering an array of debilitating symptoms which can be “*severe and frightening*”. It stated that “*a shocking lack of attention had been paid to this group of people of all ages*”. It requested the establishment of a working group, commissioning of urgent research, development of protocols and care pathways, multi-disciplinary clinics and economic support.

- 3.17.5. On 5 August 2020, LC Support gave evidence to the APPG on Coronavirus. The report published in December 2020 concluded that the UK Government had not yet formally recognised Long Covid; there were insufficient guidelines for employers and GPs on recognising and managing Long Covid and the UK government was not counting those with long lasting effects of Covid-19 as a measure of severity and impact of the pandemic. The report made recommendations to the UK Government on all three areas.
- 3.17.6. On 6 August 2020, LC Support members met with Greater Manchester Mayor Andy Burnham.
- 3.17.7. On 28 August 2020, LC Support and partners sent a letter to Jeremy Hunt, Chair of the Health & Social Care Committee which was forwarded to Matt Hancock, Secretary of State for Health and Social Care [LC/22 – INQ000248911]. It raised concerns that many of its members had been front line workers and that there was inadequate support and awareness. It said that *“too many of our UK members are reporting experiences of extremely poor, uninformed and dismissive responses from professionals in health and care sectors when we turn to them for help.”* It raised concerns about the disproportionate impact of long covid on socially and economically marginalised communities. It called for improving professional education, research, health services and better public health messaging.
- 3.17.8. On 11 September 2020, LC SOS met with Professor Stephen Powis, Medical Director of NHS England and his team. This was the start of a regular and ongoing dialogue about providing better care for people with Long Covid. It was a critically important meeting because up until that point there had been little public acknowledgement from the NHS about Long Covid and directly led to the launch of the NHSE five-part package of measures to boost NHS support for Long Covid patients in October 2020.

3.18. Advocacy from our organisations began in May 2020 about long term morbidity in the community, but it was not until 7 September 2020 that the first official government guidance was published by Public Health England: “COVID-19: long-term health effects” [LC/23 – INQ000272238]. There had been a previous NHS guidance dealing solely with recovering from Covid-19 in discharged patients on 5 June 2020 [INQ000292619].

3.19. The PHE guidance was brief, including a list of the persistent issues being reported, links to research including the PHOSP-COVID study and advice for sufferers to consult with their GP. The final paragraph of the guidance stated the following:

*“The NHS has produced guidance for primary care and community health services to meet the immediate and longer-term care needs of patients discharged following an acute episode of COVID-19.”*

As such the guidance again incorrectly suggested that Long Covid only occurs in individuals who have been hospitalised with severe Covid-19. This highlights the blind spot from within the government and healthcare profession in recognising the prevalence and potential impact of Long Covid in the community which our advocacy had sought to raise awareness about.

3.20. The WHO Emergency Use International Classification of Diseases (ICD) codes were designated for Long Covid/post-Covid conditions from September 2020. The WHO stated:

*“A set of additional codes upon request by member states were activated to be able to document or flag conditions that occur in the context of COVID-19. In particular the need for disambiguation between acute disease, late effects or lengthy course led to the neutral formulation “post-covid”. This term does not pre-empt any etiopathological links, and leaves space for linking any condition to a preceding acute COVID.*

- *Personal history of COVID-19*
- *Post COVID-19 condition*
- *Multisystem inflammatory syndrome associated with COVID-19*

3.21. It was then not until 5 October 2020 that NICE announced they would be working to “*develop a guideline on persistent effects of Covid-19 (Long Covid) on patients*” and expected it to be published by the end of 2020 [LC/24 - INQ000320249].

3.22. All our organisations were involved in the consultation process for the NICE guidelines. We raised several concerns about and during the consultation process, namely:

3.22.1. There was insufficient guidance on the range of physical symptoms which could lead to problems of diagnosis, coding, referral and treatment.

3.22.2. The use of arbitrary phases (“*ongoing symptomatic COVID-19 from 4 to 12 weeks and post-COVID-19 syndrome – 12 weeks or more*”) could create a risk of damaging patient care by creating barriers to services and investigations.

3.22.3. The online system for participating was convoluted and challenging for Long Covid sufferers and the turnaround time was unrealistically short for the volume of material being considered.

3.22.4. The guidelines used the nomenclature of ‘Post Covid-19 Syndrome’ which, as we have highlighted above, is extremely unhelpful and inappropriate.

3.23. On 18 December 2020, NICE issued the “*Covid rapid guideline: managing the long-term effects of COVID-19*” [LC/25 - INQ000283459], which contained the UK’s first clinical case definition for Long Covid:

***Ongoing symptomatic COVID-19***

*Signs and symptoms of COVID-19 from 4 weeks up to 12 weeks.*

### **Post-COVID-19 syndrome**

*Signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis. It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body. Post-COVID-19 syndrome may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed.*

### **Long COVID**

*In addition to the clinical case definitions, the term 'long COVID' is commonly used to describe signs and symptoms that continue or develop after acute COVID-19. It includes both ongoing symptomatic COVID-19 (from 4 to 12 weeks) and post-COVID-19 syndrome (12 weeks or more).*

The guidelines stated:

*"These recommendations are for healthcare professionals caring for people who have had suspected or confirmed acute COVID-19 and present to any healthcare setting, irrespective of whether they were hospitalised or had a positive or negative SARS-CoV-2 test (PCR, antigen or antibody). Be aware that both children and adults can be affected by ongoing symptomatic COVID-19."*

- 3.24. There were no guidelines issues for Long Covid in Children at this time.
- 3.25. In an article for The Lancet on 18 December 2020 [LC/26 - INQ000320251], members of LC Support raised concerns about the shortcomings of the NICE guidelines, including the following:
  - 3.25.1. It did not cover the full range and severity of symptoms as noted by patients.
  - 3.25.2. It did not acknowledge the relapsing remitting nature of the disease, which may lead to premature dismissal of patients from healthcare services.

- 3.25.3. There was an over-focus on self-management, psychological support, and rehabilitation that included exercise approaches, resulting in the potential for “watered-down” versions of NHS Long Covid services that do not provide thorough physical assessment of patients.
- 3.25.4. The guidelines did not sufficiently describe what was known about the underlying pathology and natural history of Long Covid. There was no mention of the three proposed mechanistic theories – persistent virus in immune-privileged sites, aberrant immune response, or autoimmunity. We refer to paragraph 3.4 – 3.6 of Professor Brightling and Dr Evans’ report dated 26 September 2023 [INQ000280198]. Paragraph 3.6 states *“In Long Covid, ongoing systemic (affecting the whole body) inflammation, autoimmune disease (the immune system attacking healthy tissue), micro clotting, endothelial (lining of blood vessels) dysfunction, dysautonomia (disruption of the autonomic nervous system leading to conditions such as Postural tachycardia syndrome {POTS}, viral persistence of SARS-CoV-2 or reactivation of other viruses such as Epstein-Barr virus leading to persistent immune activation have been proposed as underlying mechanisms.”* These mechanisms have been observed since 2020.<sup>18</sup>
- 3.25.5. The use of arbitrary phases (ongoing symptomatic COVID-19 from 4 to 12 weeks and post-COVID-19 syndrome – 12 weeks or more) with the risk of damaging patient care by creating barriers to services and investigations.
- 3.25.6. A more thorough participative and open process was needed to consider and determine appropriate terminology for Long Covid.
- 3.26. The LCGs continued to advocate for better information and recognition of Long Covid. For example:
- 3.26.1. LC SOS and LC Support participated in the Long Covid Ministerial Roundtables chaired by Lord Bethell on 13 October 2020 and 16 November 2020

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<sup>18</sup> British Society of Immunology, Long-term immunological health consequences of Covid-19, Aug 13, 2020

- 3.26.2. After LC SOS met with Professor Stephen Powis, Medical Director of NHS England on 11 September 2020, there were further meetings with Cathy Hassell, NHS England Director of Clinical Policy and Nikki Kanani, NHSE Medical Director for Primary Care on 25 September 2020. LC SOS continued to meet with NHS London Clinical Reference Group between October to December 2020
- 3.26.3. In December 2020, LC Support organised the Long Covid Forum in collaboration with the International Severe and Acute Respiratory Emerging Infection consortium and GloPIDR (global research collaboration for infectious disease preparedness) which was opened by the WHO Director General.
- 3.26.4. LCK, LC SOS and LC Support participated in NHS Long Covid Taskforce meetings (see paragraph 4.6 below)
- 3.26.5. In January 2021, LC Kids and LC Support gave evidence to the APPG on Coronavirus report on Long Covid [LC/27 – INQ000320252], [LC/28 – INQ000272149]. The APPG on Coronavirus published their report on Long Covid in March 2022, making a series of recommendations including a legal definition of Long Covid classifying it as a disability, care pathways for adults and children, and compensation schemes for key workers with Long Covid.
- 3.27. Although there were some positive strides in the acknowledgement and existence of Long Covid, public health messaging continued to omit references to long-term morbidity/Long Covid. For example, the Covid-19 dashboard continued to refer only to hospitalisations and deaths, even after the ONS started regularly publishing statistics on Long Covid from April 2021 and the regular government TV briefings rarely even mentioned Long Covid.
- 3.28. As far as we are aware, there was only one video and press release [LC/29 - INQ000272221] by the DHSC about Long Covid, in October 2020. It stated: *“The Health Secretary urges people to follow the guidelines to protect themselves and others from the potentially debilitating long-term impact of*

COVID-19". Despite this Long Covid was not, as far as we are aware, subject to any subsequent public health campaigns by the DHSC.

- 3.29. As a result, based on our experience and the experiences of the people we support, throughout the relevant period, neither the general public or doctors understood Long Covid, its clinical case definition, its symptomology, its diagnosis or treatment. Doctors were not properly supported to diagnose the condition because there was a dearth of information (particularly in relation to how wide ranging and varying symptoms could be), training and preparedness to promote understanding of this condition within the medical profession. GPs who were not knowledgeable made it difficult for patients to access specialist referrals.
- 3.30. Patients resorted to exchanging information on support groups to understand what medications or approaches they could ask a GP to prescribe. There was, and remains, a risk of patients seeking inappropriate medications, unprescribed drugs or treatments, and that people desperate for help are exploited financially and emotionally by unregulated organisations that purport to 'treat' Long Covid.<sup>19</sup>

*Previous awareness of the long-term health impacts of Coronaviruses*

- 3.31. Some of us, and our members, had pre-existing knowledge (either from films/media or personal experience) of the long-term effects of viruses like the Spanish flu, Epstein–Barr virus and glandular fever. We note that there was CMO-commissioned advice about likely long term effects in 2020 which refers to the evidence of long term morbidity in SARs and MERs [*“CMO commissioned literature review by Health Protection Unit, of the long term health impacts of Covid-19”* INQ000292636].

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<sup>19</sup> *“There are potential risks of self-prescription, such as harmful drug–drug interactions and use of inappropriate treatments. Medicines can be used off label, in unsafe doses, and sometimes purchased in an unregulated manner overseas. Harmful drug–drug interactions are enhanced due to the complexity and multiple symptoms of long COVID leading to use of multiple treatments”, Long Covid and Self Management , The Lancet, January 22, 2022 Brown, Yahyouche, Harron, Camaradou, Turner, Volume 399, Issue 10322*

- 3.32. As highlighted above many of us and our members sought out information early on in the pandemic to help us make sense of why we were not recovering from Covid-19. It was within those online support groups and via social media such as Twitter that many of us became aware of research into the long-term effects of other coronaviruses including SARS and MERS. As early as March 2020, there were healthcare professionals around the world raising concerns about the likely long-term effects of Covid-19:

*“Medical community has been aware of complications & long term sequelae of young SARS survivors from studies published 2005-2011 following previous pandemic showing pulmonary fibrosis and lung impairment during peak exercise. In other words, IT IS NOT LIKE GETTING OVER COLD OR FLU”<sup>20</sup>*  
– Claudel Duclos Jean-Pierre, Assistant Professor Obstetrics & Gynaecology, Baylor College of Medicine, Texas

A physiotherapist, sharing an article on the long-term impacts of SARS<sup>21</sup>, noted the following:

*“Great thread summarising a retrospective analysis of post-SARS needs- biggest HC utilisation by survivors was psychiatric and rehab. We Physios and other AHPs must flag up and prepare to meet extensive post\_COVID19 rehabilitation needs in our communities.”<sup>22</sup>* – Prof. Karen McCreesh, Professor of Physiotherapy, School of Allied Health, University of Limerick

- 3.33. In addition, many users on social media, and members of our support groups, were sharing research and testimony on the long-term effects of SARS and

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<sup>20</sup> Jean-Pierre, C. 2020 *Medical community has been aware of complications & long term sequelae* [...] [Twitter] 18 March. [Accessed 11 July 2023]

<sup>21</sup> Tansey CM, Louie M, Loeb M, Gold WL, Muller MP, de Jager J, Cameron JI, Tomlinson G, Mazzulli T, Walmsley SL, Rachlis AR, Mederski BD, Silverman M, Shainhouse Z, Ephtimios IE, Avendano M, Downey J, Styra R, Yamamura D, Gerson M, Stanbrook MB, Marras TK, Phillips EJ, Zamel N, Richardson SE, Slutsky AS, Herridge MS. One-year outcomes and health care utilization in survivors of severe acute respiratory syndrome. *Arch Intern Med.* 2007 Jun 25;167(12):1312-20.

<sup>22</sup> McCreesh, K. 2020 *Great thread summarising a retrospective analysis of post-SARS needs* [...] [Twitter] 20 March 2020. [Accessed 11 July 2023]

MERS, for example [LC/30 - INQ000320255] and [LC/31 - INQ000320256] and it became clear to us that what we were experiencing was neither unique to Covid-19, nor unexpected.

### Counting Long Covid

- 3.34. Upon realising that Long Covid sufferers were going to have to advocate for themselves and for access to treatment and care, it became clear that it was vital to accurately quantify exactly how many people were ill with Long Covid to make the case that care pathways needed to be planned for. A social media campaign ‘#CountLongCovid’ was started in early September 2020, with Professor Nisreen Alwan stating in a Tweet<sup>23</sup>:

*“Two wks ago we started the hashtag #CountLongCovid  
People from across the world are recognising the urgent need for this. If morbidity from #COVID19 is not quantified it will continue to be ignored. We can’t fight what we don’t know & we only know by measuring. Make them listen.”*

- 3.35. On 16 October 2020, following the first Long Covid Ministerial Roundtable, LC SOS contacted the ONS about the urgent need to count Long Covid and its absence from the national Covid-19 statistics as a measure of the impact of the pandemic [LC/32 - INQ000272223]. This led to meetings with the ONS on 29 October 2020, 12 February 2021 and 17 September 2021.
- 3.36. Separately, LC Support contacted ONS on 7 February 2021 [LC/33 - INQ000249020] and 12 February 2021 [LC/34 - INQ000248996] following a presentation from the ONS at the Long Covid Ministerial Roundtable on 29 January 2021. In these emails, LC Support raised concerns about the survey questions proposed by the ONS, stating that many people would not be aware of Long Covid, or consider themselves to be suffering from it. It was suggested

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<sup>23</sup> Alwan, N. 2020 *Two wks ago we started the hashtag #CountLongCovid* [...] [Twitter] 18 September. [Accessed 22 June 2023].

that the survey questions should instead ask about the symptoms being experienced, and the length of time they were being experienced. This led to a meeting with the ONS on 16 February 2021.

- 3.37. This meeting was followed up with a further email from LC Support to ONS on 22 February 2021 [LC/35 - INQ000249021], again raising concerns about the phrasing of the survey questions and providing suggested questions:

*“To reiterate, we are concerned at the phrasing of the question that presupposes a survey respondent knows that they have had Covid (let alone Long Covid). We suggest that more meaningful insights into the prevalence and impact will result from asking whether they have newly experienced any of the listed symptoms for a period of 4 weeks or more since March 2020 AND asking about the impact of these on their activities of daily living, work etc (and for how long).”*

- 3.38. The ONS published its very first bulletin on Long Covid on 1 April 2021 [LC/36 - INQ000320261]. In that release, it was estimated that 1.1 million people were experiencing Long Covid.<sup>24</sup>

- 3.39. We note that the decisions to end the ONS UK Coronavirus (COVID-19) Infection survey in March 2023 and Covid-19 and Respiratory Infections Survey in June 2023 means there is no longer any published Government data on the prevalence of Long Covid. There is also no systematic Government tracking of Covid-19 cases, and in turn Long Covid cases.<sup>25</sup> We are concerned by the lack of ongoing surveillance data and the move to ‘Living with Covid’ means no longer monitoring or publishing of national data. We are concerned that if numbers of people who continue to suffer from Long Covid are not being

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<sup>24</sup> Office for National Statistics (ONS), released 1 April 2021, ONS website, statistical bulletin, Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 1 April 2021

<sup>25</sup> The ZOE Covid Health Study is a health research project of a private British company, Zoe. It monitors self-reported Covid-19 and Long Covid infection rates and symptoms recorded using the ZOE app, which is then analysed by Kings College London.

measured, the healthcare system cannot be preparing to care and treat their long-term illness.

#### **4. Treatment and rehabilitation provided to patients for Long Covid**

- 4.1. Early responses were focused on the acute consequences of Covid-19. This meant that treatment and rehabilitation were focused on those who were hospitalised and were more critically unwell, requiring interventions such as intensive care or higher levels of care in hospital settings. That created a hierarchy: those that were hospitalised, and particularly those that were in intensive care, were deemed more likely to experience more severe and longer-term consequences, while those who had not been admitted to hospital were regarded as having mild symptoms and no longer-term consequences, irrespective of actual disease severity. There was a lack of awareness of the long-term consequences of the disease for those who were not hospitalised.
  
- 4.2. In addition to this, the understanding of Long Covid early in the pandemic was that it was respiratory-based. This was due to the prevailing view that Covid-19 was primarily a respiratory illness. It is now understood that it is a systemic disease that can impact every organ and bodily system, albeit with transmission via the lungs.<sup>26</sup> Prior to the establishment of specific Long Covid Services, patients were therefore routinely referred to respiratory clinics, and specialists. Those who didn't present with respiratory symptoms found it even harder to get the care they needed and the necessary referrals to other specialties. For example, referrals often involved spirometry tests which were usually returned as negative for Long Covid sufferers. The negative spirometry test result led to the dismissal of the individual from specialist care back to their GPs. Unless armed with knowledge gleaned from support groups and from reading published research papers (and even then), patients were in a very poor position to challenge this approach, and many found themselves very much 'lost in the system' as a result with no assessment or care. Even those

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<sup>26</sup> Beeching N, Fletcher T, Fowler R. Coronavirus disease 2019 (COVID-19). BMJ Best Practice. May 2023

who were highly educated and informed struggled to be believed and be given appropriate care. This includes medical professionals who also experienced having their symptoms dismissed by their peers and colleagues, as highlighted by Case Study 3 from LC Physio [LC/7A – INQ000356270] who is an individual that has spent over 20 years treating and helping people in need:

*“The GP service really let me down. Twice they suggested that my sudden changes in heart rate were due to anxiety and that my breathing difficulties were due to stress. I even pointed out that an extremely low heart rate was not a standard response to anxiety, but they did nothing. There seemed to be a genuine lack of interest in why a previously fit and healthy person was suddenly so unwell. I have had to direct and actively seek help the whole way which has been exhausting and financially very challenging. [...] I was being given either no advice or dangerous advice such as to exercise with obvious cardiac symptoms which turned out to be myocarditis. My private consultants were excellent. They listened and immediately tried to help. They believed me, did the appropriate tests and didn't try to fob me off with labels of being anxious. “*

- 4.3. If a patient did manage to see a healthcare professional who took them seriously and believed that they were suffering with Long Covid, they would then be referred for treatment which was in many cases inappropriate and ineffective. As stated above, because treatment and rehabilitation focused on hospital and ICU settings, the mindset of healthcare professionals was focused on critical care rehabilitation which often includes very exercise-focused approaches, including Graded Exercise Therapy and pulmonary rehabilitation. Research indicates that a high proportion of people with Long Covid experience post-exertional malaise (PEM) / post-exertional symptom exacerbation (PESE),<sup>27</sup> making rehabilitation which focuses on exercise potentially dangerous for many Long Covid sufferers. This does not mean that Long Covid

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<sup>27</sup> Wright J, Astill SL, Sivan M. 'The Relationship between Physical Activity and Long COVID: A Cross-Sectional Study'. Int J Environ Res Public Health. 22 April 2022

sufferers should be inactive but rather that they needed to work within “their energy envelope”<sup>28</sup> or by increasing activity very gently.

4.4. In October 2020, following advocacy from our organisations and others for further research and specialised treatment,<sup>29</sup> NHS England (“NHSE”) announced their five-point plan to provide Long Covid services [LC/37 - **INQ000283373**] including NICE guidance, Your Covid Recovery website, designated Long Covid Services (which would include physical assessment, diagnostic testing, cognitive assessment, psychological assessment), NIHR funding for research and the setting up of a NHSE Long Covid Taskforce.

4.5. LCK, LC SOS and LC Support participated in NHSE Long Covid Taskforce meetings:

4.5.1. The first taskforce meeting was held on 29 October 2020. In addition to the main taskforce there were four sub-groups: research; education and information; assessment services and online rehabilitation.

4.5.2. LC Support had two representatives on the main taskforce and two in each of the sub-groups. We also had numerous meetings outside of the taskforce meetings with Cathy Hassell (Director for Clinical Policy & Quality, NHSE), Kiren Collinson (Clinical Chair of Oxfordshire CCG) and **Name Redacted** Programme Manager for the Long Covid plan, NHSE). In March 2021, we received an email from Kiren Collinson thanking us for our services and explaining that going forward there would be five Level 4 patient and public voice partners (“PPVs”)<sup>30</sup> appointed to sit on the taskforce. The application process was convoluted and difficult to navigate, particularly for people suffering with Long Covid. Patients did

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<sup>28</sup> The energy envelope theory was developed in relation to myalgic encephalomyelitis and chronic fatigue syndrome. The Theory postulates that individuals may experience some increase in functioning if their level of exertion consistently remains within the limits of their available energy.

<sup>29</sup> See further the Chronology of Submissions to the Government and NHS

<sup>30</sup> *Patient and public voice partners (PPVs) are people who are willing to share their perspective and experience with NHS England to inform health services in a range of different ways. PPV partners include patients, service users, carers, families and other members of the public. The roles are categorised from Levels 1 to 4, with PPV1 contributing to open access engagement and PPV4 being part of committees that feed into and make recommendations which impact on NHSE decision-making. NHS England Patient and Public Voice Partners Policy, July 2017 [accessed 12 July 2023]*

not receive the application pack until 27 April 2021 and were required to apply before a deadline of 7 May 2021. Some members of LC Support were offered a PPV3 role as part of a patient advisory group, i.e. not sitting on the Long Covid Taskforce. This group did not start meeting until July 2021. The initial meetings were very frustrating for patient advocates as they lacked structure and did not build on the significant ground and progress that had been covered during the previous six months. At this point we requested that we be allowed to retain a seat at the table in the main Long Covid taskforce meetings as a charity, and this was agreed.

4.5.3. Two members of LC SOS were recruited as PPV4 members sitting on the Long Covid Taskforce and also had representatives in each of the sub-groups.

4.6. In addition, as referenced at paragraph 3.26, the DHSC launched the Ministerial Roundtable on Long Covid in October 2020, which LCK, LC SOS and LC Support attended at various points. We felt the creation of this Roundtable to be a positive development, and it was validating to be able to discuss Long Covid with senior DHSC officials, who seemed to be taking the issue seriously and listened carefully to what we were saying.

4.7. The Roundtables initially provided a useful forum, as the patient representatives were usually given time to make comments or presentations. However, as time went on, the meetings seemed to lack a clear purpose and, despite the presence of government ministers, our pleas for policy change on various matters including: mitigations in schools; clearer public health messaging including an accurate list of Covid-19 symptoms; provisions for long-term sick leave and benefits, and for Long Covid services to be multidisciplinary were not implemented.

4.8. LC Physio contributed to rehabilitation guidelines:

4.8.1. In April 2021, we contributed to Chartered Society of Physiotherapy rehabilitation guidelines for hospitalised and community patients [LC/38 - INQ000320263]

4.8.2. In June 2021, we collaborated with World Physiotherapy to develop a briefing paper on safe rehabilitation for people living with Long Covid [LC/39 - INQ000320264]

4.9. LC Physio advocated for safe rehabilitation at conferences, webinars, podcasts and in scientific journals, all with the aim of disseminating this information as far as possible. Despite this, safe rehabilitation is often not implemented in practice (as demonstrated below).

#### Your Covid Recovery

4.10. In July 2020 the NHS launched the website, “Your Covid Recovery”. This has been marketed as the recovery tool for Long Covid. The NHS website: *Long-term effects of COVID-19 (long COVID)* [LC/40 - INQ000320265] states the following at the top of the page:

*You can find more information to support your recovery on the Your COVID Recovery website.*

The page also includes the following in the ‘Recovery’ section:

#### ***Your COVID Recovery programme***

*The ‘Your COVID Recovery programme’ is an online recovery programme to support you while you recover from the long-term effects of COVID-19.*

*You need to be referred to the programme by a healthcare professional. You will be given a unique code to register on your computer, tablet device or smart phone.*

The 'Your COVID Recovery' website supports the programme and includes information on:

- *supporting your mind and mental health*
- *managing the effects of long COVID on your body*
- *managing long COVID with other conditions*
- *tips to help you eat well, sleep well and get moving again*

4.11. At the outset the focus of Your Covid Recovery was on recovery for those discharged from hospital with Covid-19 rather than including those suffering Long Covid in the community. Our organisations sought to ensure there would be adequate and appropriate provision for Long Covid:

4.11.1. In August 2020, LC Support had a meeting with Professor Sally Singh to discuss the Your Covid Recovery website

4.11.2. In September 2020, LC SOS had a meeting with Professor Singh to discuss the Your Covid Recovery website and raise awareness of Long Covid, but it was unclear how much of what was discussed was taken on board. At that stage Your Covid Recovery was very much focussed on a short illness without prolonged, diverse or terrifying symptoms.

4.11.3. In March 2021, LC Support met with NHSX for two sessions to discuss Phase 2 of Your Covid Recovery. The purpose of these sessions was to assess the viability of a symptom-tracking solution, and we provided significant feedback. It was never clear how much of this feedback was ever incorporated.

4.12. On 25 June 2021 the website added one page on Long Covid [LC/41 - INQ000320266], but even that page did little more than replicate the NICE guidelines in terms of symptoms and had no specific advice on recovery from Long Covid. The terminology included on that page was inappropriate, describing Long Covid as an *"informal term"*.

- 4.13. On 7 January 2022, it was updated to give advice on managing fatigue included a section on Post Exertional Symptom Exacerbation [LC/42 - INQ000320267]. Prior to this, there was no mention of PESE at all [LC/43 - INQ000320268].
- 4.14. On 21 July 2022, the entire Your Covid Recovery website underwent a redesign and a whole section on Long Covid with its own specific recovery advice.
- 4.15. Your Covid Recovery was considered by our organisations' to be unfit for purpose for most people with Long Covid. Feedback from support groups gathered by Long Covid Support in September 2021 [LC/141 – INQ000356269] demonstrate that some of the advice provided was highly inappropriate for people with Long Covid. For example, advice on 'getting moving again' promoted the benefits of doing exercise without any caveats or warnings about the risk of worsening symptoms. Additionally, the feedback highlights that:
- 4.15.1. The content and structure of the website fails to consider cognitive dysfunction and the energy limiting nature of the condition.
- 4.15.2. A lack of information about Phase 2 has led to confusion over what it is and how patients are referred to Phase 2.
- 4.15.3. The emphasis on anxiety and psychologising Long Covid which is both triggering for patients and untrue.
- 4.16. In contrast, for ME/CFS (sufferers of which also experience PEM/PESE) the NICE guideline was updated in October 2021 [LC/44 – INQ000320269] to warn against graded exercise therapy (our highlights):

*... the guideline makes it clear that any programme based on fixed incremental increases in physical activity or exercise, for example graded exercise therapy (GET), **should not be offered for the treatment of ME/CFS.***

*...*

*The importance of ensuring that people remain within their energy limits when undertaking activity of any kind is also highlighted. The guideline recommends that **any physical activity or exercise programmes should only be***

***considered for people with ME/CFS in specific circumstances and should begin by establishing the person's physical activity capability at a level that does not worsen their symptoms.***

- 4.17. Members of our organisations were involved in reviews of the Your Covid Recovery website from June 2021, as PPVs and through conversations with NHSE. As noted above, two members of LC SOS were recruited as PPVs and part of our role was to work as part of a group to review the content of Your Covid Recovery and propose changes. Any changes we proposed to the design/wording of the website had to go through various levels of approval and endorsement, and the work on the website would then be undertaken by a contractor. This meant that the whole process was extremely slow and many of the changes we suggested were not actioned.
- 4.18. Unfortunately, due to the issues with Long Covid services which we will cover below, many sufferers are signposted to Your Covid Recovery and left to follow guidance in order to self-manage without the support of medical professionals.
- 4.19. The tool remains focused on those who had been hospitalised for some time and, even when Long Covid was given specific resource on the website, it was inappropriate and to the present day still does not address the needs of Long Covid sufferers. While it now includes a wider focus than at launch, from our experience – from the way the tool has been designed, delivered and its content – it still does not fully address the broad needs of those living with Long Covid. The website still refers to helping people to get better following a COVID-19 infection and does not acknowledge that for some this might not be possible. It is very geared up (in terminology and content) as a tool for supporting people recovering from post-acute infection and not those who have lasting/unexplained symptoms. As such it could still be improved to properly assist people living with Long Covid.

### Long Covid services

4.20. With the announcement of the five-point plan in October 2020, England was the first country in the world to provide funding within its National Health Service for services specific to Long Covid. However, this grant of funding of £10 million was not sufficient to provide services for the numbers of people experiencing Long Covid. Further funding has since been set aside for Long Covid services, but this remains inadequate to address the severe issues with how Long Covid services function. As far as we are aware, there are no dedicated equivalent Long Covid services in Wales and Scotland (see Long Covid Kids has advocated for the provision of Long Covid healthcare services in Scotland and Wales [INQ000272167] and [INQ00272170]). Our organisations do not provide support in Northern Ireland so are unable to comment on the provision of services for Long Covid there.

4.21. As representatives of healthcare professionals, LC Physio has specialist insight into these issues. Our experience is that there is a wide range of difference in Long Covid service provision:

4.21.1. Services are run differently depending on which healthcare professionals are leading them: some are medically led, but some are allied healthcare or rehabilitation professional led. In the latter services, patients will often experience repeated guidance along the lines of *“if you think you will get better and move a little more you will get better”*. Some of those models of service delivery are not respecting the complex biomechanical, pathophysiological mechanisms that require medical investigation, assessment, and treatment.

4.21.2. The structure of the services varies widely. Some of them function like a one-stop shop for multiple specialists: you can see a doctor, a physiotherapist, an occupational therapist, a psychologist in one place. In many other clinics that lack in-house expertise, patients are discharged from the Long Covid clinics and instead sent to various disparate community services which operate separately.

4.21.3. There is significant divergence in the standard and nature of service provision. LC Physio are aware that the community Long Covid services

tend to be fragmented and the majority do not accept patients who are able to undertake basic tasks (e.g., showering, cooking, walking short distances). This leaves many patients in no man's land. However, there are other Long Covid services that seem to strive to see people more often and offer more after care.

4.22. In written evidence provided to the Health and Social Care Committee inquiry: Clearing the backlog caused by the pandemic [LC/45 - INQ000238630] in September 2021, LC SOS made the following observations about Long Covid services:

*A one-stop shop with a mix of specialties, professionals allied to healthcare and, importantly, a point of contact for the patient is what we would consider the benchmark for Long Covid care. Interventions should be appropriate for the highly diverse needs of those suffering from this condition and should not put patients at risk. Many centres are far from providing this, and a number of issues raise concerns:*

- *Adherence to pathways developed and disseminated by NHS England seems to vary widely, resulting in a 'postcode-lottery' in standards of assessment and care. We would like to see more collaboration between clinics so that best practice can be shared*
- *Patients who have symptoms that impact their daily lives are in some cases not being accepted into the assessment services and are instead being directed to online 'rehab' programmes and apps*
- *Some centres are referring patients to pulmonary rehab which includes goal-setting and graded exercise therapy, which can exacerbate symptoms and prolong illness*
- *Patients may be referred to IAPT or psychological services without thorough investigation of the causes of their symptoms. We have heard of cases where refusal to attend 'talking therapies' results in them being discharged from the system.*

- *Many services are not multi-disciplinary meaning that patients return to their GPs for onward referral and then join the existing specialist waitlists. Clinicians have expressed concern that patients should not be sent back and forth between different teams and but unfortunately it is frequently the case*
- *Long Covid services ought to be headed up by a qualified doctor, however we understand that this is not always the case*
- *Appropriate diagnostic tools required to establish the cause of symptoms (e.g. micro clotting, heart damage) are not available or offered at many centres and as a result patients are told there is no biomedical reason for their illness*
- *Huge numbers of people have been waiting for access to clinics for many months or sometimes more than a year during which time they have had to self-manage their symptoms, advocate or even fight for treatment, and then struggle to obtain a referral. Whilst it is acknowledged from recent data from NHSE that waiting times have reduced, this experience is exhausting, has been described by some as 'traumatic' and can lead to a deterioration in health. Patients have reported that, after eventually gaining access to a Long Covid assessment service, they find the experience of navigating the system profoundly bewildering, eventually leaving them in a position where they must once again co-ordinate their care themselves.*

4.23. Responses given to LC Support patient experience surveys given in March, April and May 2021 [LC/10 - INQ000272247] highlighted a number of issues in how Long Covid services function, including:

- The services are currently only in England, there are large geographical gaps even in England, and a lack of consistency in the service offered.
- There are significant barriers to access (being believed, identifying operational clinics, waiting times, proximity, etc.), and GPs don't know how to help patients access the clinics.

- There are significant variations in adherence to NICE guideline/NHSE commissioning guidelines for Long Covid.
- There is a lack of GP understanding of the timing from which referrals can be made (e.g. waiting for prolonged symptoms to persist for 12 weeks or more), meaning many referrals are delayed unnecessarily.
- There are long waits for referrals to Long Covid clinics, in some cases over a year, leading patients to self-manage their symptoms, potentially in risky ways, and coordinate their own care, in some cases losing their livelihoods due to a lack of appropriate care.
- Many services are not multidisciplinary, resulting in patients being referred back to GPs and joining waiting lists for onward referrals to the required specialities. Patients without respiratory symptoms often found themselves waiting for months to be referred to Long Covid services that were led by respiratory specialists, leading to inefficiency, confusion and distress.
- There is a lack of oversight/ case management by an appropriately trained clinician to assess patients holistically.
- Patients are more often referred to inappropriate exercise rehabilitation without appropriate assessment of risks (PEM/PESE/micro clots).
- Patients are sometimes referred to IAPT/other psychological services without thorough assessment of symptoms – in some cases resulting in them being discharged from the Long Covid clinic if they don't agree to attend these services.

4.24. These observations remained accurate throughout the relevant period and continue to be so to date.

4.25. Overall, it is clear that there is a disparity and inequity in the provision of Long Covid services, creating a postcode lottery. The majority of people with Long Covid are left to deal with it by themselves and this is why so many have turned to support groups and organisations like ours for expertise and signposting.

## 5. Long Covid in children

5.1. Paediatric post acute sequelae of Covid-19 or Long Covid has been described as *“complex, heterogenous, post viral condition involving multiple body systems and is likely attributable to several concurrent underlying physiological processes including damage from direct viral invasion, endovascular dysfunction and micro thrombosis, viral persistence and the development of auto immunity.”*<sup>31</sup> From the outset of the pandemic, there has been a failure to have regard to the risk of infection, transmission between, hospital admission, death and serious long-term illness, care pathways and consequences in children. This negatively impacted children and young people’s access to healthcare, the accessibility of suitable child-specific treatment pathways, public awareness, policy development, vaccine decisions, vaccine uptake and the general availability of support for children with Long Covid.

5.2. LCK was set up by parents of children who were not recovering from Covid-19. We refer to the witness statement of Sammie McFarland dated 25 September 2023 [INQ000280195] which sets out the background of the advocacy and work of Long Covid Kids, that is parents and carers of children with long covid who have advocated to get recognition and help for their unwell children. In short, initially about seven families with children who had Covid-19 but were not recovering and were experiencing extremely distressing ongoing symptoms, joined together. In September 2020, LCK produced a film: *“Our Unhappily Ever After”* [LC/46 - INQ000272195] which was put on YouTube and shared on social media. The film included words from children with Long Covid, some examples include:

*“It felt like a long time ago we were well and could do some of the fun things we like to do. We’re still at home and we are unwell. Many of us are in bed a*

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<sup>31</sup>Yonts A Brugler. Pediatric Long-COVID: A Review of the Definition, Epidemiology, Presentation, and Pathophysiology. *Pediatr Ann.* 2022 Nov;51(11):e416-e420. doi: 10.3928/19382359-20220913-06. Epub 2022 Nov 1. PMID: 36343180.

*lot of the time, it can be boring, annoying, frustrating and tiring and we miss our friends. We miss feeling well”*”.

*“You never know how you might feel when you wake up and want to play your favourite games ...you might feel ok....you might feel terrible again.”*

*“Pain, exhaustion, brain fog, tummy ache, headaches, aching arms, feeling faint, falling over, bubbles in rib cage, skin rashes, tight throat, breathing difficulties, loss of appetite, chest pain, fast heart rate, paraesthesia, stuttering, nosebleeds, seizures, organ damage. We didn’t feel like this before we got Coronavirus...we felt like you.. now we all have Long Covid and nobody knows what to do... We don’t want you to have to feel like us.”*

5.3. After sharing the film, around 300 families contacted LCK on Facebook. This number grew by 50-200 new members weekly. Each family’s experience was distressing, similar, and yet unique. All had experienced a lack of awareness and support from GPs about post-viral conditions so they each experienced the complete lack of awareness of the incidence of Long Covid in children, and in turn, the absence of treatment pathways. All had been told or made to feel, that they were neurotic or over-concerned parents. Ms McFarland, for example, was told that her daughter, who had previously led an active healthy life doing ballet and aerial silks prior to contracting Covid-19 aged 14 years old in 2020, was mimicking her mother’s illness, despite their symptoms and experiences being quite different [INQ000280195 paragraph 12]. Many parents in the group report being advised that they had been told, their children couldn’t be sick, or that their children needed to be more positive and do more exercise, even if their child was so unwell that they could not get out of bed.

5.4. In the first year of the pandemic LCK had to provide evidence that children suffered from Long Covid, as there was a widespread disbelief that children could suffer harm and adverse long term effects from Covid-19.

5.5. In LCK's opinion, a number of factors negatively impacted children with Long Covid's access to healthcare<sup>32</sup>:

5.5.1. There was no information published by the government, the Royal College of Paediatrics and Child Health and by healthcare providers on the risk of Covid-19 to children;

5.5.2. There was no paediatric clinical definition for Long Covid until February 2023 when the WHO issued the clinical definition;

5.5.3. There was a lack of data collection and reporting on hospital admissions, deaths and Long Covid in children. The magnitude of adult Covid-cases, hospitalisations and deaths, combined with their publicity, ensured that the plight of adults consistently overshadowed all child Covid-19 infection experiences.

5.5.4. At best, an adult framework was being applied to paediatric problems. There needs to be child-specific data and child centred approach: it is important that children suffering are heard and that there is a voice for all children and young people impacted by Covid-19 infection.

### Recognition

5.6. In the UK, throughout 2020, there was no information published by the Government stating that children and young people could have any, let alone have debilitating, symptoms from Covid-19 and Long Covid. Early public health statements suggested the contrary, that Covid-19 posed only a minimal risk to children.<sup>33</sup> In LCK's experience, this meant that when our families sought assistance for children suffering from harmful symptoms, they were routinely dismissed and unable to access healthcare.

5.7. This was compounded by the fact that there was no paediatric clinical definition for Long Covid for the duration of the relevant period. This is despite the WHO clinical case definition, published in October 2021, stating the following (our emphasis):

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<sup>32</sup> See for example evidence submitted to the APPG on Long Covid, published March 2022

<sup>33</sup> UK Chief Medical Officer, Statement from the UK Chief Medical Officers on schools and childcare reopening, 23 August 2020

*“Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS-CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others (see Table 3 and Annex 2) which generally have an impact on everyday functioning. Symptoms may be new onset, following initial recovery from an acute COVID-19 episode, or persist from the initial illness. Symptoms may also fluctuate or relapse over time. A separate definition may be applicable for children.”<sup>34</sup>*

5.8. It was only in February 2023 that the WHO published the first clinical case definition for Long Covid in children and adolescents.<sup>35</sup> This delay prolonged LCK members having difficulties accessing help, being believed and being diagnosed. In October 2023 the WHO published “Rehabilitation: Self Management of long Covid for adolescents” [LC/140 – INQ000356274]. This sets out practical guidance and support for adolescents with Long Covid.

#### Symptoms and prevalence

5.9. The Government’s guidance on the list of symptoms for Covid-19 did not adequately reflect children’s experience and was not updated in line with developing evidence.<sup>36</sup> Anecdotal reports of symptoms, case reports and papers were dismissed despite being repeatedly provided and/or discussed in high level meetings with ministers and NHSE.

5.10. Whilst some children and young people may recover from Covid-19 with no apparent immediate harm, for a cohort of children and young people this is sadly not true. They suffer prolonged illness from Covid-19. We have exhibited case studies from LC Kids members [LC/7B - INQ000356271] which include:

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<sup>34</sup> WHO, A clinical case definition of post COVID-19 condition by a Delphi consensus, 6 October 2021 (p.1)

<sup>35</sup> WHO, A clinical case definition for post COVID-19 condition in children and adolescents by expert consensus, 16 February 2023

<sup>36</sup> See LCK evidence to APPG; LCK symptom survey

- Case Study 5, 15 years old, initial infection April 2020, reinfected July 2021, diagnosed with Long Covid December 2021 – *“she still, nearly 2 years later endures daily pain and cannot walk properly. She has no real “life” as such, and always feels unwell. Certainly not a life that any normal 15yr old should be able to enjoy[...]Daily she struggles. Daily she is in pain. Daily she picks herself up and keeps trying to be positive – despite this horrendous illness.”*
- Case Study 4, 16 years old, initial infection September 2021, diagnosed with Long Covid November 2021 – *“Apart from well managed allergies and undiagnosed hypermobility, she had no known underlying conditions before Covid. She has been completely bedbound for 14 months and seriously unwell for 23 months. She developed a 36-degree reactive scoliosis and intense pain in her right hip at exactly the same time as Covid Pneumonia was diagnosed.”*
- Case Study 1, 15 years old, initial infection September 2020, diagnosed with Long Covid October 2020 – *“Unable to attend school, isolated from society, fearful of being reinfected, lost opportunities lost friendships unable to carry out my hobbies like horse riding or helping at the stables”.*

5.11. The ONS March 2023 estimate is that 52,000 children and young people aged 2-16 suffered Long Covid for over 12 months. Long Covid is a significant health burden which drastically impairs their quality of life, including access to education, family and social functioning. Prevalence of Long Covid in children has become highly debated and contentious often because of the different ways of reporting age data and the complexities of the condition. Also, children have difficulty articulating symptoms. We note that the Centre for Disease Control guidance on Long Covid in Children states *“Although Long COVID appears to be less common in children and adolescents than in adults, long-term effects after COVID-19 do occur in children and adolescents. Young children may have trouble describing the problems they are experiencing.”*<sup>37</sup> From our perspective this shows that a

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<sup>37</sup> Centers for Disease Control and Prevention (CDC) – Caring for People with Long Covid

precautionary s approach to public health should be taken to support young children suffering from debilitating symptoms.

#### Reporting and public health messaging

5.12. There was a lack of reporting of hospital admissions and deaths in children. While hospital admissions for adults were reported regularly, public health messaging around child admissions focussed on incidental findings and comorbidity.

5.13. Public health messaging either omitted paediatric deaths entirely or compared this with adults, allowing misrepresentation of the severity of Covid-19 for the paediatric population.

5.14. There was an apparent failure to produce a public awareness campaign for Covid-19 harm in children, including Covid-19 and Paediatric Inflammatory Multi Syndrome (PIMS symptoms;) Long Covid in children and Covid-19 outcomes for children. Previous knowledge that post-viral syndromes do occur and can affect children was not acted upon when anecdotal and clinical evidence started to occur.<sup>38</sup>

5.15. LCK believe that, as a consequence of the risk of Covid-19 to children being overlooked, there were knock-on effects. LCK believe that because the risks to children were not being adequately reported, this led to the testing of and delivery of vaccines for children not being prioritised. The identification of symptoms of Covid-19 in children, and the identification of long-term illness in children, were missed.

#### Children's experience of access to the healthcare system

5.16. As has been stated above, in the case studies [LC/7A-D – INQ000356270, INQ000356271, INQ000356272, INQ000356273] and also in letters our members

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<sup>38</sup> "It is important to recognize that long term effect of a post infectious disease is not a new phenomenon" 'Long-term outcome of pediatric infections from traditional infectious disease to long Covid.' Future Microbiology, January 2022 Buonsenso, Di Gennaro, Rose et al.

shared with us [LC/47 - INQ000320272] children with Long Covid were routinely turned away from their GPs. The experience of GPs not believing children and their parents mirrors that of adult Long Covid sufferers but was particularly heightened for families and children given the persistent lack of acknowledgement that children could experience any harm from Covid-19 infection and subsequently develop Long Covid. Those attending their GP found that they and/or their parents or guardians were forced to fight in order to get any care.

5.17. Many of those children with Long Covid were actively advised to not seek medical care given the so-called mild nature of their symptoms. Those who did attend A&E were sent home to recover without ongoing support, advice or community care. Upon later seeking further treatment for continuing or worsening symptoms, they experienced inadequate care from medical practitioners who continued to lack understanding on the variety of presentations of Long Covid and the occurrence of Long Covid in children. At best, an adult framework was being applied to this paediatric problem<sup>39</sup>. LC/7B - INQ000356271 includes for example:

- Case Study 2, 17 years old - *“In May 2021, I was seen by a paediatrician who fobbed me off saying it was my body’s way of dealing with my sister and Dad being ill and the loss of my Grandad.”*
- Case Study 4, 16 years old - *“[...] Even with a Long Covid diagnosis, many professionals seemed intent on viewing her presentation through the restricted lens of individual organs, or indeed assuming a psychological causation - despite overwhelming evidence to the contrary. This has been an ongoing, insurmountable barrier that has resulted in conflicting information and ongoing delays to formulation and treatment. [...] The paediatrician at Hospital Y was dismissive and unsympathetic, telling us he had no knowledge of Long Covid and that we needed to see the Long Covid Clinic at Hospital X. He would refer but told us not to expect any treatment. [...] She has been subjected to misdiagnosis, minimising and disbelief, due in part, we believe, to prejudice, bias and lack of awareness caused by*

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<sup>39</sup> CIDRAP, University of Minnesota, “Not little adults: Experts say long Covid undercounted and misdiagnosed in kids.” 10 October 2023.

*irresponsible public messaging and a lack of training about not only Long Covid but also Myalgic Encephalomyelitis.”*

- Case Study 5, 15 years old - *“The GP had no experience at all of Long Covid in children. They assumed incorrectly that the Long Covid Clinic at I&S would be able to help. Likewise with the local paediatrician. She has been totally let down and failed by the NHS due to a lack of knowledge and no treatment options. She was under the care of the Long Covid clinic at I&S from December 2021 - January 2023. She was discharged because they couldn’t help, and nothing they could do to treat her. We are effectively on our own to help her! To say we have been let down is an understatement.”*
- Case Study 6, 13 years old - *“[...] He deteriorated, he developed episodes of severe chest pain that would last for hours. and struggled to stand up. I begged a GP to come and visit him at home, but she refused because they did not do home visits anymore. We did a video call where she could see him struggling. I was advised to ignore him when he was screaming as it was attention seeking. We were told we need to keep him moving and he should be coming downstairs every day, not spent all day in his bed. “*

### Advocacy

5.18. From our formation, LCK challenged misconceptions and misinformation about Long Covid in children and the impact this has on their families and resulting healthcare provision. LCK as an organisation and many of our peer supporters have been subjected to harassment and abuse on social media from people that deny Long Covid in children.

5.19. LCK also worked with the World Health Organisation on their expert panels, on the nature of Covid-19 and its impact on children. As part of this work LCK shared concerns and issues raised by members of their support groups, their surveys on symptoms and other issues relating to Long Covid in children and young people.

5.20. LCK advocated for mitigation measures in schools, improved air quality, equitable education, vaccinations to minimise harm to children and young people, and high quality biomedical paediatric research on Long Covid in children. Our advocacy is laid out in the exhibited chronology, but some examples are as follows:

5.20.1. On 23 December 2020 LCK wrote to Chris Loder MP [LC/48 - INQ000320273] sharing our film *“Our unhappily ever after”* and raising other matters including the need to count Long Covid in children and the hospitalisation rates for children with COVID-19.

5.20.2. On 7 January 2021 LCK wrote to Layla Moran MP [LC/49 - INQ000272145] stating that we represented over 400 children and “almost all the stories are the same” that the healthcare support and response was inadequate.

5.20.3. On 12 April 2021, with Safe Ed for All, LCK wrote to then Secretary of State for Health and Social Care Matt Hancock raising concerns about risks and mitigation measures in schools [LC/50 - INQ000272150].

5.20.4. On 4 May 2021 LCK wrote to the then Secretary of State for Education Gavin Williamson about mitigation measures in schools as part of a campaign by Parents United [LC/51 - INQ000272151]

5.20.5. On 1 April 2022 a cohort of children and young people with Long Covid delivered LCK’s support guide to Downing Street [LC/52 - INQ000320277]. Each child represented 10,000 young people in this country who have been seriously impacted by the condition, and they had come from every corner of the UK with letters describing the toll this illness has taken on their lives.

### Treatment

5.21. With respect to treatment for Long Covid, everything that is noted above applies equally to children. Children were not able to get referrals to Long Covid services, and even if they did, the referral process was a postcode lottery. The lack of knowledge and the lack of data reinforced the lack of care for children.

## **6. Long Covid in healthcare settings**

6.1. Several of our members are health workers who contracted Long Covid in their workplace. Many front-line healthcare workers with Long Covid were infected with Covid-19 at work and had to fight for recognition and assistance throughout the pandemic<sup>40</sup>. We use healthcare worker here to include both private and NHS settings. They suffered and continue to suffer chronic illness and disability as a result of the healthcare sector's failure to prepare for, protect from and respond to, the possibility of long-term illness from infection of Covid-19. In addition to the physiological impact of Long Covid, the ongoing failure to recognise Long Covid as an occupational disease has resulted in a failure to provide adequate recourse to social security and employment rights.

6.2. We refer to the following example case studies from Long Covid Physio at LC/7A - INQ000356270:

- At Case Study 8, a diagnostic radiographer aged 40 states – *“I was sent home from work with a cough end of April 2020. The DWP has deemed my contracting Covid an industrial accident (and myself 50% disabled). During working in the pandemic I lived alone, walked to work and back by myself, didn't see my family or partner and had food delivered to my front door. It is the only place I could have contracted it. Plus our workload was chest x-rays for probable and positive Covid patients ... We only wore surgical masks, apron and gloves for all patients, including positive patients. The only place we wore full FFP and full body gowns was positive ICU and theatre, deemed as aerosol generating procedures.”*
- At Case Study 11, a former registered nurse aged 50 states – *“Long Covid has had a devastating effect on my health. Infection with Covid-19 resulted in immune dysfunction, dysautonomia, cognitive difficulties, chronic fatigue and Post Exertional Malaise ... I am no longer able to work and have lost my professional registration, a devastating end to a thirty-year career.”*
- At Case Study 2, a children's physiotherapist aged 33 states – *“I continue to struggle significantly with severe fatigue impacting daily tasks. I still experience*

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<sup>40</sup> See for example LC Support report with the Trade Union Congress, March 2023

*brain fog, black outs, muscle aches, headaches, low grade fevers, shortness of breath and sensory sensitivity ... It is hard to live within a tiny envelope of energy and try to meet the demands of life. I am unable to work as the cognitive and physical demands are too much ... It's exhausting to continually fight for basic needs – even with my sats regularly dropping to below 90 the current advice has been to ignore it.”*

6.3. The number of healthcare workers impacted by Long Covid is significant. According to ONS data, 4.4% of healthcare workers report having Long Covid symptoms and 3.25% have symptoms after having been first infected one year or more previously.<sup>41</sup> In addition, many thousands have been forced into early retirement or worse – losing their jobs, registration to practice medicine or nursing, without any ill health retirement or compensation. Reporting in January 2023, the BBC Panorama documentary: *“Forgotten Heroes of the Covid Front Line”* highlighted that up to 10,000 NHS workers could be off sick with Long Covid. Yet, there is much uncertainty in exactly how much of the NHS is impacted by Long Covid due to inadequate reporting.

6.4. In the NHS, anybody who contracts a disease whilst at work is required to have a RIDDOR<sup>42</sup> submitted on their behalf. However, in the experience of LC Physio this was not happening during the pandemic and, in some NHS Trusts, there was no RIDDOR reporting of healthcare professionals with Long Covid. A report<sup>43</sup> by the BMA and Long COVID Doctors for Action noted the following:

*“The employer is responsible for determining entitlement for injury allowance. Therefore, having COVID reported by an employer to the Health and Safety*

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<sup>41</sup> Office of National Statistics (ONS) (February 2023) ‘Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK’

<sup>42</sup> Reporting accidents and incidents at work. A brief guide to the Reporting of Injuries, Diseases and Dangerous Occurrences Regulations 2013 (RIDDOR): *RIDDOR is the law that requires employers, and other people in control of work premises, to report and keep records of: work-related accidents which cause death; work-related accidents which cause certain serious injuries (reportable injuries); diagnosed cases of certain industrial diseases; and certain ‘dangerous occurrences’ (incidents with the potential to cause harm).*

<sup>43</sup> British Medical Association, ‘Over-exposed and under-protected: the long-term impact of COVID-19 on doctors’, 4 July 2023

*Executive under the terms of the RIDDOR (Reporting of Injuries, Diseases and Dangerous Occurrences Regulations) may assist with claims. However, there was gross underreporting of these cases through RIDDOR making access to NHS Injury Allowance more difficult for staff who should receive it, and importantly payments run out after a year.”*

Up to the present, there is still no formal mechanism within the NHS in England and Wales to gather data on the number of healthcare professionals suffering with Long Covid in the UK. As a result of this inadequate data, the problem of healthcare workers suffering with Long Covid continues to be ignored.

- 6.5. The only certain way to avoid Long Covid is to avoid contracting Covid-19. Yet, there were severe issues with the infection prevention and control measures early on in the pandemic and since that resulted in huge numbers of frontline workers being infected with Covid-19, a proportion of those then suffering with Long Covid.
- 6.6. The PPE measures in place were inadequate to prevent Covid infection in staff. A Channel 4 investigation [LC/53 - INQ000320278] in May 2020 revealed that *“45% of the 19,909 boxes holding PPE supplies had exceeded their use-by dates”* on the day Covid-19 was declared an international emergency. Further, the DHSC 2020–21 Annual Report and Accounts [LC/54 - INQ000320279] noted that PPE was *“purchased that did not always meet requirements”*, including *“£4 billion of unusable PPE that will not be used in the NHS and needs to be disposed of.”*
- 6.7. In June 2021, results published from a study carried out in Cambridge [LC/55 - INQ000320280] showed that hospital transmission was reduced to near zero by using FFP3 instead of surgical masks in Covid-19 wards. This suggests that significant numbers of infections in staff could have been prevented, had they been provided with better PPE.
- 6.8. This is not an issue that has gone away. What is missing from the dialogue surrounding PPE is the continued problems in relation to reducing risk of acquiring

Covid-19 now that the risk of Long Covid is better understood. There are no mask mandates in many healthcare settings.

6.9. Further distress has been caused by the removal of the special sick pay provisions for Covid-19. In March 2020, special provisions were inserted into the terms and conditions for NHS staff which meant that *“normal contractual rules were suspended and NHS staff were able to receive full pay when away from work as a result of covid, no matter the length of absence”*.<sup>44</sup> In July 2022, the DHSC announced that these provisions would be removed:

*“Under transition arrangements, from 1 September 2022 all staff receiving the special covid sick pay reverted to standard sick pay rules, set out in the terms and conditions of their contracts.*

*From then on, any staff member absent from work owing to long covid would be able to claim full pay for as long as six months and then half pay for the following six months. Many staff with long covid are expected to get reduced payments from 1 March 2023, when the first six months of the transition period ends”*.<sup>45</sup>

6.10. As a result, those who had already been off sick with Long Covid for extended periods saw their pay drastically cut once these provisions ended. Further, those who contracted Covid-19 and Long Covid after these provisions ended have found themselves forced to return to work despite suffering severe ongoing symptoms, putting their health – as well as patient safety – at serious risk.

6.11. In November 2022, the Industrial Injuries Advisory Council (IIAC) recommended prescription of a number of long-term symptoms associated with Covid-19, designating it an occupational disease for Health and Social Care

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<sup>44</sup> Wilkinson E. Covid-19: Pandemic sickness pay rules for NHS staff to come to an end BMJ 2022; 378 :p1648

<sup>45</sup> Waters A. Covid-19: Reduction in payments for NHS staff with long term symptoms is “short sighted” BMJ 2023; 380 :p274

Workers who have experienced five named complications [LC/56 – INQ000320281].

- 6.12. In March 2023, LC Support produced a joint report with the Trades Union Congress (TUC): *“Workers’ experience of Long Covid”* [LC/57 - INQ000272240]. In this report, LC Support and the TUC called upon the government to designate Covid-19 as an occupational disease:

*“We urge the government to accept the recommendation of the IIAC and in addition recognise Covid-19 as an occupational disease beyond health and social care and those five named complications. This would entitle more frontline workers to protection and compensation if they contracted the virus while working and be essential for people who have lost income and work as a result of Long Covid.”*

- 6.13. The BMA and RCN has also called for the recognition of Long Covid as an occupational disease<sup>46</sup>. Thus far, the UK government is yet to designate Covid-19 as an occupational disease. It is important to us that the Inquiry considers the evidence in relation to Covid-19/Long Covid being designated an occupational disease. For example, a member of Long Covid Physio has been found to have suffered a workplace injury by the DWP. There is a risk of inconsistent and unfair decision making if there is not joined up thinking about Long Covid and in our view any relevant evidence or recommendation in the Inquiry should be referred, for example, to the Industrial Injuries Advisory Council for review.

- 6.14. This approach in the UK is in contrast with the approach of other nations, for example:

6.14.1. A report compiled by the International Labor Organization detailed the recognition of Covid-19 as an occupational disease and associated

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<sup>46</sup> The British Medical Association (BMA), “BMA and RCN urge Government to take urgent first steps to recognising Long Covid as an occupational disease”. 17 November 2023.

compensation schemes introduced by more than 50 countries [LC/58 - INQ000320283]

6.14.2. The Dutch government announced compensation payments of €15,000 for healthcare workers who are still unfit for work as a result of Long Covid.<sup>47</sup>

6.15. Further, the report by the BMA and Long COVID Doctors for Action found the following<sup>48</sup>:

- Around 60% of doctors with Long Covid reported that Long Covid impacted on their ability to carry out day-to-day activities on a regular basis
- Almost one in five respondents (18%) reported that they were now unable to work due to Long Covid
- Less than one in three (31%) doctors said they were working full-time, compared to more than half (57%) before the onset of their illness
- Nearly half (48%) said they have experienced some form of loss of earnings as a result of Long Covid

6.16. Long Covid has had a devastating impact on healthcare workers. To quote an article published in the British Medical Journal [LC/59 - INQ000320284], from a doctor suffering with Long Covid:

*Many of these people are ill because they were trying to save other people's lives, without looking after their own. To neglect them now because they can no longer provide the same level of productivity is shameful.*

## **7. The effect of Long Covid on mental health and wellbeing**

7.1. Long Covid is physiological (see all the research referenced above). The Inquiry has in the Rule 9 request dated 19 April 2023 asked us to address "*the effect of*

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<sup>47</sup> NL Times, 'Healthcare workers with Long Covid eligible for 15,000 euros compensation', 29 April 2023

<sup>48</sup> BMA, 'First major survey of doctors with Long Covid reveals debilitating impact on health, life and work', 4 July 2023

*long Covid on the mental health and well-being of long Covid sufferers during the relevant period*". These are profound given the devastating broad health impacts of the disease. But it is disappointing that the Inquiry is not also asking questions about the physiological impact, which means we fear it is unfortunately falling into the false characterisation of Long Covid as being caused by anxiety, insomnia or depression. These are false narratives which have been, and continue to be, extremely harmful to patients trying to seek help for their continuing symptoms. Long Covid causes physiological harm, as explained above.

7.2. There are also psychological consequences to people with Long Covid being repeatedly disbelieved.

7.3. As has been stated above, many suffering with Long Covid were dismissed by doctors and being told they were 'just' depressed and anxious and there was nothing wrong with their bodies. This disbelief of physiological symptoms has had significant negative impact on the mental health of those suffering with Long Covid. We consider that it is vital that the Inquiry does not compound this by disproportionately focussing on mental health consequences of disbelief, rather than providing an appropriate scrutiny of the physiological consequences of infection from Covid 19.

7.4. This does not mean that those with Long Covid do not suffer mental health problems. Of course, some patients do, which is understandable given the trauma from having to deal with a new chronic illness with little or no support, and for some those psychological problems arising from chronic illness are extremely challenging and further exacerbated by the loss of autonomy and employment. However, Long Covid is not a mental illness.

7.5. For many people trying to access healthcare was, and continues to be, a traumatic and exhausting experience. People were forced to advocate for themselves and had to fight to be believed in order to receive care. Many describe this as one of the worst aspects of their illness experience; and this has led some to go on to

develop Post Traumatic Stress Disorder. This was even more problematic for children; they and their families continue to face particularly difficult challenges when trying to obtain a diagnosis and care.

7.6. People with Long Covid suffer significant impacts to their mental health and wellbeing, including but not limited to:

- Losing weight due to loss of sense of smell and altered taste
- Gaining weight due to inability to undertake the activities they used to
- No longer being able to enjoy food due to loss of taste/smell
- Loss of identity due to significant cognitive impairment
- Loss of social contact due to significant ill-health; and
- Breakdown of family relations due to care needs or inability to care for others.

7.7. Isolation and loneliness have a significant impact on those with Long Covid, and there are unfortunately several documented cases of people who lost their lives to suicide as well as a number who have contemplated suicide<sup>49</sup>. Often this may not be due to depression but the constant unbearable pain, loss of jobs, homes and families/relationships, loss of identity and purpose, and not being believed by health professionals, friends and relatives. Feeling a failure when “pushing through” and enduring the physiological impact of Long Covid or trying to do their best to continue is also an exacerbating factor.

7.8. Our organisations have sought to draw attention to the psychological trauma experienced by people with Long Covid. Experiencing a serious infectious disease followed by prolonged, debilitating and frightening illness with an uncertain prognosis and invalidation from health professionals and loved ones has led to a great deal of trauma and mental ill-health. Many people, even those who were not deemed sufficiently ill to be admitted to hospital despite multiple visits to A&E, wrote their end of life wishes and spoke to loved ones about the prospect of not

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<sup>49</sup> The Guardian, *'My wife had long Covid and killed herself. We must help others who are suffering'*, 12 January 2022

surviving the illness. LC SOS presented at the National Suicide Prevention Strategy Advisory Group on 21 October 2021 about lived experience of those with Long Covid and risk of suicide. Sadly, as advocates, we recognise from our members and supporters the feelings of despair and hopelessness in the face of chronic illness, particularly where symptoms are dismissed.

7.9. Mental health and wellbeing are further negatively impacted by the pervasive and rational fear of the risks of reinfection. This is exacerbated by people with Long Covid not being regarded as a priority group for vaccinations, boosters or antiviral treatment, despite having proved to be particularly at risk to Covid-19.

## **8. The other effects of Long Covid**

8.1. Long Covid has had a profound effect on the lives of people and their families. The financial consequences of loss of work and burden of seeking treatment can be traumatising.

8.2. Since the pandemic, there has been a vast increase in the numbers of people who are economically inactive and out of the labour force due to long term sickness. It is self-evident that Long Covid is partially responsible for this. This is borne out in our members experiences, many of whom have been unable to work. The ONS stated in November 2023:

*“The number of working-age adults who are out of the labour market (known as “economically inactive”) because of long-term sickness has been rising since 2019, from around 2.0 million people in spring 2019, to about 2.5 million in summer 2022. This rise in long-term sickness started before the coronavirus (COVID-19) pandemic, but since the pandemic hit the UK in early 2020, the number of people out of work because of long-term sickness has risen by 363,000. A range of factors could be influencing this recent increase. We introduce some of these in this article, but more understanding is needed about the impacts of National Health Service (NHS) waiting times, long COVID, and the ageing workforce. Younger people have also seen some of the largest*

*relative increases, and some industries such as wholesale and retail are affected to a greater extent than others.”<sup>50</sup>*

8.3. In the above-referenced joint report of LC Support and the TUC [LC/57 - INQ000272240], half of respondents said they had to use their savings to financially support themselves, one in sixteen had taken out a private loan or debt service and one in sixteen were using food banks. One in seven respondents had lost their job because of reasons connected to Long Covid.

8.4. Furthermore, Long Covid significantly affects children’s and young people’s education. Preliminary evidence from LCK’s *Long Covid in Children and Young People (CYP) Education Experiences and Attendance Survey* [LC/60 - INQ000320285] shows that 69.2% of respondents report that their education status has been affected in some way by infection from Covid-19. Changes in education status include a significant reduction in hours, leaving education entirely and the implementation of a new provision of hybrid or home learning by the Local Authority.

8.5. The survey also shows that a child with Long Covid will lose an average of 20.6 learning hours per week and when scaled up to the total respondents of this survey it is 171,882 lost learning hours per year. When expressed relative to confirmed Long Covid diagnoses nationally for children and young people with symptoms for more than 12 months this equates to 1,091,800 lost learning hours per academic year. A total of 10.4% of respondents are currently temporarily away from school/college ill and 9.5% are currently too unwell to be in education.

8.6. There is substantial evidence that Long Covid is a disabling condition. For example, on 9 October 2023 a research team at the University of Leeds published ‘A National Evaluation of Outcomes in Long COVID services using Digital PROM Data from the ELAROS Platform’ [LC/64 – INQ000320289]. This study found that

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<sup>50</sup> Office for National Statistics (ONS), released 10 November 2022, ONS website, article, Half a million more people are out of the labour force because of long-term sickness

out of a sample of 5,318 patients, 3,395 showed significant new-onset symptom burden, functional disability, and deterioration of overall health since their first infection with Covid. Furthermore, the study found that in 3,438 patients the burden and disability in Long Covid are worse than in Diabetes Mellitus, COPD, Heart Failure, and Multiple Sclerosis. The study concludes that Long Covid “*is a new-onset condition with a significant burden of symptoms, functional disability and decline of overall health in affected individuals*” and in some individuals, persistent LC (>2 years of symptoms) is a Long-Term Condition with fluctuations that require long-term care with a similar strategy as other LTCs. This is clear evidence that Long Covid is an impairment capable of inflicting a substantial and long-term adverse effect on an individual’s ability to carry out normal day-to-day activities. Long Covid is therefore capable of being recognised as a disability under the Equality Act 2010 and should be treated as a disabling condition.

8.7. A recent study reported that Long Covid can significantly impair quality of life.<sup>51</sup> Functional impairment was worse than in patients who had a stroke (mean WSAS score of 16) and comparable to patients with Parkinson’s disease (the mean WSAS scores ranged from 22.9 to 24.8), both debilitating neurological conditions. The study found that over half of survey respondents reported losing one or more working days in the previous month.<sup>52</sup>

## **9. Research into Long Covid**

9.1. The delay in recognising Long Covid as a possible outcome of Covid-19, particularly amongst those who had not been hospitalised, subsequently delayed research into Long Covid and in particular research for those who had had Covid-19 in the community. Long Covid Support have been providing PPI involvement with PHOSP-COVID since November 2020 and have raised questions about the bar for hospital admission being set so high initially that there were patients with

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<sup>51</sup> Walker S, Goodfellow H, Pookarnjanamorakot P, et al Impact of fatigue as the primary determinant of functional limitations among patients with post-COVID-19 syndrome: a cross-sectional observational study BMJ Open 2023;13:e069217.

<sup>52</sup> Impact of fatigue as the primary determinant of functional limitations among patients with post-Covid-19 syndrome: a cross sectional observational study; British Medical Journal Open access 2023; 13: e069217

severe symptoms excluded from access to care. We have specified at paragraph 3.3 above specific examples. In our view these early assumptions may have contributed to the initial lack of prioritisation for research into non-hospital patients.

9.2. The first studies funded by the NIHR were only for those who had been hospitalised e.g. PHOSP-COVID and, later in Spring 2021, HEAL-COVID. However, there was no equivalent consideration funded by the established research funding councils that aimed to investigate the long-term effects that may be suffered by those who were not hospitalised, even where their symptoms were serious. There is extensive research showing that non-hospitalised patients suffered serious symptoms and harm to health.<sup>53</sup>

9.3. On 15 October 2020, the NIHR published the first “Living with Covid19” Themed Review [LC/61 - INQ000058418]. Members of LC Support participated in a focus group with Elaine Maxwell, the author of the review, in June 2020, which would provide evidence of the patient experience for the review. As noted in the introduction to the review:

*“Given the importance of the subject matter and the need for information to ensure people receive care now, we have taken the unusual decision to write this review despite the relatively small amount of published evidence. We worked with a steering group and a patient reference group who provided us with a broad range of expertise and perspectives.”*

9.4. The early conclusions of the review stated the following (our emphasis in bold):

*The evidence we have drawn together demonstrates a **significant and growing burden of need in a significant proportion of people who have been living with ongoing Covid19.***

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<sup>53</sup> ‘The prevalence and long term effects of Long Covid among hospitalised and non-hospitalised populations: a systemic review and meta-analysis’ December 2022, The Lancet

We found that:

- *There is a **current widespread perception that people either die, get admitted to hospital or recover after two weeks** but it is increasingly clear that for some people there is a distinct pathway of ongoing effects.*
- *A working diagnosis that is recognised by healthcare services, employers and government agencies would facilitate access to much needed support and provide the basis for planning appropriate services. While it is too early to give a precise definition, guidance on reaching a working diagnosis and a code for clinical datasets is needed*
- *People experience a wide range of fluctuating and multisystem symptoms that need to be acknowledged. A common theme is that symptoms arise in one physiological system then abate only for symptoms to arise in a different system.*
- *Ongoing Covid19 needs to be considered holistically (both in service provision and in research).*
- *The varying degrees of dependency mean support in the community should be considered alongside hospital one stop clinics.*
- *There are significant psychological and social impacts that will have long-term consequences for individuals and for society if not well managed.*
- ***Health and social care services are not equipped to support people living with Covid19. Staff need better information and education on the ongoing effects.***
- ***There is an urgent need to better understand the symptom journey and provide realistic expectations about progression.***

9.5. There was no public funding for Long Covid in non-hospitalised patients until the first NIHR funding call was announced in November 2020.<sup>54</sup> In this funding round, £18.5m was allocated to four large projects in February 2021 which were mainly

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<sup>54</sup> NIHR, 'New £20m call for research into physical and mental effects of 'long COVID'', 12 November 2020

focussed on the epidemiology and characterisation of Long Covid.<sup>55</sup> These projects are still ongoing and are now producing valuable data, for example the impact of Covid-19 infections on cardiovascular events.

9.6. By February 2021 it became clear that further funding was urgently needed to run more agile studies in order to identify potential therapies for people with Long Covid. The Long Covid Groups have consistently called for research, treatment and patient involvement. We refer to LC/1 - INQ000320227 of our advocacy including presentations to the NHS. Following advocacy from our organisations and a direct appeal from LC SOS to Matt Hancock, the second NIHR £20m call was focussed on treatments, healthcare services and diagnostics.<sup>56</sup>

9.7. In August 2021, the Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Address and Transform Existing Integrated Care Pathways (STIMULATE-ICP) study began. LC SOS has been a key collaborating partner in several ways: Lyth Hishmeh (co-founder) has been Patient and Public Involvement lead since design of the study; Ondine Sherwood, (co-founder) is on the Trial Steering Committee and Amitava Banerjee (trustee) is chief investigator of the STIMULATE-ICP study.

9.8. STIMULATE-ICP and other nationally funded studies for Long Covid have faced three types of challenges:

9.8.1. The embedded drug platform trial which was intended for repurposed therapeutics in Long Covid, faced delays, ranging from delays in consideration and approval of drugs by the COVID-19 Antivirals and Therapeutics Taskforce, delays of up to 6 months in approval of amendments by the MHRA. The approval of such amendments needs to be rapid and adaptive in any trial, but particularly in platform studies to ensure patient safety and scientific and clinical utility, which happened during the acute Covid trials such as RECOVERY and PANORAMIC.

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<sup>55</sup> NIHR, '£18.5 million awarded to new research projects to understand and treat long COVID', 18 February 2021

<sup>56</sup> NIHR, 'NIHR launches second £20 million Long COVID funding call', 25 March 2021

These delays are partly due to resource issues across healthcare and research during the pandemic and a lack of prioritisation of Long Covid research.

9.8.2. Resource constraints and strain on the NHS have meant that the Long Covid services, where STIMULATE-ICP is based, have had changing clinic models, lack of clinical and research staff due to both recruitment/retention issues and staff sickness (including due to Long Covid).

9.8.3. Misinformation regarding Long Covid remains an issue for STIMULATE-ICP and other Long Covid research and clinical practice, across health professionals, researchers and patients/public, and in both mainstream and social media. Incorrect information in some of these groups has affected recruitment to STIMULATE-ICP and underlines the central role of good quality scientific information about Long Covid.

9.9. There have been no further commissioned calls for research into Long Covid in community cases. Investigators are now required to apply to disparate funding streams for Long Covid research. This means that there is no coordinated response which would easily allow large collaborations and linking of investigators across disciplines. Of those studies which were funded, there have been delays in setting them up as the NIHR didn't prioritise Long Covid studies to the same extent as studies into acute Covid. The result is that two years since the funding for the second commissioned call was announced, only one of the funded studies has reported results (the PC-COS study).

9.10. In respect of Long Covid in children, to date there are no paediatric biomedical studies. The main research is the CLoCK Study [LC/62 – INQ000320287]. However, only a limited number of symptoms reported in Long Covid were assessed and it did not adequately account for the relapsing and remitting nature of Long Covid in children. LCK are collaborating with the University of Derby on researching Long Covid in children. LCK are also working with the Post Covid Condition Core Outcome Set in Children (PC-COS-C) study which is an

international collaboration. 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 7 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 [LC/63 - INQ000231940].

## **10. Inequality related issues**

10.1. From the early days of the pandemic, our experience is that people suffering with Long Covid symptoms have had to advocate for themselves in order to obtain healthcare. The condition was not recognised, even though post-viral illness is not new. As detailed above, people consulting their GPs were often met with disbelief and were diagnosed with anxiety or depression. This was also the case for highly educated professional people, including doctors, who were themselves disbelieved and dismissed by their colleagues.

10.2. If those from more privileged backgrounds were unable to receive help and acknowledgement, including by accessing private healthcare, then it is clear that those who were already subject to pre-pandemic health inequalities faced (and continue to face) many more barriers to care.

10.3. Much of the information sharing between patients has taken place online. Especially in the early days, informed patients were more knowledgeable about their condition than the doctors they consulted – as stated above, Long Covid is a condition where the impetus to drive forward research and develop treatments has come from the patient body<sup>57</sup>. Our organisations have observed through our membership that people from under-served groups and areas of deprivation suffer structural barriers to accessing patient support organisations for Long Covid sufferers. This means a disproportionate impact on those in under-served groups

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<sup>57</sup> Perego and Callard, How and why patients made Long Covid, *Social Science & Medicine Journal*, published on 7 October 2020

and areas of deprivation.<sup>58</sup> These inequalities extend to research, where minority groups are under-represented.<sup>59</sup>

10.4. The impact of inequality on the prevalence of Long Covid that our membership organisations have observed is reflected in the data from ONS showing that those in the most deprived quintile are 81% more likely to suffer from Long Covid as compared to those in the least deprived quintile.<sup>60</sup> Long Covid data from the Department of Health and Social Care dated 14 April 2022 also supports that patients from most deprived areas were disproportionately represented [INQ000193812].

10.5. Further, data from the Long Covid services suggests that the majority of the people who access the clinics are white, yet Covid-19 more severely and disproportionately affected those from minority ethnic communities. There are concerns around under reporting in minority ethnic communities.<sup>61</sup> A study by Southampton University aims to raise awareness among black and minority ethnic communities [LC/65 – INQ000320290]. Under-reporting in our opinion may demonstrate the adverse impact that the failure of public health communications about Long Covid had on health inequalities.

10.6. Research also suggests that more women experience Long Covid.<sup>62</sup> We already know that healthcare misogyny exists, and women struggle to get access

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<sup>58</sup> Ramasawmy M, Mu Y, Clutterbuck D, Pantelic M, Lip GYH, van der Feltz-Cornelis C, et al. (2022) STIMULATE-ICP-CAREINEQUAL (Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Address and Transform Existing Integrated Care Pathways) study protocol: Defining usual care and examining inequalities in Long Covid support. PLoS ONE 17(8)

<sup>59</sup> Smyth N, Alwan NA, Band R, Chaudhry A, Chew-Graham CA, Gopal D, et al. (2022) Exploring the lived experience of Long Covid in black and minority ethnic groups in the UK: Protocol for qualitative interviews and art-based methods. PLoS ONE 17(10)

<sup>60</sup> Office of National Statistics (ONS) (February 2023) 'Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK'

<sup>61</sup> Smyth N, Alwan NA, Band R, Chaudhry A, Chew-Graham CA, Gopal D, et al. (2022) Exploring the lived experience of Long Covid in black and minority ethnic groups in the UK: Protocol for qualitative interviews and art-based methods. PLoS ONE 17(10): e0275166.

<sup>62</sup> Bai F, Tomasoni D, Falcinella C, Barbanotti D, Castoldi R, Mulè G, Augello M, Mondatore D, Allegrini M, Cona A, Tesoro D, Tagliaferri G, Viganò O, Suardi E, Tincati C, Beringheli T, Varisco B, Battistini CL, Piscopo K, Vegni E, Tavelli A, Terzoni S, Marchetti G, Monforte AD, 'Female gender is associated with long COVID syndrome: a prospective cohort study', Clin Microbiol Infect. 2022 Apr;28(4)

to services, especially services that are proportionate for their needs. This has been no different when it comes to accessing services for Long Covid, and LC Support provided evidence to the DHSC 'Women's Health Strategy: Call for Evidence' in June 2021 [LC/66 - INQ000272255].

10.7. The healthcare response to Long Covid also suffered from a historical inability to be disability inclusive. Disability is always an afterthought and a secondary response when dealing with healthcare conditions.

10.8. Additionally with respect to Long Covid services, as we have highlighted above, there is significant variation in the treatment offered around the country resulting in a postcode lottery of care. Because of this, inequalities exist between those who can afford to pay privately for treatments, specialists and tests and those who must rely on the NHS.

10.9. The pre-pandemic structural inequalities which resulted in those from minority ethnic, deprived and under-served communities being disproportionately affected by Covid-19 also follow through to those who suffer from Long Covid. Patients from such communities have found it even more difficult to convince healthcare professionals of the existence of their illness, and then struggled to access treatment and rehabilitation.

## **11. SUGGESTED LESSONS TO BE LEARNED AND RECOMMENDATIONS FOR FUTURE PANDEMICS**

11.1. The Long Covid Core Participant Group respectfully invites the Inquiry to make the following recommendations:

11.2. **Recommendation 1:** We believe that it is essential when considering the health impacts of any infectious disease that **resulting morbidity is given sufficient weight in decision-making from the earliest possible point in time.** This was not the case during the ongoing Covid-19 pandemic. A fundamental

aspect of a 'healthcare systems' approach is whether lessons were learned from previous coronavirus infections (including SARS and MERS) in regard to the likelihood of chronic illness. There was a body of evidence that survivors of SARS and MERS suffered from a constellation of persistent symptoms similar to Long Covid, yet despite this, the healthcare system was completely unprepared for the long-term morbidity caused by infection from Covid-19.<sup>63</sup>

11.3. **Recommendation 2:** Healthcare systems can only respond adequately to longer-term sequelae when they are actively monitoring and counting it. The UK should ensure that **decision-makers prioritise the early collection of syndromic surveillance data of longer-term sequelae**. This must extend to include ongoing monitoring of prevalence data on longer-term sequelae so that healthcare systems can prepare for a unified approach to the clinical definition, diagnosis, care and treatment of longer-term illness, from an early stage in a pandemic.

11.4. **Recommendation 3:** The Government should work with partners such as ISARIC who have protocols in place to prepare for novel pathogen outbreaks including case reports from long term sequelae. Also, it should seek to develop a closer working relationship with the World Health Organisation in regard to clinical guidance, identification of symptoms both acute and longer term and infection control.

11.5. **Recommendation 4:** An emphasis was placed on protecting the NHS so that it would not be overwhelmed during the acute phase of infection. The onset of long-term illness on a significant cohort of the population impacts healthcare and

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<sup>63</sup> In the Academy of Medical Science report commissioned by Chris Whitty, CMO, "Preparing for a challenging Winter 2020/21" post-acute sequelae were recorded to be "*well documented*" from previous pandemics.; Nalbandian, A., Sehgal, K., Gupta, A. et al (2021) 'Post-acute COVID-19 syndrome' Nat Med 27, 601–615 : *Post-acute COVID-19 syndrome* stated that "*survivors of previous coronavirus infections, including the SARS epidemic of 2003 and the Middle East respiratory syndrome (MERS) outbreak of 2012, have demonstrated a similar constellation of persistent symptoms, reinforcing concern for clinically significant sequelae of COVID-19*"

other social support services – and the economy – for an indefinite period into the future. It is important that **future planning for a pandemic takes into account the long-term costs and consequences of infections on individuals who do not recover within a short period of time** as well as the short-term consequences of high levels of acute infections.

11.6. **Recommendation 5:** The disease burden on children and young people should be recognised without comparison to adults. Children and young people who suffer illness should be heard and listened to. They should be provided with appropriate care pathways and be given appropriate educational support.

11.7. **Recommendation 6:** Patients should be at the heart of planning provision and service development. The voices and lived experience of patients should be heard and actively engaged with by decision makers. Patient and patient groups should participate in research and planning.

11.8. **Recommendation 7:** Ventilation, clean indoor air measures and PPE measures must be at the forefront of planning and lessons learned from this pandemic. That lesson has not yet been learned: for example, mask mandates in hospitals have largely been removed despite the constant cycle of reinfection from Covid-19.

11.9. **Recommendation 8:** Decision makers should measure the impact of the pandemic using metrics like QALYs and DALYs to ensure their policies account for the devastating impact that chronic illness has on the population's quality of life. Other measurements like EQ-5D-5L are also useful to inform clear data and metrics to assess health related quality of life.

11.10. **Recommendation 9:** There must be practical and financial support for workers and those adversely affected by Covid-19 contracted at work. The number of people not working in the UK due to long term sickness has risen to a new record, with nearly two and a half million not working due to health problems according to

the ONS, with “perhaps Long Covid having an impact”. As noted above, the Netherlands is among the countries that have introduced a statutory scheme for compensation to healthcare workers who suffer Long Covid and **we support Long Covid being recognised as an occupational disease and disability with support for those that require long term sick pay or other compensation.** The special provisions for Covid-19 have ended and now healthcare workers can only claim statutory sick pay. Employers also **should** be required to make reasonable adjustments for people with Long Covid, taking account of the fact that recovery is not linear. There needs to be consideration of the episodic fluctuating and multi-dimension disability of Long Covid with adequate support for employees to facilitate and retain employment when appropriate. The Inquiry should refer relevant evidence and recommendations to the IIAC. Furthermore, it is imperative to consider the impact on the economy more broadly on account of a higher number of economically inactive people as well as those unable to work to their former capacity.

**11.11. Recommendation 10: A more focussed and better funded approach to research** into Long Covid would lead to deeper understanding of the mechanisms behind post-viral illness, help develop better therapies and thereby avoid repeating the same mistakes in the next pandemic. Clinical and scientific societies should be created for post viral illnesses. These should have dedicated funding to account for the historical neglect of these illnesses. Although there was some research into Long Covid during the first year of the pandemic, there is still a paucity of publicly funded studies into developing treatments for the condition, leaving most suffering with no prospect of therapeutic intervention. Many patients have been forced to pay privately in the hope of receiving better care and wider access to repurposed drugs, which are currently not approved by NICE due to the lack of randomised controlled trials. However, this then disadvantages and excludes many patients who are unable to pay privately. Therapeutic trails for long-term sequelae must be rapid and adaptive in the same way that acute Covid19 trials were during this pandemic.

11.12. **Recommendation 11: A preventative approach** to safeguard future health should be applied to government policy and practice. Those that have suffered harm from a disease or virus should be listened to and the primary consideration of the State should be about providing timely, accurate and transparent public health information, disseminating training and knowledge amongst healthcare service providers and prioritising the overall health of the public. Dismissing patients because a new disease is not adequately understood has been profoundly harmful and dangerous. It must not be left to ill patient advocates to fight to be taken seriously, receive recognition and receive treatment.

### Statement of Truth

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth.

Personal Data

Signed: \_\_\_\_\_

Sammie McFarland

Dated: 28 November 2023

Personal Data

Signed: \_\_\_\_\_

Dr M A Faghy

Dated: 28 November 2023

Personal Data

Signed: \_\_\_\_\_

Ondine Sherwood

Dated: 28 November 2023

**Personal Data**

Signed: \_\_\_\_\_

Natalie Rogers

Dated: 28 November 2023