UK COVID-19 PUBLIC INQUIRY

MODULE 8

DOCUMENTS IN SUPPORT OF THE CORE PARTICIPANT APPLICATION ON BEHALF OF LONG COVID KIDS AND LONG COVID KIDS SCOTLAND

Witness Name: Sammie McFarland
Statement No.: 1
Exhibits: SM/1 – SM/50
Dated: 25 September 2023

UK COVID-19 INQUIRY – MODULE 2

WITNESS STATEMENT OF SAMMIE MCFARLAND
ON BEHALF OF LONG COVID KIDS

Introduction

1. My name is Sammie McFarland. I am the Chief Executive Officer and co-founder of Long Covid Kids. Long Covid Kids is a registered charity (Charity Registration 1196170). The charity's registered address Fletcher & Partners, Crown Chambers, Bridge Street, SALISBURY, SP1 2LZ.

2. I make this statement on the basis of my own knowledge or belief. Where something is outside my own knowledge, I will refer to the source. I am happy to give oral evidence to the Inquiry in Module 2 to expand upon the matters set out in this statement or address any other issues arising.

3. In this statement I will detail:
   I. Who we are and what we do;
   II. Long Covid in children;
   III. Long Covid Kids' engagement with and representations made to Government
   IV. The impact of Government decision making on children with Long Covid
   V. Case studies of Long Covid children's experiences.

4. I rely on the Long Covid Kids' Rule 9 questionnaire response dated 15 December 2022 and will add to that statement.[1] Since preparing Long Covid Kids' Rule 9 questionnaire response I have identified further documents relevant to the Inquiry's Terms of

[1] INQ000099699

Reference and the scope of Module 2 which I now refer to and exhibit to this statement. I will also, in this statement, set out various reports on the impact of the pandemic and government decision making on children with Long Covid as well as my own view based on my own experiences and those gathered from my contact with people with Long Covid.

5. For most children initial recovery from acute Covid-19 will be swift. For some children, however, that is not the case; 186 children have died from Covid-19 **[SM/1 - INQ000272156]** 38,079 children were hospitalised with Covid-19 **[SM/2 INQ000272168]** and an estimated 69,000 children are living with Long Covid [**SM/3 INQ000272181**]

6. The World Health Organisation ("WHO") states that in children and young people "*symptoms generally have an impact on everyday functioning such as changes in eating habits, physical activity, behaviour, academic performance, social functions (interactions with friends, peers, family) and developmental milestones.*"[2]

7. Thousands of children have suffered varying degrees of life changing and long-term harm to health. In a recent study relating to the Omicron wave, 12-16% of infected children and young people met the research definition of Long Covid at 3 and 6 months after infection.[3]

8. The importance of their voices to this Inquiry cannot be understated. To my mind these children have suffered twice over; from both the direct and indirect impacts of the pandemic. They have felt both the devastating impact of the response to the pandemic - in terms of lockdowns, loss of face-to-face education, interference with education, social contact with peers and all the disadvantages children suffered generally, and then on top of that they have suffered ongoing harm to their health from prolonged and debilitating symptoms of Covid-19.

9. Children, their short-term and their long-term health, should be taken seriously. The experience of children suffering from long-term health impairments and disability caused by Covid-19 should be at the heart of this Inquiry. All parents should be told

[2] World Health Organisation (2023) 'A clinical case definition for post COVID-19 condition in children and adolescents by expert consensus' at page 6.
[3] Pereira, Mensah, Nugawela, Xu, Shafran et al (2023) 'Long COVID in Children and Youth after infection or reinfection with the Omicron Variant : a prospective observational study, The Journal of Paediatrics. Available here: https://www.jpeds.com/article/S0022-3476(23)00311-6/fulltext.

about the risks, including the risks arising from re-infection. Whether your child develops Long Covid is a roulette and there should be adequate warnings about this risk.

I. My personal experience

10. I did not ask to be a patient advocate; I have had to become one. The devastating experience of Long Covid on my daughter's health means I have found myself fighting for children who have suffered harm. I have received abuse on social media, been harassed and told that I am making up the daily battles with her health struggles.

11. It is hard to express in words the devastating impact Covid-19 had on my youngest daughter, KM. Before she contracted Covid-19 she was a healthy, extremely active 14-year-old. She trained in ballet, aerial silks (circus aerobics like Cirque de Soleil), and aerial hoops. She was extremely fit and able. Like many children that we support, over a period of weeks, she did not get better and was completely exhausted and exhibiting a myriad of symptoms. As one example, after a short dog walk, she would turn white and sleep for 3 hours. I knew something was wrong, yet it was difficult to obtain a medical appointment for her.

12. However, in June 2020, during a blood draw for myself, a nurse who had never met my daughter before, told me that she was mimicking my symptoms (I also experienced fatigue and multiple other symptoms after the Covid-19 infection although not the same symptoms as my daughter). This was devastating to hear. I felt that I had been a bad mother and had failed to care for my daughter. I complained to the GP Surgery about the comments made by the nurse, and I received a letter of apology dated 25 June 2020 [**SM/4** **INQ000272193**]

13. There was no information provided to us about post-viral conditions let alone Long Covid. I had sought advice from my GP over the telephone, and in person when he came to our garden to take blood. On more than one occasion I was advised to "do more each day to get better". I was so keen to get better and followed the advice despite feeling significantly unwell after activity. I set up a fun and gentle assault course in the garden to motivate us to "do more" and rebuild her stamina just as the GP had advised. KM started the assault course but after less than ten minutes she experienced

agonising pain in her chest, she turned white and clutched her chest. After this collapse, she was unable to get out of bed for eight months unaided, or without immediate deterioration to her health. She was unable to maintain her personal care or complete any of her normal activities and was not attending school. Sometimes she was unable to respond to us. She has suffered many consequences; she cannot participate in fulltime education or usual activities, and the duration of her illness and the ongoing dismissal of her symptoms have impacted her mental health and affected her higher education options. It has been extremely distressing to watch my child who had been previously completely healthy, happy, and dancing around being unable to move and full of self-doubt. It was like watching my child fade away - she is no longer the child she was.

14. Sadly, KM's experience was not isolated – there were in 2020, and remain to this day, several thousands of children who have suffered life changing loss of health due to infection from SARsCOV-2. I have included within my statement case studies of other families who have been affected by Long Covid.

15. Whilst the narrative that Covid-19 is mild in children is widespread, as a parent and person who has borne witness to the devasting harm caused to children in our group, this is difficult to hear as there is no way of knowing which child will next suffer prolonged damage to health from mild Covid-19, and in some cases varying degrees of disability.

II. **A brief overview of Long Covid Kids**

16. Long Covid Kids was established in September 2020 by a group of families whose children became victims of Long Covid. Long Covid Kids supports, represents, and advocates for children and young people living with the ongoing symptoms of Covid-19 known as Long Covid. This includes the families/caregivers and education and health professionals working with them. Long Covid Kids is managed by me, one part-time employee, a small team of volunteers and the Charity's Board. Our volunteers have suffered long-term harm from SARS-CoV-2 infection. Long Covid Kids supports over 11,000 families and has over 29,000 Twitter followers and over 4,000 Instagram followers.

17. Long Covid Kids campaigns to reduce the risk of children becoming infected with Covid-19 by providing information on infection harms and layers of protection available in order that parents and carers can make informed choices and risk assess for the benefit of the children that they care for. We also lobby for adaptions to be made for affected young people in educational establishments.

18. We raised awareness that children were getting sick with Covid-19 and not recovering, raising concerns about the range of symptoms children experience, lack of paediatric clinical case definition, lack of public health messaging and the urgent need for health care support. We also raise awareness about the impact of Long Covid on children including the loss of education caused by children being on long-term sick leave from school and lack of support and awareness in education settings. We also advocate to raise awareness of the impact on parents being unable to work due to the need to look after chronically ill children, the impact on siblings, the need for vaccines for children and called for biomedical research for children.

19. Long Covid Kids was set up by me with the support of Frances Simpson in September 2020. Both Ms Simpson and I contracted Covid-19 in March 2020. Both our children also contracted Covid-19, and thereafter did not recover. In stark contrast to the public health messages we heard, we did not experience short symptoms and our acute illnesses, deemed mild or non-severe, extended to debilitating and long-term damage to health. We connected with other people through social media that suffered ongoing debilitating symptoms. I initially was in contact with about seven families with children who had Covid-19 but seemed not to have recovered and were experiencing extremely distressing ongoing symptoms. I should be clear that the impact and daily impairment from Long Covid can be very significant: it is a serious illness and can cause varying degrees of disability as I have described in my daughter's case above.

20. In order to raise awareness about Long Covid in children, Long Covid Kids made a film in September 2020. The film "Our Unhappily Ever After", released in October 2020, was put on YouTube and shared on social media. [**SM/5** **INQ000272195**]

21. After sharing the film, around 300 families contacted Long Covid Kids on Facebook. Suddenly we were offering support to families that had been through the same experience as our core group of seven families had. They described it as a "life raft." I

felt validation as other families were experiencing the same lengthy recovery despite Government messaging that children were not affected by Covid-19 infection. This awareness gave me the strength to start campaigning. Each family's experience was equally as distressing as ours; similar, and yet unique. I couldn't leave people struggling and there was no help for my own daughter either.

22. As a group of families, we had not had any support from General Practitioners ("GPs") about post-viral conditions and there was a complete lack of awareness (and therefore treatment). We had all been told or made to feel, that we were neurotic parents. It remains a point of frustration and hurt that we were made to feel like this when it was well-known that some people, including children, contract Long Covid, and enduring post-viral illness is not a new phenomenon. [**INQ000146629**, **INQ000192120**]

III. Paediatric Long Covid

23. From the outset of the pandemic, there has been a failure to adequately communicate the risk of infection, death and serious long-term illness and consequences in children. This negatively impacted children and young people who suffered long-term damage to health from Covid-19. We have consistently been concerned about the lack of information published by the government, the Royal College of Paediatrics and Child Health, and by healthcare providers on the risk of Covid-19 on children. Early public health statements suggested that Covid-19 posed only a minimal risk to children, however our members and supporters' children's lived experience was completely contrary to this. It remains extraordinary to me that in the face of growing evidence of long-term sequelae in children, the response was to minimise the experiences of these children.[4]

24. Long Covid Kids participated in stakeholders' meetings with the WHO about the definition of Long Covid for children. We raised concerns about the focus on anxiety as a key symptom when the evidence from FAIRHealth's 2022 exercise shows that in 0–12-year-olds, it was not even in the top five diagnoses.[5] As parents that have had to

[4] UK Chief Medical Officer, Statement from the UK Chief Medical Officers on schools and childcare reopening, 23 August 2020

[5] FAIRHealth (2022) Patients Diagnosed with Post-COVID Conditions – An analysis of Private Healthcare claims using the official ICD-10 Diagnostic Code. Available here: https://s3.amazonaws.com/media2.fairhealth.org/whitepaper/asset/Patients%20Diagnosed%20with%20Post-COVID%20Conditions%20-%20A%20FAIR%20Health%20White%20Paper.pdf.

fight for help for our children and have repeatedly been dismissed as being over anxious or for having mental health problems causing symptoms, this is a concern. Mental health problems certainly arise in unwell children, not least because of their poor experience of health care and their loss of health, of social interaction and of education, as well as the pain and concern they experience from suffering prolonged symptoms whilst everyone else in their peer group moves on.

25. Prevalence of Long Covid in children has become highly debated and contentious, partly because of inconsistencies in age groups reporting data. From our perspective a cautious approach should be taken to support the children suffering from debilitating symptoms. It is a significant health burden which drastically impairs their quality of life, including access to education, family and social functioning. Rather than dismissing children, the voices of children with Long Covid should be listened to so that their experiences can be at the centre of changes and improvements.

IV. Our engagement with government and decision makers

Overview of key engagement with government

26. From an early stage, we sought to engage with the Government, healthcare providers and schools. Harm to children from Covid-19 infection has been consistently overlooked and public messaging about the risks of Long Covid to children has even been dismissive despite the Government being presented with evidence of its devasting effect upon some children. Long Covid Kids has raised concerns about rates of transmission of the disease, infection harms, risks of Long Covid, mitigation measures in schools and asked that Long Covid be taken into account in decision making on non-pharmaceutical interventions (NPI).

27. We were the first to identify the risks of Long Covid in children as we saw our children suffer and fail to recover. Despite turning to the Government and GPs for help, we received no treatment and witnessed our children suffer.

28. One of our members, Ms Simpson joined our group because she was concerned over the fact that her children were sick and did not seem to be recovering. Ms Simpson had connected with other families through adult Long Covid networks and found that there were many families that had children with suspected Long Covid who were not getting

support from the health care system. In order to prove that there was a substantial cohort of children with Long Covid, Ms Simpson conducted a survey on Long Covid in children and young people which was published in the British Medical Journal in October 2020 [**SM/6** **INQ000272196**

29. In the first year of the pandemic, Long Covid Kids had to demonstrate that children and young people also suffered from Covid-19 as there was little public information available that children and young people could suffer from debilitating symptoms and from Long Covid. On the Long Covid Kids Facebook page members would support each other to draft letters to hospitals, to GPs, and to Members of Parliament ("MPs") to gain recognition that Long Covid existed and raise awareness so that other children and young people would be protected from harm with mitigations. Members received responses throughout the first year offering minimal support or minimising the risk of Long Covid in children [**SM/7** **INQ000272197** We therefore spent the first year evidencing the impact of Covid-19 infection and Long Covid on children and young people using lived experiences.

30. We used social media to build up awareness of Long Covid, sharing examples of cases, images and quotes from families, and ran surveys and polls in our support group which we would then share the results of to generate conversation about Long Covid in children.

31. I refer to and produce a chronology of the work Long Covid Kids has undertaken between January 2020 and Spring 2022 [**SM/8** **INQ000272218** I have identified some of the key events here.

32. On 23 December 2020, I wrote to Chris Loder MP on behalf of Long Covid Kids, 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 [**SM/9 - INQ000272219**

33. On 7 January 2021, Long Covid Kids wrote to Layla Moran MP (who led the All Party Parliamentary Group ("APPG") on Coronavirus) stating that Long Covid Kids represented over 400 children and "*almost all the stories are the same*", they were all struggling to receive adequate healthcare support. [**SM/10 -** **INQ000272145**

34. In the lead up to the first parliamentary debate on Long Covid on 11 January 2021, Long Covid Kids wrote to MPs as part of the Parents United Against Unsafe Schools campaign, raising concerns about infection rates and Long Covid in children and young people. This took the form of a briefing sent to MPs on 11 January 2021 [**SM/11 - INQ000272147** The briefing stated:

> *"A 70% more transmissible variant is now in play, and the prevalence of long-term symptoms and life-long disability being incurred by children and young people as the result of coronavirus infection is uncertain. Before attempting to widen the opening of schools, we recommend the government ensure:*
> - *A significantly lower rate of infection within the population*
> - *The development of safety measures such as class size limits to facilitate social distancing and the reduction of the risk of airborne transmission, based on published and appropriate scientific data*
> - *That schools are provided with sufficient resources to enact the safety standards set out above".*

35. From early 2021, members of Long Covid Kids attended the Long Covid Ministerial Roundtables, initially chaired by Lord Bethell of Romford. At these meeting we raised concerns about the minimization of the risk of serious long-term illness in children. Long Covid Kids attended Ministerial Round Tables on Long Covid on 23 February 2021 [**INQ000060080**], 30 March 2021 [**SM/12** **INQ000272148** 16 June 2021 [**INQ000061094**], 21 July 2021 [**INQ000061418**], 23 September 2021 [**INQ000067049**] and 7 December 2021 [**INQ000067606**].

36. On 26 January 2021, Fran Simpson and Charlie Mountford-Hill and myself gave evidence on behalf of Long Covid Kids to the APPG on Coronavirus which was relied upon in its report on Long Covid in March 2022 [**SM/13** **INQ000272149** I shared my personal experience and raised concerns that the Government had not communicated that children can suffer long term lasting effects and the common symptoms of Long Covid in children. I also said that I wanted the Government to recognise transmission via aerosol transmission to stop people becoming infected and ensure that schools were safe for children.

37. At paragraphs 17 – 23 of the report, the APPG made findings and recommendations relevant to Long Covid in children. Notably the APPG found that the UK Government's Covid-19 Policy applicable to educational settings failed to adequately protect pupils from contracting Covid-19 and therefore resulted in their developing Long Covid. The APPG acknowledged the wide range of symptoms experienced by children; it found that the UK Government had failed to adequately acknowledge the prevalence of Long Covid among children and that the UK had failed to establish specialized care pathways for children living with Long Covid.

Engagement concerning schools – Safety, Ventilation and Mitigation measures

38. The administrative decision-making around advice to schools is an important aspect of our work; much of our work is centred on minimising the risk of Long Covid in children and young people in schools.

39. On 12 April 2021, with Safe Ed for All, Long Covid Kids wrote to then Secretary of State for Health and Social Care, Matt Hancock MP, raising concerns about risks of acquiring Covid-19 and mitigation measures in schools. [**SM/14** **INQ000272150** The letter requested a meeting and stated:

> *"Schools – Mitigation Measures Required URGENTLY*
>
> - *Improved ventilation and monitoring in all classrooms to reduce the risk of SARS-CoV-2 airborne transmission*
> - *Masks (multi-layer) mandated in secondary, encouraged in primary*
> - *Social distancing in primary and secondary*
> - *Remote learning / rotas to reduce the numbers in school classrooms*
> - *Suspension of fines during the pandemic (as per Scotland & Wales)*
>
> *Please do whatever you can to help the Department for Education understand that safety improvements are necessary".*

40. On 4 May 2021, Long Covid Kids wrote to the Secretary of State for Education, Gavin Williamson MP, (copied to Education Secretaries for the Devolved Administrations) about mitigation measures in schools. [**SM/15** **INQ000272151** This was part of a campaign by Parents United. The letter stated:

"It is essential that the UK achieves effective suppression of Covid19, and the safe reopening of schools plays an essential part in this. A further spike in infections following the current lockdown would pose a range of unacceptable risks, including:

- *the proliferation of further variants, which threaten our reliance on current vaccines as a pathway out of the Covid crisis*
- *compounding the already abhorrent UK death toll, presently standing at around 114,000 increased numbers of Long Covid suffers, whose condition is poorly understood and may yet prove to cause permanent disability*
- *further prolonged lockdowns, harsh restrictions, economic decline, psychological damage, and harm to the education and well-being of children*

The previous full reopening of schools in September contributed significantly to the current wave. Government data indicates that, when schools were fully open, school-aged children were twice as likely as the general population to be the index case within a household, with secondary school-aged students being 7 times more likely to be the index case."

41. Long Covid Kids did not receive a response to this letter.

42. On 9 July 2021, Long Covid Kids wrote to the then Secretary of State for Health and Social Care, Rt Hon Sajid Javid MP [**SM/16** **INQ000272152** stating that:

"*We urge you to consider the lived experience of children with Long Covid, and early evidence from researchers when creating policy. The health devastation of Long Covid on children is already impacting the workforce, creating poverty as parents lose their jobs while caring for children enduring unnecessary chronic health issues.*"

43. In this letter, we raised various concerns that there was no paediatric clinical case definition for Long Covid and so our members reported having difficulties accessing help, requested that the list of acute symptoms be updated, that the government acknowledge children could get Long Covid and requested measures to minimise infection. The measures suggested included the reinstatement of face masks in schools and funding for CO2 monitors and high efficiency particulate air (HEPA) filtration for schools. We received no response to this letter.

44. On 23 September 2021, Long Covid Kids met with Rt Hon Sajid Javid MP who chaired a Ministerial Roundtable on Long Covid [**INQ000067049**]. Long Covid Kids recorded a blog post on 28 September 2021 which sets out the matters we raised with Sajid Javid. [**SM/17** **INQ000272153** These were:

> • *"The symptom list on the NHS and Government websites needs updating*
> • *Masks must be reinstated in schools including primary schools*
> • *Statistics: 31% of all cases are currently in ages 5-14 years olds. 80% of hospitalised children are admitted "due to" Covid. 60% of those have no underlying medical condition.*
> • *Children are unable to obtain referrals to Long Covid hubs.*
> • *Chris Whitty states that it is inevitable that unvaccinated children will catch Covid.*
> • *Prevention needs to be a focus. We need mitigation measures in schools to protect NHS resources and the long-term health of children and families.*
> • *The average age of children in our Long Covid support group is 10 & this age group has no protection.*
> • *There is no cure for Long Covid, prevention must be the focus. We need a child focused public awareness campaign.*"

45. On 2 November 2021, Long Covid Kids published a statement raising concerns about the decision of the JCVI not to recommend vaccinations for children. [**SM/18 - INQ000272154**]

46. On 29 November 2021, Long Covid Kids attended a meeting with Rt Hon Jeremy Hunt MP. Long Covid Kids stated that tens of thousands of children and young people are at risk of developing Long Covid, without us fully understanding the development impact of this and that a key action would be to offer vaccination to children, with the aim of reducing individual risk, as well as that of communities and wider society and educational disruption [**INQ000249053**].

47. On 21 February 2022, Long Covid Kids issued a joint statement with Long Covid SOS raising concerns about removing all Covid measures [**SM/19 - INQ000272155**]

> "*Long Covid has never formed part of policy making decisions during this pandemic, despite repeated requests on our part both in writing and in person to ministers. People with Long Covid need to protect themselves from reinfection, which can seriously*

exacerbate symptoms. They and the millions of clinically vulnerable will effectively be forced to shield and become prisoners in their own homes. Since we do not know who will get Long Covid, or how long those living with Long Covid will remain sick, all members of society remain vulnerable."

48. In March 2022, Long Covid Kids wrote to Layla Moran MP, Damien Hinds MP and Andrew Gwynne MP [**SM/20** INQ000272157 **SM/21** INQ000272158 **SM/22** INQ000272159 requesting their support for the scheduled visit of children and young people with Long Covid to the Prime Minister's office at 10 Downing Street on 1 April 2022.

49. On 1 April 2022, a group of children and young people with Long Covid delivered Long Covid Kids' support guide to Downing Street [**SM/23** INQ000272160 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 addressed to Boris Johnson MP describing the toll this illness has taken on their lives [**SM/24 -** INQ000272161 Extracts from some of these letters have been reproduced below:

    49.1. K's [age 16] letter to Boris Johnson stated **"***I got infected with Covid in March 2020. My symptoms started off as mild; a slight cough, heart palpitations and weakness…I started getting better, for a month I felt more like my previous self. This is when Long Covid came in, it hit me like a brick. I was severely weak needing help to eat, drink and go to the loo. I was like this for 8 months. It took a massive hit onto my mental health. I became very depressed, I started self-harming and my anxiety increased to the level of having a panic attack every time I left the house. During this time everyone was telling me I still wasn't ill. I started getting bullied at school and online it felt like the whole world was against me. I have been diagnosed with 2 ovarian cysts, POTs, and a heart murmur with many things unsolved. We have only got a diagnosis because we pushed hard for it…I am still in pain every day. I am on so many meds (which come with awful side effects). I struggle to eat and drink, I can't go to school. I am in so much pain mentally and physically. Please help to stop others becoming like me. I shouldn't have had to get this ill for someone to do something. I deserve a normal happy life. So open the windows and make tests free again. Make a difference. Stop making everyone ill. Stop ignoring us.* "

49.2. A's [age 10] letter to Boris Johnson stated "*I lived[…]with my mum, step-Dad and three cats, Tiny, Storm and Evie. My Dad lives near you in London and he comes to see me every month. I have had Long Covid for 2 years, since I was 7 and it has been absolutely horrible[…] I have a wheelchair now because my legs hurt when I walk and I am too tired to do anything, even fun things. I saw my friends last weekend and that was the first time since before Covid started. I feel like they are not my friends anymore because we are all different now. They don't understand why I've not been at school and they don't understand what Long Covid is like.*"

49.3. J's [age 11] Letter to Boris Johnson stated: "*I am 11 years old and I have had Long Covid for nearly 15 months after getting Covid in January 2021. It's been a very difficult journey for me. Having Long Covid means I can't do anything I used to enjoy, like sports, school, walking my dog and even caring for my bunny. I used to go to dance classes, swimming, gymnastics, karate, I used to go on long walks with my family, I was able to hang out with my friends, go to sleepovers and I was also able to do a full day at school; I can't do any of that now and I need a wheelchair as I can't walk long distances. My arm has started to hurt just writing this letter. Now I struggle to do two hours of school. It doesn't feel like school anymore. I haven't done a full week or a full day in months. I used to be so excited about the future, but now I don't know what it will be like. Here are some questions I would like to know the answers to; Why isn't there more research into Long Covid in children like me? Will you try to help me and the thousands of other children with Long Covid to get better? Why won't you or the government make schools safer and decrease the amount of Covid? I am worried about more children getting sick. I have missed a year of school, how will you help me to catch up and how will it affect my future? I can't do school since I had Covid for a second time last summer, because my brain just doesn't work and I can't think or concentrate. It stresses me out and I get frustrated and that makes my Long Covid and PANS symptoms even worse. I can't even write this letter properly because my hands hurt so I had to type and need my Mum to help me a lot because typing this letter has taken me 3 days so far!*"

50. The visit was planned in coordination with staff at Downing Street, so Long Covid Kids had to provide the details of the children and adults attending for security. The children were assured that their individual letters would be received by the Prime Minister's office. The visit to Downing Street required significant effort. I refer to and produce [**SM/25** **INQ000272162** being the letter I sent forwarding the Prime Minister's office the letters.

51. Unfortunately, neither the Prime Minister nor anyone from his office met the children and they did not receive a response to their handwritten letters; instead, we received a response from DHSC, on behalf of the Prime Minister, dated 1 June 2022 [**SM/26** **INQ000272163** We were therefore deeply shocked and upset by the response received. Instead of recognition of the children's physical experiences, or the work of our charity led by volunteers, we received what appeared to be a standard letter on the impact of Covid-19 on children's mental health.

52. On 28 June 2022, I followed up in writing to the Prime Minister by letter [**SM/27 - INQ000272165**] reflecting these views. Long Covid Kids received a response from James Morris MP, on 6 September 2022, in which there is brief acknowledgement of the letters written by Long Covid Kids members [**SM/28** **INQ000272166**

53. We raised our concerns with all of the relevant decision makers involved in policy on school openings and closures. Almost non our letters evidencing lived experience were acknowledged or responded to. We are still campaigning for improved ventilation and air quality in schools.

Engagement with decisionmakers in Scotland

54. Long Covid Kids Scotland is a separate charity and were refused Core Participant status in Module 2A. To assist the Inquiry, I have exhibited and set out below a short summary of their advocacy in Scotland [**SM/29 -** **INQ000272167**

    54.1. Attendance at roundtables on Long Covid with Cabinet Secretary for Health and Social Care and the Clinical Priorities Unit on 22 November 2021 and 21 February 2022

54.2. Attendance at Cross-Party Parliamentary Group for Long Covid on 8 September 2021, where we presented to the CPG, and at further meetings on 8 December 2021, 9 March 2022, 8 June 2022, and 26 October 2022

54.3. Submitted a Scottish Parliament Long Covid Debate briefing note to Members of the Scottish Parliament (MSPs) on 19 May 2022

54.4. Updated the SIGN Long Covid Guidelines Implementation Support Note to support paediatric Primary, Secondary and Allied Healthcare professionals in Scotland from March to July 2022

54.5. Attended an in-person meeting on 28 June 2022 at the Scottish Parliament with then Cabinet Secretary for Health & Social Care, Humza Yousaf, with families in Scotland whose children were affected by Long Covid.

55. Through our advocacy in Scotland, Long Covid Kids emphasised that lived experience is essential to understanding the nature of Long Covid, and must be included in policy creation, decision making and the planning and implementation of robust and meaningful support services.

Engagement with the Welsh government

56. There is no separate organisation advocating for the rights of children with Long Covid in Wales, so Long Covid Kids engage in advocacy with the Welsh Government directly. The below is a summary of this advocacy:

56.1. On 21 May 2022, Kate Davies, Long Covid Kids lead in Wales, wrote to Jeremy Miles in his capacity as MS for Neath for him to hear the personal story of a child living with Long Covid and issues relating to education in Wales [**SM/30** **INQ000272169** On 30 May Jeremy Miles' office replied to arrange a meeting.

56.2. On 22 June 2022, Long Covid Kids wrote to the First Minister asking for insight into the Long Covid Expert Group that they had established for a pathway to treat children.

56.3. On 10 July 2022 Long Covid Kids received a reply from the Health Secretary's department promising insight into the final pathway once it had been finalised.

56.4. On 2 July 2022, Long Covid Kids' representative for Wales, Kate Davies, wrote to the First Minister of Wales about the expert subgroup on Long Covid in children.

56.5. On 19 July 2022, Long Covid Kids received a letter from Lois Hullen [**SM/31** **INQ000272170**], Women and Children's Health Branch stating that once a final pathway was in place it would be shared with Long Covid Kids.

56.6. On 10 October 2022, Long Covid Kids had a discussion with members for the Welsh Government Education department to discuss installing CO2 monitors and adequate ventilation in schools.

56.7. On 6 December 2022, Long Covid Kids met with Sian Jones and Sian Garstang of the Welsh Government Education Department where they agreed to distribute Long Covid Kids resources via school newsletters.

Engagement with the Northern Ireland Executive

57. Long Covid Kids has also tried to advocate in the Government of Northern Ireland on behalf of children with Long Covid. Most notably, in April 2022, Long Covid Kids engaged with Gavin Robinson MP [**SM/32** **INQ000272171** to discuss the lack of Long Covid support for under 16s, lack of mitigation measures in schools and lack of testing. This meeting led to Written Questions and letters from Gavin Robinson to DHSC.

Long Covid in Children and Young People Study (CLoCK)

58. Long Covid in Children and Young People Study (the CLoCk Study) is a UCL research project which is the only paediatric study funded by NIHR which aims to determine the symptoms of Long Covid, define Long Covid and determine how many young people suffer from it. The CLoCk Study was a study in relation to Long Covid in children due to the lack of research into this area. Long Covid Kids was invited to participate in monthly meetings after the project's first findings were released. However, from our experiences, we had concerns about how the study was conducted and how it has since been interpreted.

59. We contributed to discussions on patient and public involvement in the study, but we withdrew our support from the study because we were not being meaningfully involved in co-producing the study. Decision making was not shared between researchers and patient groups, and we were not afforded the opportunity to make the material changes that we deemed necessary to ensure that the CLoCk study addressed the real needs of children and young people with Long Covid. Our view was that our involvement had

been purely cosmetic rather than enabling us to represent the Long Covid Kids community.

60. In our experience, the CLoCk study has been problematic because it has been wrongly portrayed as showing Long Covid as a consequence of the pandemic, rather than as a physiological consequence of infection from Covid 19. For example, in the Ministerial Roundtable on 7 December 2021 [**INQ000067606**] which I attended, it was said that there was an "overlap of symptoms" between the children. It was pointed out at that meeting that people with Long Covid could have physiological biomarkers including organ damage and blood clots and that these are biomarkers for Long Covid, albeit they are not yet identified as such.[6] However, the CLoCk survey was presented as showing that fatigue and anxiety were the main symptoms of Long Covid in children but that these were also found in children without that diagnosis. Of course, children suffered in the pandemic, however, to extrapolate overlapping symptoms as there was no such thing as Long Covid in children is obviously wrong and not consistent with our personal experiences.[7]Due to the concerns above likely impacting the conclusions and study, there is an urgent need for further paediatric biomedical research. This is a finding of the CLoCk study as well.

61. As there are no blood tests for Long Covid it is dependent on children articulating symptoms which is difficult and can be hard due to their young age. Amongst our members, children, and young people with Long Covid have been found to have myocarditis, muscle aches, fatigue, loss of taste or smell, shortness of breath, nausea, vomiting, diarrhoea, mood changes, rashes, loss of appetite, fevers, coughs, headaches, stomach aches and nasal congestion [**SM/33** **INQ000272174**] Their experiences are real and are not simply a reaction to the pandemic but a consequence of their Covid-19 infections.[8]

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[6] Lai Y-J, Liu S-H, Manachevakul S, Lee T-A, Kuo C-T and Bello D (2023) Biomarkers in long COVID-19: A systematic review. Front. Med. 10:1085988.

[7] SARS-CoV-2 can cause disseminated infections that result in multi-system tissue damage, dysregulated inflammation, and cellular metabolic disruptions. The tissue damage and inflammation has been shown to impair microvascular circulation, resulting in hypoxia, which coupled with virally-induced metabolic reprogramming, increases cellular anaerobic respiration. Both acute and PASC patients show systemic dysregulation of multiple markers of the acid-base balance. Based on these data, we hypothesize that the shift to anaerobic respiration causes an acid-base disruption that can affect every organ system and underpins the symptoms of PASC

[8] Buonsenso, D.; Camporesi, A.; Morello, R.; De Rose, C.; Fracasso, M.; Chieffo, D.P.R.; Valentini, P. Social Stigma in Children with Long COVID. Children 2023, 10, 1518

V. The impact of government decision making on those with Long Covid

Overall Impact

62. The only way to avoid Long Covid is to avoid being infected with Covid-19. There was growing evidence from early summer 2020 that people suffering from infection of Covid-19 were not recovering.

63. Given the known risk of Long Covid, Long Covid Kids is concerned about the impact of specific decisions which led to the high prevalence of Covid-19 throughout 2020 (for example Eat Out to Help Out). Decisions that promoted the spread of infection of Covid 19 inevitably led to more children and young families being infected with Long Covid and increased the incidence of Long Covid. Long Covid Kids is concerned that the known risk of Long Covid in children and young people was not adequately factored into decision making around the spread of Covid 19. Specifically, Long Covid Kids is concerned that the Government's decision making set out in the 2021 Spring Roadmap and in its vaccine strategy, all contributed to leaving schools without adequate safeguards for children, exposing them to avoidable harm.

64. As people with Long Covid, we have been subject to abuse on social media telling us that the daily suffering we experience is not happening. It is very difficult to imagine any other circumstances where a child suffering such life changing consequences of a virus would be disbelieved. The harm done to those children by social media led narratives, the dismissal by healthcare professionals and the oversight by government decisions makers cannot be underestimated and it simply should not happen. To this day, my daughter and other children harmed by Covid experience stigma and bullying due to their disease because of the early narrative that became entrenched.[9] Children's experiences should be listened to and factored into government decision making.

Impact of inadequate non-pharmaceutical measures in educational settings

65. Policy decisions concerning the use of non-pharmaceutical measures in educational settings have a direct impact on transmission, and therefore, on Long Covid. By failing to take the appropriate action when it was needed, children were and are being left to

[9] Buonsenso, D.; Camporesi, A.; Morello, R.; De Rose, C.; Fracasso, M.; Chieffo, D.P.R.; Valentini, P. Social Stigma in Children with Long COVID. Children 2023, 10, 1518

face the dire consequences of becoming infected in settings where they are meant to be safe.

66. As set out above, we have advocated for the UK Government to ensure a sensible, safe and sustainable approach to education during the pandemic. We were concerned that schools would be reopened without appropriate safety measures in place and wrote to the UK Government in January 2021 as part of Parents United about our concerns.

67. In Spring 2021, schools returned and thereafter the few mitigations that were in place to protect children, were removed. We believe this was in no small part due to undue influence from certain pressure groups. Children and younger people were a major factor in the transmission of the Delta variant in Autumn 2021, as well as the first and ensuing Omicron waves since BA.1 replaced Delta in November and December 2021. This is because classes generally spend protracted time periods mingling at close quarters in poorly ventilated spaces, particularly in colder weather, plus asymptomatic infections and mild illness are more common at these ages, leading, unwittingly, to the overall spread of infection.

68. There are concerns that the high levels of infections among children, particularly in Jan/Feb 2021 and Jan/Feb 2022 resulted in hospital admissions for children with Covid-19, increased incidence of Long Covid, PIMS-TS cases and child deaths [**SM/11 – INQ000272147**]

69. The Government has done little to improve air quality in schools or provide HEPA filters, yet still saw fit to remove the mandatory use of masks and to halt random testing for Covid-19. Indeed, it was shown by random testing, that prevalence tracks with school openings and closures [**SM/34 INQ000272175**] Moreover, households with children were more likely to experience infections than those without, during waves [**SM/35 INQ000272176**] Government policy has finally started to recognise the need to focus upon clean air, although little support has been provided to implement this.

70. On 11 September 2023, part of the results from the Bradford trial on impact of air cleaning technologies in schools was published in a report prepared for Child of the North and the All-Party Parliamentary Group [**SM/36 INQ000272177**]. Schools in

Bradford participated in a study that provided direct evidence of significant reductions in Covid-19 illness absences when schools were fitted with air cleaning technologies. The report states: "*by combining health records with school absences, the study found that schools that had these relatively low-cost air cleaning technologies fitted showed significantly lower absence rates*". Long Covid Kids have consistently advocated for these results to be published over the past two years through social media.

Inadequate Public Health Warnings to Parents

There was no public awareness campaign for Covid-19 in children, including sharing information about the symptoms in children of Covid-19 and Paediatric Inflammatory Multisystem Syndrome (PIMS); Long Covid in children. Long Covid Kids believe that as a consequence, testing of children was not prioritised and the symptoms of Covid-19 in children were missed.[10]

71. 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. This also resulted in the symptoms of Covid-19 and Long Covid in children being missed. Long Covid Kids published graphics in August 2021 that challenged the failures of Government guidance for children and listed the symptoms children experience that were not mentioned in Government guidance. [**SM/37** **INQ000272178**

72. Long Covid Kids are concerned that during the pandemic the Government advisors underestimated the effect of Covid-19 on children, ignored incidences of and the effect of Long Covid on children and did not consider risk of transmission from schools. [**SM/38** **INQ000272179** We are concerned that may have led to inadequate consideration for mitigation measures in schools and inadequate information to parents and members of the public.

73. Vaccination lessens the risk of Long Covid in adults and children. However, messaging around juvenile vaccine programmes has, in our view, been poor and has led to vaccine hesitancy. Messaging that focused on how Covid-19 did not pose a threat to children discouraged parents from choosing to vaccinate their child. The conversation focused

[10] APPG report found that children experience a wide range of Long Covid Symptoms and that these symptoms can differ from those displayed in adults. Paragraph 21 of the report [**SM/13** **INQ000272149**

on the unknown risk of harm to children from a new vaccine rather than the known risk of harm from Covid-19. Vaccines were advertised for adults for a long time before being advertised for children, which created a separation in the perceived need for children to be vaccinated. We believe that this created space for anti-vaccine campaigns to grow and has contributed to a decline in vaccine uptake generally. [**SM/39** **INQ000272180**

74. Unhelpful comparisons being made between children and adults meant that the risk to children was considered to be low, because the risk of acute severe Covid-19 was lower relative to adults. However, it would have been more accurate to consider the risk from Covid-19 to children in comparison to other diseases which we vaccinate children against (e.g., Mumps, measles, varicella and rubella) **INQ000272179**]. This metric would have potentially led to a different evaluation of risk and had an impact on public health measures taken.

75. In summary, the concerns raised included our concerns about the high level of infection rate in children, the lack of public information messaging about Long Covid, the obstacles our members and supporters reported in accessing appropriate treatment pathways for their very ill children, mitigation measures in schools and other such issues.

Inadequate data and surveillance

76. Children are commonly asymptomatic or atypical and therefore unrecorded in government data and to the best of our knowledge, Paediatric Inflammatory Multi system syndrome (PIMS-TS8) data has never been publicly available in the UK or centrally recorded (PHE/UKHSA may hold the most complete set of it).

77. We are aware of two separate methods of data collection, one through the orange card system filled out by paediatricians and the other through PICA net which records PICU admissions. Data informs decisions made in health and education and without accurate information on prevalence, the Government cannot assess the significance of an issue. In our view, the limitations outlined above resulted in inadequate consideration as regards to mitigation measures in schools and inadequate information to parents and members of the public.

78. I note that there has also been variance when assessing the prevalence of Long Covid in children. Prevalence estimates for Long Covid specifically in children and young people vary from 1%-70%.[11][12] As there was no consensus on what should be included in these studies, these estimates produced vary because each study uses a different method which sometimes led to inaccurate reporting. In addition, there was a significant delay in the research and recognition of Long Covid in children. Long Covid Kids have been working on rectifying this issue so that studies are more consistent and comparable to each other.

79. I co-authored an article [**SM/40** **INQ000272182** in response to an analysis of Zoe application (app) data by Erika Molteni and colleagues assessed the symptom profile and duration in children with a confirmed positive SARS-CoV-2 test which evidences this issue. In this article, we stated:

> "*The study provides important information about symptomology but probably underestimates the true prevalence of Long Covid in children. According to the Methods section, the study appears to only assess children with a defined illness duration (onset and recovery). Recovery was defined as a return to asymptomatic condition or the cessation of symptom logging. As such, this would exclude all children with on-going disease and classify children that stop recording as recovered, even if they might still be experiencing symptoms. The authors tested their assumption that cessation of recording indicated recovery by removing those patients from their calculation and found no significant difference in Long Covid prevalence or average symptom duration. However, if patients that ceased recording continued to experience symptoms, these longer duration symptoms would not be identified by the study and their effect would not be accounted for in the existing assumption test*."

80. When put together, the unavailability of data due to underreporting and the uneven approach to looking at prevalence of Long Covid in children, have had an impact on the public's ability to learn about the risk of Long Covid in children and the decisions made by decision makers who relied on this data.

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[11] Pellegrino R, Chiappini E, Licari A, Galli L, Marseglia GL. Prevalence and clinical presentation of long COVID in children: a systematic review. Eur J Pediatr. 2022 Dec;181(12):3995-4009
[12] Zimmermann P, Pittet LF, Curtis N. How Common is Long COVID in Children and Adolescents? Pediatr Infect Dis J. 2021 Dec 1;40(12):e482-e487

Impact on educational experiences and attendance

81. Long Covid has had a demonstrable impact on children of compulsory school age. This issue is highlighted by the Department for Education's latest statistics on pupil attendance:

> *"Both overall absence and persistent absence rates have been driven by illness during the 2022/23 academic year"*[13] and *"illness absence (which includes positive Covid cases) remained higher than pre-pandemic levels, at 3.7% during Spring term compared with around 2.5% pre-pandemic."*[14]

82. Children and young people have a right to education regardless of their health status and it is a matter of considerable concern to us that children and young people with adverse health preventing their participation in education have been, and are continuing to be, ignored and inadequately supported. We anticipate that this will be addressed in further detail in a dedicated module for children and young people and we are willing to provide further evidence in that Module.

83. Preliminary evidence from Long Covid Kids' Long Covid in Children and Young People (CYP) Education Experiences and Attendance Survey [**SM/41** **INQ000272183**] shows 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. 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. 10.4% of respondents are currently temporarily away from school/college ill and 9.5% are currently too unwell to be in education.

[13] Department for Education (4 July 2023) 'Pupil attendance in schools'. Available here: https://explore-education-statistics.service.gov.uk/find-statistics/pupil-attendance-in-schools/2023-week-24.
[14] Department for Education (13 July 2023) 'Pupil attendance in schools'. Available here: https://explore-education-statistics.service.gov.uk/find-statistics/pupil-attendance-in-schools.

84. 75.3% of respondents reported that their attendance has been greatly impacted by and 54.9% say that their progress with learning has been greatly impacted. 40.2% of respondents from the survey mentioned above thought that the school lacked an understanding of the impact that Long Covid has had on their child or young person's education and a further 25.9% have experienced pressure from schools to send their child or young person to school when they have been unwell.

85. As evidenced above, children and young people living with Long Covid face enormous disruption to education. From an early stage, Long Covid Kids has sought to engage with the Government, health providers and schools. Harm to children from Covid-19 infection has been consistently overlooked and missing from reports and articles that consider education and attendance. Rather than dismissing children, the voices of children with Long Covid should have been listened to so that their experiences can be at the centre of changes and improvements.

VI. Experience of our Members – Children's testimony

86. Whilst some children and young people may recover from Covid-19 with no apparent immediate harm, for some children and young people this is sadly not true. They suffer prolonged illness from Covid-19. Most of the families we support have children who have been severely unwell for 12 months or more and unable to attend full time school. In most cases we do not see children recovering and 'getting better', instead we see our members having to learn to manage symptoms and mitigate the harm they suffer. Many children have been disabled even though they only suffered a 'mild' infection of Covid 19, to the extent that they must now use wheelchairs full or part time.

87. In our short film "Our Unhappily Ever After", Long Covid Kids included testimonies from children who had contracted Covid-19 and had not recovered, suffering serious debilitating illness. Some of the testimonies in this video include:

    87.1. *"If 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 still unwell. A lot of us are in bed a lot of the time, it can be boring, annoying, frustrating and tiring and we miss our friends"*

87.2. *"We miss feeling well"*

87.3. *"We want to feel better again"*

88. I exhibit to this statement anonymised case studies from Long Covid Kids members suffering with Long Covid [**SM/33** **INQ000272174** These case studies explain the impact that Long Covid has had on their children's personal lives, education, and health, as well as the wider impact on their family. Additionally, the case studies address the effectiveness of public messaging about Long Covid and the difficulties obtaining diagnosis and treatment. Below are extracts from the exhibited case studies which describe the impact of Long Covid on children:

88.1. H, 15 years old, initial infection April 2020, reinfected July 2021, diagnosed with Long Covid December 2021 - *"H 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."*

88.2. E, 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 condition 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."* When asked about the response from healthcare professionals: *"It was glaringly obvious to E and to us that this was a multisystemic response to Covid. 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."*

88.3. E, 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"*

88.4. C, 17 years old, initial infection October 2020, diagnosed with Long Covid in May 2021 - *"professionals looking to blame it on his Mental Health played it all down"*

88.5. T, 19 years old, initial infection August 2021, diagnosed with Long Covid September 2021 - *"I missed one year of school after completing year 12. I returned to school a year later but couldn't manage 3 A levels so dropped 2 subjects. I now have one A level and would like to go to University but I am unable to at the moment because my Long Covid illness is hampering my ability to obtain the necessary qualifications to be accepted on a university course."* On what public messaging they saw about Long Covid: *"None before I was ill and I don't remember seeing anything since"*

88.6. S, 13 years old, initial infection September 2021, diagnosed with Long Covid March 2022 - *"He lost all his friends. The occasional visit he received only showed how much they have all moved on while he is left behind, unable to do so. The one hour of chit chatting would completely wipe him out and caused him post exertional malaise. Those have now stopped. His siblings, tutors and occasionally family friends are the only people he interacts with."*

89. In addition to the individual experiences shared above, I produce [**SM/42** **INQ000272184** showcasing further lived experience shared by families, children and young people shared on our website to raise awareness. Some examples include:

89.1. J, age 10, living with Long Covid since November 2021: *"No one at school or in health believed me until I ended up in crisis in hospital with a feeding tube. All the doctors asked about was how I see myself in the mirror*". J "*was very active and loved to roller skate with her family. Now she needs a wheelchair and can't walk or attend school. Our whole family are suffering along with her. It's not fun for anyone*." J "*just wants to be back to normal, she is on a lot of medication to help with constant pain, nausea, brain fog and fatigue*".

89.2. C, age 11, living with Long Covid since September 2021: *"I used to be really active, not it's hard to get up in the morning"*. C *"used to be so full of life, always outside, always on the go, played numerous sports. Following Covid, missed*

about a year of school. She now managed school (most of the time) but our weekends are now taken up with her resting to enable her to attend school during the week. Days out are few and far between due to the crashes afterwards. An 11-year-old should not be 'living' this way"

89.3. C, age 8, living with Long Covid since November 2021: "*Long Covid has made me feel annoyed, less energetic, sad and I don't enjoy as much as I used to*" says C, "*On big days out I now have to use my wheelchair because otherwise I get too tired, and I would have an energy crash*". C "*used to run, jump, skip along on days out, now uses a wheelchair to enable her to manage / pace days out so that she can still experience fun with her family and friends*" says her mum.

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.

Signed: Personal Data

Dated: 25th September 2023

Overview Statement on behalf of Long Covid Kids Scotland
On the impact of the handling of the Covid-19 pandemic
Presented by Helen Goss 2 November 2023

0.1 My name is Helen Goss I run Long Covid Kids Scotland ("LCKS") under the umbrella of (UK organisation) Long Covid Kids ("LCK") where I am the Chief Operating Officer. I am also the mother of [redacted] a child whose life has been turned upside-down from the debilitating effects of Long Covid. I also suffer from the effects of Long Covid which makes fighting on her behalf against the multi-organisational barriers we face even more difficult. These are organisations who should be in place to help us; but our lived experience proves the opposite.

0.2 LCKS was established to support and guide Scottish families with children and young people ("CYP") with Long Covid. We advocate for the recognition, support, and recovery for Long Covid in children and young people. Currently the Scottish branch provides support to over 250 families with this number growing all the time. The importance of my previous sentence cannot be more emphasised. Long Covid isn't something that happens to a) already unwell children (quite the opposite in fact in our experience the children affected were very healthy, with active busy social lives, filled with extra-curricular activities), and b) only as a result of the peak of the pandemic (Long Covid is still a real and live risk).

0.3 Often, we find there is an emphasis from organisations we collaborate with in focusing on Covid-19-related deaths and/or Covid-19 hospitalisations with acute infection. What about those who didn't die but didn't ever recover? Supported by expert advisors, LCK provides lived-experienced support from peers, via advocacy, and assistance trying to navigate the various systems we now have to cross.

0.4 When people talk now about Covid-19, often it's around lockdowns, restrictions, and how happy they are to be back to "normal". For many CYP they've never and may never go back to what "normal" looked like to them. There's this misconception even to this day that Covid-19 (let alone Long Covid) is only a risk to the infirm or elderly which is simply not true. This is a misconception held by people in positions of healthcare, policy, and education, people in positions that should know better by now. For those who didn't die or weren't hospitalised at the peak of the pandemic but are still suffering our injuries today, we've been forgotten.

0.5 As of May 2022, there was believed to be over 10,000 children in Scotland suffering from Long Covid[1]. In the same vein that Covid-19 was not and is not "just the flu" Long Covid is not "just tiredness". People suffering with Long Covid struggle with - what would have previously been for them - simple daily tasks, with cognitive disfunction so severe they can forget basic personal information. In children and young people Long Covid causes neurological, musculoskeletal, gastrointestinal, and cardiovascular symptoms, serious cognitive impairment,

[1] Jackie Baillie MSP, Long Covid debate at the Scottish Parliament

headaches/migraines, and muscle ache. Symptoms also often overlap with conditions such as ME/CFS, PEM, PANS, and MCAS. Some go on to develop PIMS-Ts.

0.6 LCKS are supported and championed by practicing experts and professionals in a range of fields, such as law, paediatrics, occupational therapy, immunology, and virology. We work closely with academia and other charities and are recognised by organisations such as the World Health Organisation, the Centre for Disease Control, and we are a recommended resource in NICE guidelines. We are key stakeholders in high-level meetings with the Scottish Government, the NHS, and in research collaborations such as with Derby University on healthcare[2] and education.[3] The organisation is unique in that it documented and tracked the post-Covid-19 impacts on children in real time as the pandemic unfolded. We provide evidence and concerns on the risk of Long Covid as a Post-Covid Condition, that is as a long-term chronic illness and/or disability.

0.7 Our position strongly is that the Scottish Government's measures and key decision-making did not (and still does not) go far enough to safeguard the health and development of children and young people. This is in contrast to their own "Getting it right for every child" ("GIRFEC"). Children and young people living with Long Covid are dismissed and ignored to the detriment and expense of their health, education, and welfare. Policy has not changed for the better and new evidence is being ignored, with mitigation measures that were already poor being dropped. Our position is that the Scottish Government have been negligent both in the discharge of their responsibilities and their failure to keep up to date with contemporary research.[4] We make particular reference here to the Jason Leitch letter of March 2022 where at p4 evidences they only took mortality into account and not morbidity (that is, long term consequence like Long Covid), and his further letter of April 2022 at p5 where he advises children can go into school if they are symptomatic.

0.8 The Long-term Effects of COVID-19 Strategic Network was established in March 2022 with a £10million support fund from Scottish Government over a three-year period. In February this year one of the clinical leads for one of the NHS Health Boards told me he didn't realise CYP needed to be provided for. You can imagine my shock hearing this from someone in that role after all we've campaigned for. I must speak frankly here in that this network has so far been entirely ineffective, with a series of failures and serious concerns, little to no transparency and absolutely no accountability.[5] Over a year and a half in they still can't tell us where any of this £10 million support fund has been spent. Service user involvement is non-existent which strikes at the heart of the very purpose of publicly funded strategic networks.

0.9 Our key areas of concern to be addressed are currently as follows:

1. LACK OF PUBLIC HEALTH INFORMATION AND COMMUNICATION

1.1 It became apparent early in the pandemic that children transmitted Covid-19. However, there was, and still is, poor public awareness of the risks of long-term sequelae associated with Covid-19 infection in children and young people, and the increased risk associated with reinfections. The Scottish Government continued to repeat the narrative that the risk of children contracting and

[2] https://www.longcovidkids.org/post/feedback-on-the-long-covid-clinics-preliminary-healthcare-experiences-survey-findings
[3] https://www.longcovidkids.org/post/how-does-long-covid-impact-attendance-and-educational-experiences
[4] https://twitter.com/drclairetaylor/status/1624772290599591937?s=20
[5] https://twitter.com/HelenMMGoss/status/1673105071922466816?s=20

transmitting Covid-19 was low[6], despite evidence to the contrary. There was also no accurate data on the prevalence of Covid-19 and Long Covid amongst children and young people in Scotland.[7] Public Health Scotland modelling (which has now ceased) reflected the ongoing and escalating problem, but this did not measure prevalence. ONS findings were also only good for the whole of the UK[8]. There is no Scotland-specific focus.

1.2 Symptoms were being presented beyond the 3 "cardinal" ones yet Scotgov would not permit attendance at testing[9]. Additionally, children and young people do not present the same in acute infection. The Scottish Government and NHS Scotland did not update their symptoms list on their websites in a timely manner. There was also a discrepancy between NHS Boards and Local Authorities in relation to their symptoms list.[10] This led to many families not prioritising testing especially in instances of asymptomatic acute infections, or missing symptoms.

1.3 Public Health Scotland in their three-part survey "Are the Kids Alright?" excluded the direct harms on CYP experiencing Long Covid. Their response to questioning was that the EAVE II study addresses this, however this is false as it only covered prevalence of Long Covid at baseline population level and did not take account of age, gender, demographics, let alone the views, feelings, or lived experience of children and young people suffering from Long Covid.

1.4 In December 2020, the Scottish Government published '*Coronavirus (COVID-19) framework for decision making – assessing the four harms,'* there was another failure to address Long Covid within any section of the framework; it was excluded entirely.

2. LACK OF ACCESS TO HEALTH AND SOCIAL CARE

2.1 We recognise that healthcare professionals have been left unsupported and untrained, which results in many not recognising Long Covid symptoms and failing to refer patients to appropriate care. Because HCPs are not appropriately trained, they aren't recognising symptoms therefore no diagnostics. No diagnostics means no treatment. There's also a culture of failing to refer patients, or refusing to refer patients where they or their family have conducted their own research. This further results in inconsistent care across NHS Health boards leaving CYP at a postcode lottery of what diagnostic testing, treatment, and support they will receive. Families are having to learn about Long Covid alone, with many resorting to private healthcare in a desperate attempt to find some relief for their children. They then face further barriers with NHS staff refusing to collaborate with private healthcare.

2.2 There is nothing being done at policy level to ensure Long Covid is tracked.[11] Primary and secondary care each have their own individual systems, both where the condition is often listed as Post Covid Syndrome or Post Acute Sequalae of Covid, so many can't find when they search for Long Covid. This has obvious and serious implications for data collection, with an underreporting

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[6] 'Open letter to parent and carers' by Jason Leitch, 16 Sept 2021

[7] *Clinical characteristics, activity levels and mental health problems in children with long coronavirus disease: a survey of 510 children'* by Danilo Buonsenso, Ferran Espuny Pujol, Daniel Munblit, Davide Pata, Sammie McFarland & Frances K Simpson, Future Microbiology, 1 April 2022; pre-print version published on 9 Mar 2021

[8] Funding to ONS to continue its work was withdrawn as of Mar 2023

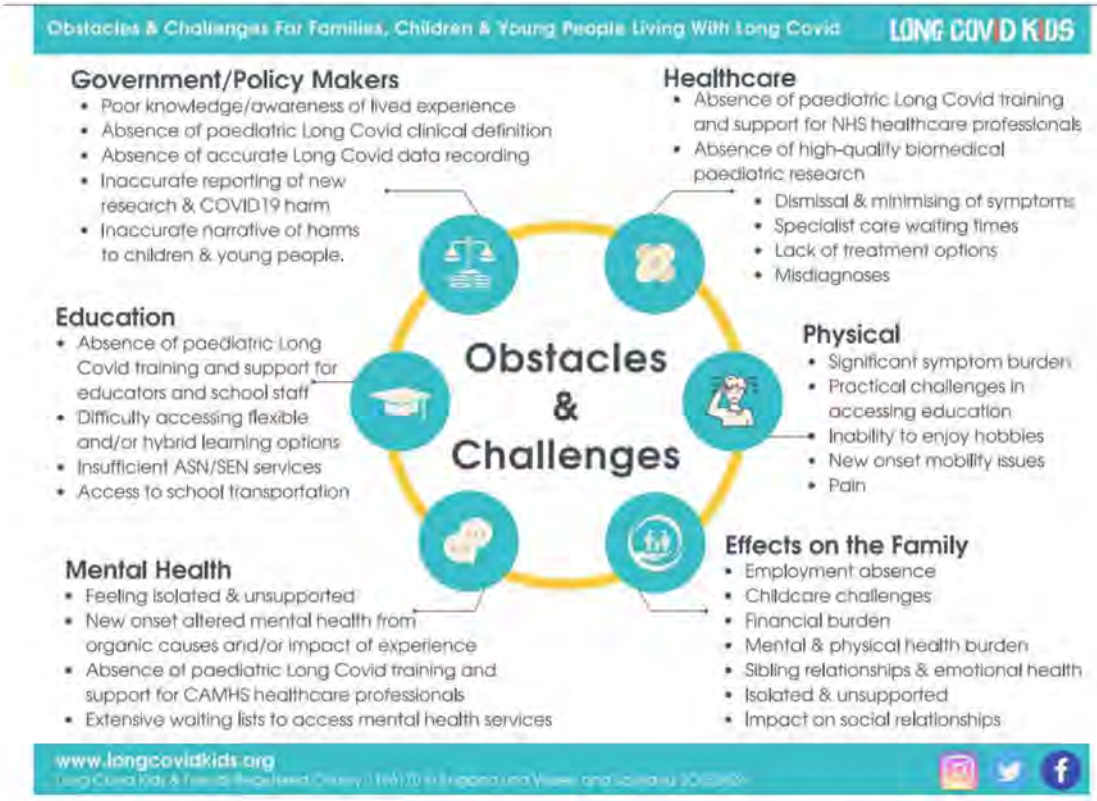
[9] Jason Leitch, Clinical Director of National Health speaking at the Covid-19 Recovery Committee, Scottish Parliament, Session 6, 28 Oct 2021, Official Report, p.7

[10] Letter by NHS Lothian to parents/carers dated 9 Sept 2021 (Aug 2021 version); Letter by Aberdeenshire Council (Education and Children's Services) to parents/carers dated 17 Sept 2021

[11] Planning a Gold Standard Long Covid Service for Children | Long Covid Kids Vision | PEN | 27.07.23 - YouTube

of the prevalence of Long Covid and the assumption that paediatric Long Covid is not of significant concern. It is paramount that partnerships are created through the NHS, private practitioners, and families, and we consider this can only be appropriately managed at government level. [12]

2.3 We are also suffering inappropriate treatment such as graded exercise therapy even though this is not recommended in NICE guidelines which state the harm in doing so[13]. HCPs are also recommending Cognitive Behavioural Therapy. You cannot exercise your way out of a chronic condition with untreated underlying pathology, and similarly CBT may be beneficial as a supportive measure, but it is not a treatment. Children and young people who have Long Covid may also suffer from symptoms such as chronic pain that leaves them immobile yet are not being provided with mobility aids.



2.4 CYPs have languished so long in the healthcare system with no proper help that they are now transitioning into adult services. However, the transition from paediatric to adult health care services is poorly planned and coordinated. An anomaly also appears to exist where a child or young person is not considered old enough to see a consultant if they are 16 to 18 years of age, but they can see a consultant if they are still in "system" and have used health services prior to the age of 16. The care and treatment of Long Covid is being recognised by health and social care professionals as a specialist area. Whilst adult and paediatric hubs were opened in England during the pandemic, the Scottish Government rejected this route. Such services, however, could provide a multi-disciplinary and holistic approach to the care and treatment of people living with Long Covid, in the same vein as diabetes or cardiology clinics. It is still unclear what has been achieved with the funding of £10over 3 years across the 14 NHS Boards that was

[12] DAY 1 LONG COVID WEBINAR 2023: Session 2 - Long COVID clinics in Wales, Scotland and N. Ireland - YouTube
[13] 'Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management,'

committed during the pandemic. Also, this figure of £10 million is to be contrasted with Jackie Baillie MSP's calculations of £22 million over 3 years using the Barnett Formula.

2.5 The absence of high quality and biomedical paediatric research has also led to poor outcomes for children and young people. Understanding the pathology and mechanisms that cause Long Covid, could however, improve our understanding of other illnesses such as ME/CFS[14] and help us to ultimately find appropriate diagnostic testing and effective therapeutics.

3. INADEQUATE EDUCATION PROVISIONS

3.1 Children and young people who suffer from Long Covid can be too unwell to attend school. As a result, they have missed out on years of formal education and qualifications. They have been deprived of the wider school experience leading to social isolation.

3.2 It appears that the school system in Scotland cannot sufficiently accommodate children and young people who have illnesses that are unpredictable in nature and include symptoms such as lack of mental energy and muscle ache/pain. Most teachers do not understand the impact Long Covid can affect the ability to learn meaning school reports inaccurately reflect the effort they are putting into their education. Often the targets and expectations set out in these reports do not match CYP capacity. There is a failure to support pupil attainment with many young people missing out on qualifications when a more flexible approach would have enabled this.

3.3 There is no one size fits all approach to supporting children and young people with chronic illnesses such as Long Covid. Children and young people need supportive staff to help them access their education in a range of diverse ways that support their wellbeing. Teachers also need guidance to be informed of children's needs and adopt strategies to best help them achieve e.g., home learning with reasonable adjustments, or hybrid learning, both which can assist children and young people who are often not well enough to attend school in person. Alternative education is difficult to obtain and is dependent on the Local Authority's understanding of Long Covid and their willingness to support. Where it is available is not always offered at the point of need and does not offer a broad curriculum.

4. LACK OF MITIGATION MEASURES IN SCHOOLS AND HOSPITALS

4.1 There was a lack of preventative action to make indoor spaces safer such as a clean indoor air policy, as is recommended by RCPCH,[15] whilst more and more children contracted Covid-19. There are very low levels of vaccine uptake in children as the decision to include them came much later than adults. This was after a string of absurd policy decisions involving young people, including at one-point close contact only counting if they had been at a sleepover together. [16]

4.2 Research shows that measures such as using HEPA filters can reduce transmission rates of illnesses such as Covid-19[17], yet the Scottish Government's approach was to prioritise natural

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[14] There is a significant overlap in symptomology between Long Covid and ME/CFS.

[15] 'The inside story: Health effects of indoor air quality on children and young people', (Royal College of Physicians and Royal College of Paediatrics and Child Health, Jan 2020)

[16] https://twitter.com/LCKScotland/status/1438534108657881091?s=20

[17] 'Increasing ventilation reduces SARS CoV-2 airborne transmissions in school: A retrospective cohort study in Italy's Marche region' by Giorgio Buonanno, Luca Ricolfi, Lidia Morawska and Luca Stabile (Frontiers in Public Health, 9 Dec 2022) - study shows ventilation can cut school Covid cases by 82%
Also: 'Mask Use and Ventilation Improvements to Reduce COVID-19 Incidence in Elementary Schools — Georgia, November 16–December 11, 2020,' (MMWR, 28 May 2021, Vol 70, No. 21)

ventilation, which was not practical during cold seasons and inefficient when numbers of children in a classroom was high[18]. A study in 2021 found that schools were "chronically under-ventilated, impacting children's health and concentration."[19]

4.3 Contact transmission in the classroom was also still possible despite introducing staggered drop off/pick up times. The *Coronavirus (COVID 19): Advisory Sub-Group on Education and Children's Issues* did not address any of these issues.

5. LACK OF FLEXIBLE EMPLOYMENT, CARERS, AND CUMBERSOME WELFARE SYSTEM

5.1 Supporting and caring for children and young people with Long Covid can be cognitively and physically exhausting, especially if parents/carers have Long Covid themselves. Peer support[20] is invaluable to families and can play a vital role in offering a safe space to be heard, as well as moral support and practical assistance. We are unaware of any families in our support groups that have been able to successfully access social care support, even though some have identified a clear need for it. Many are on waiting lists for a caseworker but wait times are long.

5.2 Families often suffer financial impacts because of having a child with Long Covid. They may have to reduce their working hours to meet increased care responsibilities and bear additional costs associated with care and support. Families are stuck in a cycle of re-infection and worsening health exacerbating the situation. Some single parent families are left reliant on welfare, with many reporting report welfare forms are inaccessible as too long and complicated which puts them off from applying. For many families, they aren't even aware that they could apply or that they were eligible for support.

6. HUMAN RIGHTS FAILURES

6.1 Prolonged illnesses such as Long Covid have implications on children's rights to life, survival & development, education & health,[21] and their wellbeing. Children and young people have a right to have their best interests considered and implemented at policy level. We urge the Scottish Government to recognise the significance of Long Covid in children and call upon it to address its human rights implications in line with GIRFEC[22], The Children and Young People (Scotland) Act 2014, and the United Nations Convention on the Rights of the Child.

6.2 On 6 August 2020, the UN Committee on the Rights of the Child published a statement expressing concern about children globally due to the effects of Covid-19. The Scottish Government set out its approach in relation to 11 areas highlighted by the Committee[23] yet there are no mention of children and young people suffering from Long Covid.

6.3 The lynchpin of our organisation is that multi-layered protections against contracting Covid-19[24] are the only way to drive case rates down and reduce the spread of the virus which would

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[18] 'High C02 Levels and poor ventilation raises concerns for children's health and covid risk' by Sian Norris. Byline Times, 25 April 2022

[19] 'Designing infectious disease resilience into school buildings through improvements to ventilation and air cleaning,' The Lancet, April 2021

[21] Article 24 of the United Nations Convention on the Rights of the Child

[22] 'Getting it right for every right child' – the National Practice Model

[23] UN Committee on the Rights of the Child: Covid-19 statement – 6 Aug 2020

[24] Swiss Cheese Model—How Infection Prevention Really Works (infectioncontroltoday.com)

in turn reduce the incident of Long Covid. It is vital the Scottish Government leads this and upholds their duties.

Dear Prime Minister

My name is K, I am 16 years old, and I got infected with covid March 2020. My symptoms started off mild; a slight cough, heart palpitations and weakness. We reached out to the NHS for advise on the matter, they decided not to help and instead told my mother I was faking being ill for attention, that I was copying my mothers symptoms of covid. My mother had difficulty breathing and weakness, where as my symptoms were to do with my heart and a fever. We were being told kids couldn't get covid, they couldn't of been more wrong.

After 2 weeks I started getting better, for a month I felt more like my previous self (a fit healthy teenager with no underlying health conditions). This is when Long Covid came in, it hit me like a brick. I was severely weak, needing help to eat, drink and go to the loo, I was like this for 8 months.

This took a massive hit onto my mental health. I became very depressed, I started self harming and my anxiety increased to the level of having a panic attack every time I left the house. During this time everyone was telling me I still wasn't ill.

I started getting badly bullied at school and online, it felt like the whole world was against me, I had no friends, no one I could talk to.

Over the next year my mental health has still not improved because of the society, doctors are still not helping and I am still ill. I have been diagnosed with 2 ovarian cysts, POTT's, and a heart murmur (with many things still unsolved) we have only got diagnoses because we have pushed so hard for it. The cysts would cause me to loose consciousness often because of the pain, this caused many complications in everyday life.

I have just hit my 2 year mark, yet I am still very unwell, I am still in pain everyday. I am on so many meds (which all come with awful side effects). I struggle to eat and drink, I can't go to school, I am in so much pain, mentally and physically.

Please help to stop others becoming like me, I shouldn't of had to get this ill for someone to do something, I deserve a normal happy life. So open the windows, make tests free again. Make a difference.

Stop making everyone ill, stop ignoring us.

Thank you for listening.

Yours sincerely,

K

Rt Hon Boris Johnson MP
Prime Minister
10 Downing Street
LONDON SW1A 2AA

1st April 2022

Dear Prime Minister,

The 20th September 2020 was the day my journey with Long Covid began. It started with a cough which persisted, and the next day my mum took me for a test and two days later it, surprisingly, it came back negative. I then went on to lose my sense of taste and smell and so a week later we went for another test – this time it came back positive and from that point on things progressively got worse.

My first hospital visit was on the 1st October when overnight I developed a full body rash as if it were sunburnt. My lymph nodes on my neck had also become so swollen that it became difficult for me to move my head. Although they weren't supposed to see people with Covid in person, my GP at the time cleared the surgery to see me and immediately sent me to the hospital where I was admitted. One of paediatricians at the time suspected I may have MIS-C, the Kawaski-like disease, but the Registrar overruled him the next day because she said I wouldn't be smiling if I was seriously ill despite developing a fever overnight. I was discharged home after 24 hours with no follow-up plan.

My GP did her best to support me but there were no referral pathways for me specifically related to ongoing Covid illness. By December she had referred me to the community paediatrician who we spoke to on a telephone appointment 2 days after my 16th birthday. When he heard about my ongoing list of symptoms, he decided I needed to be admitted immediately for testing and sent us to our local hospital. Upon arrival, we were told the Doctor we were sent to see did not exist and an A&E doctor would assess me instead. The A&E doctor said to us " unfortunately I am one of those doctors who doesn't believe in Long Covid" but she went to talk to the paediatric team about being admitted for tests. We waited for 4 hours. The only test I had was a chest xray. Then we found out that the paediatric team and the adult team couldn't agree who should admit me because of my age. The A&E doctor told my mum that if I was her daughter, she'd just leave, so we did.

My mum wrote a complaint that night to the hospital and the next day we were sent to that same hospitals' day assessment unit. They were extremely understanding and did lots of blood tests and an ECG but they could not understand why I had been referred to them and did not provide us with any answers.

The lowest point in my Long Covid journey was actually on Christmas Eve 2020 when throughout the day I had developed nerve pain that was so severe I ended up crying to my parents because I couldn't even lie down. After trying to make it through the night, I got up on Christmas Day to find

that I couldn't even walk to the edge of the bed without my chest cramping up. At this point I told my mum I felt as though dying. She drove me to the hospital as I was fading in and out of consciousness and vomiting from the pain. When we got there, we were seen pretty quickly by the nurse and then seen by the A&E Doctor within 20 minutes. The first question the doctor asked me was if I'd been on a ventilator and when I responded no, he went on to imply that Long Covid only affects people who have had severe covid illness and hospitalisation. He then told me that Long Covid doesn't exist in kids as he hadn't seen it with his own eyes, despite figures having been released just days earlier stating that Long Covid did in fact exist in children. After asking about my moods, and me responding that I had been dealing with low moods since I got ill, he told me that this flare up must have all been in my head because of my low moods. He went on to comment – and this is my particular favourite – "depressed? Why are you depressed? If I was 16, I'd be so happy. You should just go home and enjoy Christmas". He didn't give me any tests, or any pain medication, because he stated I was too young for that.

I am now 18 months on. I have been formally diagnosed with Long Covid. My GP is very caring, and reviews me regularly, but can offer no treatment or support other than a sympathetic ear. I have been seen by the Long Covid clinic, but they only offer rehabilitation which doesn't address the source of my symptoms. My parents have spent hundreds of pounds on private medical appointments to try and help. Although my school have been fully supportive and helped as best they can, the grades achieved at GCSE were lower than predicted because I missed over 6 months of school . I am studying 3 A-level subjects but was meant to be doing more, as I had always been a high achiever, but I'm on a supported special educational needs plan now because of the chronic symptoms I suffer including slower cognitive processing and memory lapses. I'm still suffering regularly with fatigue, chronic headaches, nausea, nerve pain, rashes, chest cramps, tinnitus, brain fog, memory loss and joint pain.

What I want you as our Prime Minister and the wider Government to know is that Long Covid in kids is real. Responding insensitively to children and parent's concerns has a negative impact mentally and physically on children's well-being. We need to be listened to, and we need there to be priority given to addressing the root cause of our illness so that the identification of effective treatment can be prioritised. How many other young lives have to be thwarted before someone will stand up for us?

Thank you for listening.

Yours sincerely,

L

Prime Minister,
10, Downing Street,
London
SW1A 2AA

Dear Prime Minister,

My name is V and I want to tell you about my covid experience.

I contacted covid when my CEV brother brought it home from school over 8 months ago. Since then my life has changed. I wasn't too bad when I got covid, it was manageable and just felt like a really bad cold, so it was quite a shock when I got diagnosed with long covid. I was sad because my brother tested positive on my 12th birthday and I had to cancel all birthday plans.

Before covid I was a busy, active 11 year old doing an after school activity most days and extra Mandarin lessons in school on Thursdays and Fridays as part of my schools Mandarin Excellence Programme. I was learning to play the cello, a member of a lifeguarding club and a Guide. I was in school every day of the week and going in even if I wasn't feeling 100%. I really enjoyed school and my favourite lessons were History, Geography and English Before I got covid I managed to get my bronze open-water and beach lifeguarding medals. I also loved baking from scratch, cooking and hanging out with my friends almost every Friday.

I never fully recovered from Covid, I was always ill afterwards, I had a tummy bug straight afterwards, chest pain and constantly felt like I had a cold. I had about 3 days where I felt well. On about the 15th October, I was told by my doctor that I had long covid. I felt really sad because I had to stop swimming and had to put my life on hold. At this news, I just wanted to be well.

Now that I have long covid, I can only do 1 after school activity every couple of weeks, completely stopped going to my lifeguarding club for the moment because the practical part was too much, my doctor told me to stop swimming and rest. The theory part was too much because I couldn't concentrate and the room was too noisy and too bright. I'm not in school, I haven't been since the 12th October 2021. I see my friends about once a month, this takes a lot out of me and afterwards I feel bad, ill, sometimes I feel like I will never wake up if I go to sleep the pain, coughing and tiredness is so bad. I am doing Mandarin lessons once a week via zoom outside of school to try and keep up, my mum has to pay for it, I get very little support from my school. I have had to pick my options this term, I can't do all 10 GCSE's so have chosen 3 rather than 4 options, but know that even 3 is too much. I haven't even been able to pick the ones I really wanted to do, I wanted to do Drama and Hospitality and Catering, but I cannot physically and mentally cope with those. I am worried about how I will cope with

my GCSE's as I am still so unwell. I can only bake once every other month with the support of my mum, and even then it's out of a box rather than weighing the ingredients myself. And it wears me out for days.

Some of my main symptoms are: feeling tried all the time no matter how much sleep I get, pain all over which gets unbearable in a blink of an eye, a cough that won't go away and makes my throat and chest hurt a lot, brain fog and struggling to think, ankle swelling, reactions to certain foods, light and noise sensitivity, heart racing, strange vision and randomly feeling hot and cold.

I don't like that the covid regulations are being lifted because it's too soon and makes the risk of people with long covid getting covid again higher. I am exempt from wearing a mask at the moment due to it being to hard to breathe. I don't like that I can't wear a mask because I have always been cautious with covid as I am the only one in my household that isn't CEV. I'm scared to go out in case someone does have it and I catch it again.

I don't like feeling like this because I feel like I'm missing out and my life is on hold. I'm missing my clubs, my friends and mandarin trips. I just want to be well and never want anyone else to go through this.

Yours sincerely,

V

Hand delivered to
No. 10 Downing Street
Westminster
London

Dear Boris Johnson,

I'm J. I am 11 years old and I have had Long Covid for nearly 15 months after getting Covid in January 2021.

It's been a very difficult journey for me. Having Long Covid means I can't do anything I used to enjoy, like sports, school, walking my dog and even caring for my bunny.

I used to go to dance classes, swimming, gymnastics, karate, I used to go on long walks with my family, I was able to hang out with my friends, go to sleepovers and I was also able to do a full day at school; I can't do any of that now and I need a wheelchair as I can't walk long distances. My arm has started to hurt just writing this letter.

Now I struggle to do two hours of school. It doesn't feel like school anymore. I haven't done a full week or a full day in months. I used to be so excited about the future, but now I don't know what it will be like.

Here are some questions I would like to know the answers to;

Why isn't there more research into Long Covid in children like me?

Will you try to help me and the thousands of other children with Long Covid to get better?

Why won't you or the government make schools safer and decrease the amount of Covid? I am worried about more children getting sick.

I have missed a year of school, how will you help me to catch up and how will it affect my future?

I hope you can help.

Yours Sincerely,

J

23rd April 2022

Dear Boris Johnson

My name is E, I am 9 years old and in early September 2021 I tested positive for covid. I caught covid in the second week of being back at school, I must've picked it up from someone in my class, who was showing no covid symptoms, but there were a lot of "colds" going around. After three days my body was in extreme pain and I was unable to move. I lost the ability to use my left leg and my back, shoulders, neck and leg gave me so much uncontrollable pain. I was also very tired and suffered other covid related symptoms.

Sadly after my isolation period was up, I was no better, my parents couldn't control my pain with over the counter pain relief, and the pain I was in was getting worse and I couldn't describe it. My parents had to carry me to the bathroom, had to dress me, wash me and care for me as if I were a toddler or baby. I lost all of my independence and confidence. I couldn't get downstairs and stayed in bed most of the time to try to keep comfortable, sometimes my parents would have to feed me too.

I ended up in hospital but the Doctors could do nothing for me and told me it was just covid and I would get over it. I didn't and I went back into A&E several times, before I was admitted for 13 nights in November. This brilliant Doctor at our local hospital, helped me more than I had been helped before and he made sure my pain was decreased and tested and scanned me for very serious conditions.

When I came out of hospital I was referred to the Paediatric long covid hub, physiotherapy services and the chronic fatigue team too. All of the NHS services are so over full because thousands of children are being really badly effected by Long covid. This means that I have only just started seeing these services, and physiotherapy I only see once a month as they are so busy. It is vital that you give more money to services like this that are helping children with Long Covid so they can expand and help more children like me.

After being in hospital I decided that I wanted to support the NHS and raise awareness of Long covid in children. I have been relearning to walk again since September and now use a walker to get about (before covid I was healthy and fit and had no underlying health issues). I have been walking laps of my garden since 1st December 2021 to raise money for the NHS charities together, and so far have raised over £7000. This is something which is very important to me and I hope will raise the awareness of how covid is effecting children.

In January I started back at school for the first time since September, I started doing a short session a few times a week and am now building this up to 2.5hours-3hours a day. This is because I am suffering with chronic fatigue, constant pain but also brain fog (alongside other covid related issues) which makes concentration very difficult. Since being back at school, I have noticed a large number of children being affected by covid, luckily most of them have not suffered with long covid, but 1 in 7 children will go on to get Long Covid. It is important that schools are safe, with clean air and good ventilation. It is also very important that Primary school children get the vaccine as soon as possible, so we can be protected against covid and long covid.

Although you think taking down covid restrictions is a good idea, I would disagree. Wearing masks protects you and others and is not a hard thing to do. Isolation is important as it stops the spread of covid and means less people will get infected, meaning less work for the NHS. Which would mean more support and money for people with Long covid.

I am still suffering with a weakness in my left leg, constant pain in my leg, back, shoulders and neck, brain fog, chronic fatigue, stiff fingers, gastric issues, hearing problems and sight problems, Long covid has changed my life but I choose to stay positive and keep fighting.

My hopes for the future is that I will get stronger and go back to school full time and do all of the hobbies I love to do. I hope that this letter may have influenced your mind just a tiny bit and that you think again that children can just bounce back from covid.

Yours Sincerely

E

Hand delivered to
No. 10 Downing Street
Westminster
London

Dear Boris,

My name is A and I am 9 years old. I&S I&S

I have had Long Covid for 2 years, since I was 7, and it has been absolutely horrible. The doctors don't know how to help me and some of them don't even believe I am sick. That makes me feel really angry and I don't like to be treated like I am making it up. I can't get to my appointments sometimes because I feel too ill, but they won't come to my house even though Mum asked them to. So I don't really have any help from doctors or physiotherapy or CAMHS or anyone yet. Some of them tell me to just go back to school and then I'll get better. Well, I tried that lots of times and it made me much much worse, so...

I have a wheelchair now because my legs hurt when I walk and I am too tired to do anything, even fun things. I saw my friends last weekend and that was the first time since before Covid started. I feel like they are not my friends anymore because we are all different now. They don't understand why I've not been at school and they don't understand what Long Covid is like.

I can't do school since I had Covid for a second time last summer, because my brain just doesn't work and I can't think or concentrate. It stresses me out and I get frustrated and that makes my Long Covid and PANS symptoms even worse. I can't even write this letter properly because my hands hurt so I had to type and need my Mum to help me a lot because typing this letter has taken me 3 days so far!

I don't know why the Government hasn't helped us yet and that makes me pretty angry and quite depressed. Why don't people think Long Covid is that bad? I know how bad it is but everyone is ignoring it and pretending it's not here. I think as the Prime Minister you can fix this? Maybe you could speak to Nicola Sturgeon and come up with a plan to help us? We need help.

I really hope that you and the Government can help us and do something about this because I really need everyone to understand why I am sick and how I feel every single day. Especially the doctors. I really need you to make things better, please? Not just for me and my Mum, but for all the of the kids who have Long Covid because we're all sick but no one cares.

I hope that you read my letter and I hope that you can do something to help us.

Thank you,

A

EXHIBIT SM/33

CASE STUDIES PROVIDED BY LONG COVID KIDS

Please note that some of these case studies were written by adults on behalf of the child concerned.

Case Study 1

Personal information	E, 15 years old
When did you first fall ill with Covid?	September 2020
When did you become aware that you had Long Covid?	October 2020
What did you know about Long Covid *before* you found out that you had Long Covid?	I didn't know anything about Long Covid
Did your GP or other healthcare provider know what Long Covid was?	Medical professionals just reported as it's so new we don't know enough about it or if you will ever recover or what the future will hold. Or they said it does not affect kids! There were no clinics available for kids.
What public messaging had you seen or heard about Long Covid before you fell ill and thereafter?	Only information/support that I received was from LCK and Bath Fatigue Clinic.
Were you aware of the 'Long Covid' video published by the Department of Health and Social Care in October 2020?	No
What impact did Long Covid have on your health, please specify symptoms, any particular damage e.g. myocarditis etc, and health impairments generally?	Headaches fatigue dizziness impaired vision muscle aches joint pain, pins and needles, rashes, bruising, tinnitus, gastrointestinal issues, difficulty sleeping and costochronditis.
How did Long Covid affect your employment or financial circumstances?	Student not employed

What was the impact on the child or young person's education and school life?	I am unable to attend school, isolated from society, and fearful of being reinfected. I have lost opportunities, lost friendships and am unable to carry out my hobbies such as horse riding or helping at the stables.
What impact did Long Covid have on your personal life?	We are unable to be spontaneous like we used to be. We have adapted pleasure family outings so as not to use much energy and often have to cancel at the last minute.
How did Long Covid affect you home and family life?	It's put a lot of strain on my parents working extra to save for private treatments.
How is your health now – do you continue to suffer health impairment?	I'm slightly improved but am aware I have to be careful and pace so as not to relapse/crash.

Case Study 2

Personal information	C, 17 years old
When did you first fall ill with Covid?	October 2020
When did you become aware that you had Long Covid?	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.
What did you know about Long Covid *before* you found out that you had Long Covid?	I suspected I had Long Covid as my sister was also diagnosed in October 2020.
Did your GP or other healthcare provider know what Long Covid was?	No. We were told that children were not affected by covid!
What public messaging had you seen or heard about Long Covid before you fell ill and thereafter?	LCK was helpful when professionals were looking to blame it on my mental health and played it all down
Were you aware of the 'Long Covid' video published by the Department of Health and Social Care in October 2020?	No

What impact did Long Covid have on your health, please specify symptoms, any particular damage e.g. myocarditis etc, and health impairments generally?	Dysautonomia, anxiety, unable to sleep, fatigue, new food intolerances, dizziness, water allergy, nose bleeds reflux gastrointestinal
How did Long Covid affect your employment or financial circumstances?	Student
What was the impact on the child or young person's education and school life?	I was unable to attend school/college. I only managed maths and English exams.
What impact did Long Covid have on your personal life?	I had to give up football and was isolated from my friends.
How did Long Covid affect you home and family life?	We are unable to just do what we like. Things have to be planned but also be cancelled last minute if required.
How is your health now – do you continue to suffer health impairment ?	I have improved quite a bit although when I have done too much I struggle cognitively and struggle with word finding or processing spoken word.

Case Study 3

Personal information	T, 19 years old
When did you first fall ill with Covid?	August 2021
When did you become aware that you had Long Covid?	September 2021
What did you know about Long Covid *before* you found out that you had Long Covid?	Nothing
Did your GP or other healthcare provider know what Long Covid was?	They were aware of it. My GP said they could refer me to the Long Covid clinic after 12 weeks of being ill but couldn't do anything else to help.
What public messaging had you seen or heard about Long Covid before you fell ill and thereafter?	None before I was ill and I don't remember seeing anything since. The public messaging was about Covid, not Long Covid.
Were you aware of the 'Long Covid' video published by the	No

Department of Health and Social Care in October 2020?	
What impact did Long Covid have on your health, please specify symptoms, any particular damage e.g. myocarditis etc, and health impairments generally?	Fatigue, brain fog, headaches, dizziness, nausea.
How did Long Covid affect your employment or financial circumstances?	I was unable to look for work in school holidays.
What was the impact on the child or young person's education and school life?	I missed one year of school after completing Year 12. I returned to school a year later but could not manage 3 A levels so dropped 2 subjects. I now have one A level and would like to go to university but I am unable to at the moment because my Long Covid illness is hampering my ability to obtain the necessary qualifications to be accepted on a university course. I am unable to take part in sport and had reduced participation in school activities such as school plays.
What impact did Long Covid have on your personal life?	I was unable to socialise in and outside of school leaving me feeling isolated. All my year group left school and moved on to university or jobs. I rejoined school in a new year group having to try to make new friends while coping with long Covid. I am able to socialise more now but it can leave me exhausted and in bed for a few days.
How did Long Covid affect you home and family life?	Long Covid has Limited family activities as I am unable to walk far. My family can't leave me for too long as my fatigue means I would struggle to shop for food and cook for myself. Holiday plans and trips are affected by my lack of energy because it limits the options available to my family.
How is your health now – do you continue to suffer health impairment?	I have slowly improved over the last 2 years, but I am still unwell and suffer from fatigue, headaches, brain fog and dizziness meaning I spend parts of everyday lying down and have to try to pace myself.

Case Study 4

Personal information	E, 16 years old
When did you first fall ill with Covid?	E tested positive for Covid (PCR) on the 23 September 2021 having been infected in school. She was asymptomatic at the time of the PCR but was advised to test due to several of her school friends testing positive. On 27 September 2021, the school advised in writing to parents that there were 63 confirmed cases (no other family member tested positive or experienced symptoms within the same time period). This was prior to vaccinations being rolled out for young people of her age. E started displaying symptoms within a couple of days of testing positive– mild at first. E was first diagnosed with costochondritis, then covid pneumonia by the GP and then with transient synovitis in A&E. She then lost the ability to read and experienced blurred vision with visual disturbances from 7 October 2021 and started fainting. She soon lost her sense of taste / smell and developed tinnitus, hyperacusis, allergic reactions, vomiting, low blood oxygen, fast heart rate, migraines, back pain, hip pain, rib pain and insomnia. She also developed a sudden and prominent (36 degrees) curvature of the spine and was diagnosed with scoliosis (now thought to be reactive scoliosis).
When did you become aware that you had Long Covid?	The sudden onslaught of debilitating symptoms during and following what was diagnosed as covid pneumonia in a previously very fit, happy and healthy young person clearly indicated that the covid infection had triggered a multisystemic physiological response. The GP confirmed that E was experiencing Long Covid symptoms a few weeks following infection. She received a formal diagnosis from Paediatrics at Hospital Y in November 2021. It seemed unlikely that so many multisystemic (musculoskeletal, neurological, cardiorespiratory, dermatological, vascular, visual, ENT, gastrointestinal) symptoms appearing suddenly, during, and following a covid infection could be attributable to anything other than a response to the infection. It was glaringly obvious to E and to us that this was a multisystemic response to Covid. 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.
What did you know about Long Covid *before* you found out that you had Long Covid?	I was aware of Long Covid prior to E's illness through a work colleague having been affected by Long Covid but not through public messaging. As a family, throughout the pandemic, we had carefully followed advice regarding social distancing, handwashing, face covering (standard rather than FFP3) as we were especially mindful of an older family member who was identified as clinically vulnerable. I followed Independent Sage and Professor Christina Pagel and followed the ONS UK Covid data. As such, as parents, my husband and I were uncomfortable about sending our children back to their respective high schools in September 2021 without adequate ventilation and vaccinations etc. but felt we had no other option at the time.
Did your GP or other healthcare provider know what Long Covid was?	The GP (by their own admission) was not very well informed about Long Covid and was only aware of one other patient in the practice who had been affected but he was sympathetic and when we informed him of the Long Covid Clinic at Hospital X, he immediately made a referral. The referral was declined stating that only paediatricians could refer to the Long Covid Clinic. We managed to get a referral to paediatrics via A&E at Hospital Y. 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. E asked what she could do to get better as she had already missed a couple of months of school. He told her she would have to 'wait for the research'. E was then seen in General Paediatrics at Hospital X in December 2021. The Doctor assumed her insomnia must have been due to 'subconscious anxiety' and reluctantly made referrals only when we insisted that this was not in any way anxiety related. Her first appointment with the Long Covid Clinic was in May 2022 (eight months after the onset of symptoms and missed school) with a nurse who told us she had not received any specific training regarding Long Covid and had only been allocated 8 hours per month for Long Covid patients.

	Although E has since had lots of involvement from multiple departments at Hospital X, there has been very little in the way of meaningful intervention. She has been subjected to misdiagnosis, minimising and disbelief, due in part, we believe, to prejudice, bias and lack of awareness caused by irresponsible public messaging and a lack of training about not only Long Covid but also Myalgic Encephalomyelitis. George Monbiot has referred to the situation regarding Myalgic Encephalomyelitis as 'one of the greatest medical scandals' of the last century www.scottishlegal.com/articles/david-j-black-cherchez-la-shrink and https://thesciencebit.net/2023/07/12/the-cries-for-help-are-getting-louder-and-thats-a-goodsign/. E has also been severely affected by delays in treatment and broken promises. Moreover, she has been subjected to several unnecessary investigations that have not informed her care and advice that is contrary to NICE guidelines for ME. Our daughter is not alone in being the subject of misplaced pseudo-psychological hypothesising under the auspices of the (bio)psychosocial approach, with biomedical theories somehow being far less prominent than psychosocial theories in formulation. The DHSC's Interim Delivery Plan 'My Full Reality' highlights how misunderstood ME is amongst medical professionals. Messages based on misinformed assumptions about deconditioning, hypervigilance, anxiety, lack of motivation / effort in relation to severe ME are not only unscientific and unethical, they are also potentially dangerous. E has been subjected to all of the above, again despite overwhelming evidence to the contrary. We were advised by hospital X to access external support with a promise that the hospital would work with external experts. We have been fortunate to be able to access support from Dr William Weir, Dr Binita Kane, Dr Sanjay Gupta and Dr Asad Khan. IV saline treatment recommended by external consultants to restore blood volume was agreed via an MDT at the hospital was then cancelled at the last minute after admitting her for this treatment and continues to be withheld. We still view this decision as contrary to E's best interests and human rights and despite our many requests have received no explanation that might help us to understand things

	differently. Immuno-adsorption recommended by external experts in September 2022 has still not even been considered insofar as we are aware. Hospital and Community staff involved, who are merely monitoring our daughter's decline, tell us that they feel powerless to help and that they have to abide by the rules of the institution in which they work.
What public messaging had you seen or heard about Long Covid before you fell ill and thereafter?	I do not recall seeing or hearing any public messaging about Long Covid before my daughter became ill or since. As a psychologist working in schools, I attended a multidisciplinary event regarding the return to school and distinctly recall Professor Callum Semple stating that serious complications for children were 'vanishingly rare'. Professor Semple was also quoted in the media to this effect: https://news.sky.com/story/coronavirus-childrens-chances-ofdying-from-covid-19-are-tiny-study-suggests-12057738 I recall commenting to my husband that the phrase 'vanishingly rare' seemed more poetic than scientific. When E became ill, I accessed support via the Long Covid Kids Charity. Without LCK and advocates from the ME patient community, there would have been no support available to us.
Were you aware of the 'Long Covid' video published by the Department of Health and Social Care in October 2020?	I do not recall being aware of the 'Long Covid' video published by the DHSC in October 2020.
What impact did Long Covid have on your health, please specify symptoms, any particular damage e.g. myocarditis etc, and health impairments generally?	Before Covid Pneumonia in September 2021, E (now 16) was fit, healthy, performing well academically with good social networks, dancing six times weekly and a gifted musician. Apart from well managed allergies and undiagnosed hypermobility, she had no known underlying condition 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. E now has multiple diagnoses and debilitating symptoms including but not limited to: Long Covid, Severe Myalgic Encephalomyelitis (characterised by Post Exertional Symptom Exacerbation, insomnia, cognitive impairment, extreme sensitivity to light, sound, touch and motion), disease related malnutrition (feeding tube), vasculitis,

	post retinal abnormality (constant blurred vision and frequent double vision), optic neuritis, bilateral vestibular hypofunction, endothelial damage, hyperactivated platelets, microclots, hyperviscosity, low circulating blood volume, orthostatic intolerance / dysautonomia (frequent and persistent fainting after minimal exertion e.g. turning in bed, talking), vestibular migraine with aura, Mast Cell Activation Syndrome, chronic pain, reactive scoliosis (Orthopaedics have said 'it will resolve when everything else resolves', painful subluxations in shoulders, elbows, hips, collar bone, ankles, knees, fingers tinnitus, loss of taste / smell, autoantibodies (Anti Muscaranic Cholinergic Receptor 5 (M5), Anti ß1 adrenergic receptor antibodies, Anti ß2 adrenergic antibodies, Anti Muscaranic Cholinergic Receptor 3 (M3), Anti Muscaranic Cholinergic Receptor 4 (M4).
How did Long Covid affect your employment or financial circumstances?	Prior to E becoming unwell, I was working as a self-employed Educational Psychologist. Having always worked, I have been unable to work due to E requiring full time support. We were forced to take a mortgage holiday and fundraise for treatment. E's illness has had a significant impact on all aspects of our lives including employment and financial.
What was the impact on the child or young person's education and school life?	Prior to covid, E was fit and well with good social networks, performing well academically and a gifted musician. E was supposed to be receiving her GCSE results in August 2023 – just one example of something that Covid, severe Myalgic Encephalomyelitis and delays in treatment have stolen from her. She has been too unwell to engage in any learning since October 2021. She has not only missed out on 2 years of school and GCSEs but also countless learning / social experiences and events during her formative years.
What impact did Long Covid have on your personal life?	E has been unable to read (regardless of font size) or even listen to music since October 2021, going on to develop a range of other multi-systemic debilitating symptoms. She is unable to shower or bathe and even basic self-care is too energy consuming and causes her to faint repeatedly.
How did Long Covid affect you home and family life?	E is a very important part of a close, loving family who miss her dearly. Since December, she has left her bedroom on just 2 occasions – both times being carried downstairs by ambulance crew. The impact on our family has been immense. We try to keep things as normal as

	possible for our other child (13 years) who has had covid twice (but recovered well) whilst balancing this with E's complex needs. I rarely leave the house and managing E's environment especially in terms of limiting her exposure to noise, infection and smells are constant considerations so we are much more isolated than we would wish to be. Friends and even close family find it unbelievable that she is not receiving treatment given the severity of her illness, feel powerless to help and do not know what to say. Our son is the only child in his school still wearing a mask (FF3). He insists on doing so because, in his words 'I know what I know' and wants to protect his sister from further infection. He ignores ignorant comments and says 'if this had happened to someone in their family they would be wearing a mask too'. E has been too unwell to see friends or extended family. She very occasionally manages to send a message using voice to text software, but the energy required to do this always causes payback in terms of post exertional symptom exacerbation.
How is your health now – do you continue to suffer health impairment ?	E is bedbound and tube fed in a darkened quiet room, has very little interaction and is extremely sensitive to light, touch, noise, motion, temperature, and smells. The diagnoses and symptoms detailed in the previous section about the impact of Covid on her life remain current and have progressively worsened. She cannot currently tolerate being upright and even faints while lying down. She has an abnormal response to exertion of any kind including laughing, talking, digesting food and sneezing. She has very limited quality of life and is in constant pain. Evidence available suggests that she is unlikely to spontaneously recover and yet the treatment that was promised to restore her blood volume continues to be withheld. E somehow maintains hope and positivity and knows that we are fighting for the right support for her. She has all the same dreams and ambitions but is realistic that she will need treatment first. She refuses to accept that things cannot be better than this. We demand change for her and will continue to be her voice for as long as she is too unwell to advocate for herself. The following statement is my opinion informed by our experience over the last 2 years: As can be seen from this account, schools were not 'safe' for all, children were affected by Covid and Long Covid and serious harms were not, as it turns out, 'vanishingly rare'. Our daughter's whole life has been reduced to

	collateral damage because the government chose not to follow the science and she continues to pay the price (without treatment) for their recklessness. The very least the government can do now is to acknowledge the harms caused, fund biomedical research, trials, and treatments for children and young people with Long Covid and Myalgic Encephalomyelitis (especially those severely affected) and ensure they receive the health, care, educational and social support they need.

Case Study 5

Personal information	H, 15 years old
When did you first fall ill with Covid/ Chronology of symptoms	April 2020 (Age 12) - 1st Covid infection. Poorly in bed for 2-3 weeks. Recovered after this infection. July 2021 (Age 14) – 2nd Covid infection (Positive PCR) - H was incredibly poorly and in bed for 2-3 weeks August 2021 – Sept 2021 (Age 14) H appeared to be slowly getting over this infection. Sept 2021 (Age 14) - When H returned to school it became apparent after a few weeks that she was struggling. H was generally "unwell" on and off, several days off school (previously always had full school attendance) throughout September and October. Late September / Early October 2021 – H's symptoms intensifying and getting continually worse. • Severe headaches • Complained of body burning inside • Intense itchiness all over • Rashes • High fever / temperature • Chest pains / struggling to breathe • Problems with eye pain / stye on eye developed • Muscle aches and pains

	• Skin peeling on hands / fingers • Sensitivity to light • Extreme fatigue / sleepiness – very difficult to wake 20 October 2021 – H was admitted to hospital. Whilst in hospital at X, the Paediatricians couldn't work out what was wrong with her. Suspecting Long Covid, the hospital referred H to a Long Covid Clinic. December 2021 – H had her first appointment at a Long Covid Clinic, the Evelina Hospital. She was diagnosed with Long Covid.
When did you become aware that you had Long Covid?	December 2021 H was formally diagnosed with Long Covid at this point. The team were kind and lovely, and we had several meetings with them but couldn't really offer anything by way of medical assessments or treatments. We have since had no option but to seek care and treatment from Private Consultants at our own expense.
What did you know about Long Covid *before* you found out that you had Long Covid?	We were aware of Long Covid because I had been referred to the Long Covid Clinic in Kent in April 2021 but I was never seen or assessed/treated. I had to do my own research and pay to see a specialist that advised and provided knowledge/treatments.
Did your GP or other healthcare provider know what Long Covid was?	The GP had no experience at all of Long Covid in children. They assumed incorrectly that the Long Covid Clinic at The Evelina 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. H was under the care of the Long Covid clinic at The Evelina 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.
What public messaging had you seen or heard about Long Covid before you fell ill and thereafter?	None!
Were you aware of the 'Long Covid' video published by the Department of Health and Social Care in October 2020?	No – never seen it.

what was the impact on the child or young person's education and school life?	She has been robbed of her secondary school experience. She started secondary school in September 2019, and because of lockdowns and illness has not been able to attend school since. H should be starting Year 11 next week. Earlier this year, Hannah tried to go into school for an hour a day, twice a week, but this was stopped due to H suffering from severe PEM/PESE. H is now 2 years behind in her education. We are trying to organise an Education, Health Care Plan (EHCP) so that H can access education at the level that she needs. H had a trial of this during the summer term and it worked well. She was offered just 2 hours a week for Maths and English to see how she would cope. We are hoping that this will continue in September. There are absolutely no systems or protocols in place for children suffering with Long Covid – a complete failure of the education system. H is far behind her peers at school – socially she is unable to spend time having the fun that she should be having too. She desperately wants to see friends but most of the time is unwell. She also desperately wishes to be in school too to learn, but with no provisions this is not possible.
What impact did Long Covid have on your personal life?	H 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 15year old should be able to enjoy. She may be able to enjoy a "light" activity in an afternoon but she barely has any form of social life and if she does plan to have a friend visit, quite often this is cancelled due to her having a "bad day" physically. If H does spend time doing something fun and/or sees a friend, she will then need to rest and she will quite often suffer with PEM, because she cannot stop herself from over-doing it if she is enjoying herself. Daily she struggles. Daily she is in pain. Daily she picks herself up and keeps trying to be

	positive, despite this horrendous illness. H's friends have moved on without her.... H used to love her dance classes, that she had been having since she was 2 years old, with a lovely group of friends. She has been unable to attend the classes, and friends have moved forward without her. This makes H very unhappy, and she cannot even go to watch them in the dance shows now, because it hurts her too much with what she is missing out on.
How did Long Covid affect you home and family life? How did Long Covid affect your employment or financial circumstances?	Long Covid has affected home and family life detrimentally as we are no longer able to enjoy family days together. H has an older sister, who is also missing out; a lot of focus has to be around H's needs. Her older sister has had to grow up so much and has seen her sisters suffering. We don't have so many friends visit now, because H can't cope with the noise and busyness. Family life is just so different generally as I don't have so much time to do fun activities at home or outside. H also has to attend a lot of hospital appointments – which we have to pay for/ finance privately, as nothing available through NHS. We also take her to private hydrotherapy sessions that help with her pain/mobility in a very gentle manner – we were unable to access anything like this under the NHS. Financially Covid / Long Covid has had a massive impact on our income, as I have had to become a full-time carer for H. I am only able to work part-time juggling around H's needs – but sometimes I have to drop everything to care for her or to take her to appointments, and being self-employed, I get nothing if I am not working. If H is going to attend school and any meetings, this takes up half a day because maximum she will cope with attending is for an hour, then I'll need to collect and take her home. I was working full time hours (40hrs +) prior to having Covid / Long Covid.
How is your health now – do you continue to suffer health impairment?	Following covid infections, H now suffers with CFS/ME, PEM/PESE, POTS symptoms, MCAS, immune dysregulation, inflammation and abnormal Clotting / circulatory issues, forming part of her Long Covid

	Symptoms. It is still unclear what is wrong with Hannah's legs, but she suffers daily with constant pain and mobility problems. H also suffers with cognitive / memory / reading. I can honestly say that Covid / Long Covid has devastated our lives. Failure of the Government to protect our Children when in school is the biggest failing.

Case Study 7

Personal information	S, 13 years old
When did you first fall ill with Covid?	S caught Covid mid-September 2021 at school
When did you become aware that you had Long Covid?	The Covid infection was mild, some fever and cough , fatigue but no hospitalisation was required and he was home for two weeks. His brother, sister and myself became unwell few days later. We recovered and S went back to school for a week or so. Unfortunately, he started having fever with cold symptoms every 3-4 weeks, he would need to stay at home for few days to rest and then go back to school again. His fatigue was increasing, he suffered with a really bad nasal congestion and struggled every morning to get up. By early November I rang GP and had a phone consultation and was prescribed antibiotics which did not help. We managed to have two face to face appointments but only with a nurse. To see a GP doctor was almost impossible. I insisted on blood tests but because he was under 12 he needed to have an appointment which took 6 weeks to book. During this time we were told GP would not see him until we had the blood tests results. By January 2022 his attendance at school was only 50%. We were resisting the school pressure as much as we could, they wanted him in even with 'cold symptoms'. He was more seen as a child with anxiety struggling to settle at a new school rather than a child being unwell. On his twelth birthday in January 2022 he managed few hours outside but the next day he developed extremely high fever with a migraine that lasted a couple of days. He begged me to help him to sleep so he can wake up when all his pain is over.

	It was around this time I found Long Covid Kids Facebook page and figured out that S was most likely suffering with Long Covid. We have not seen any video published by the Department of Health and Social Care in October 2020.
Did your GP or other healthcare provider know what Long Covid was?	I pushed for immediate referral to see a paediatrician and he was seen early February 2022 at Queen's Mary Hospital at Romford. His blood results only picked up low vitamin D and low levels of iron. We discussed the possibility of Long Covid with the doctor but he had not knowledge of a Long Covid clinic for children in the UK. The Doctor promised to look into it. We were advised to encourage S to attend the school full time. We were told this is most likely increased anxiety as he was starting year 7 at grammar school and felt peer pressure. He managed one day and crashed for few days, this was half-term. We were dreading the return to school. We managed to get an appointment the following week at the hospital and saw a different consultant who actually said this is their first child with suspected Long Covid and provided us with a letter for school with an advice for reduced timetable. During the follow up appointment with the first Doctor on 8 March 2022 we were told a referral to Long Covid clinic was made together with a referral to CAMHS. I quote "Thank you for seeing this young boy who has been suffering severe symptoms with anxiety, low mood since he had Covid in September and he has not been able to function normally. He is missing school, he is spending most of his time in bed. If you could kindly support him with regards to his symptoms." The month of March 2022 was extremely difficult. We made a visit to A&E, S was quite breathless and very fatigued, we were monitoring his oxygen on oximeter at home and his oxygen level was dropping at some point, only to be told he should be running around as any other young boy and the oximeter was probably not working properly. Within a week S 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 any more . We did a video call where she could see S 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. During March 2022 we called for an ambulance because of his chest pains and breathlessness. The paramedic assessed him, because his vitals were normal we were told he just needed some rest. On second occasion when we called 999 , the ambulance was refused and we were told to bring him in ourselves. At this point S had constant chest pains that came in waves, kind of contractions, happening day and night, he struggled to sleep. We were unable to bring him downstairs, we could not pick him up , he was in pain. His sensitivity to touch, movement, sneezing, burping, yawning .. any vibration stayed with him until today. At this stage, once the referral to long covid clinic was made, no one was willing to look after him, GP, paediatrician even at AE the doctors were telling us that long covid clinic will look after him. We made it to A&E on another occasion, his chest pains were really bad and he was diagnosed with suspected costochondritis. Finally we had the first appointment with UCL Long Covid Clinic were S was assessed and diagnosed with long covid syndrome. We was also diagnosed with POTS by a cardiologist at GOSH, Functional neurological disorder (confirmed by neurologist at GOSH) and assessed for autism due to his severe sensory sensitivities. FND and Autism were later on revoked.
What public messaging had you seen or heard about Long Covid before you fell ill and thereafter?	It was around this time I found Long Covid Kids FB page and figured out that S was most likely suffering with long covid
Were you aware of the 'Long Covid' video published by the Department of Health and Social Care in October 2020?	We have not seen any video published by the Department of Health and Social Care in October 2020.
What impact did Long Covid have on your health, please specify	In April 2022 S was not able to walk anymore and he became a wheelchair user, we had to moved his bed

symptoms, any particular damage e.g. myocarditis etc, and health impairments generally?	downstairs to a living room where he has been living since so he can be part of a family and not isolated upstairs. This means he only has an access to downstairs toilet and no access to a bathroom facilities. S was attending rehabilitation program with focus on physiotherapy and OT at UCLH for a year. During the November 2022 stay at UCLH he caught second covid infection, unfortunately there was no testing in place at the hospital at that point. In September 2022 S's liver markers became elevated, he developed hyperphagia, gain excessive weight, got diagnosed with hyperinsulinemia and developed fatty liver. He was put on diabetes medication. He developed skin condition which took several weeks to clear. We were unable to treat it with any creams or ointments as it gave him painful burning sensation. We had access to 6 sessions of PT and OT locally through NHS. We asked for a help from Social care OT at Barking and Dagenham in terms of alteration to the property to create wet room for S but were told he needs to mobilise on the stairs and were only offered at first a bath board, later it was changed to bath lift. Unfortunately due to his extreme sensitivity to vibration he finds it painful and is not able to use it. We were told due to the uncertain outcome of S's disability they are not going to assist with creating a wet room for him, even though he has had to live downstairs for over a year now.
What was the impact on the child or young person's education and school life?	His education has been completely ruined. From starting a grammar school in September 2021 he is now only able to have two 30 min sessions online with the tutors, one in the morning Math and one in the afternoon English provided by the Alternative education school.
What impact did Long Covid have on your personal life?	He lost all his friends. The occasional visit he received only showed how much they have all moved on while he is left behind , unable to do so. The one hour of chit chatting would completely wipe him out and caused him post exertional malaise. Those have now stopped. His siblings, tutors and occasionally family friends are the only people he interacts with.
How did Long Covid affect you home and family life?	This has had a huge impact on our family life. Both our close relatives live abroad, we have no family members in UK and we have not been able to visit the grandparents. My husband lost his father during the

	lockdown and has not been able to visit the family since pre-pandemic. The family holidays are on hold, we managed a weekend away in the south of England but one of us had to stay with S at the property, he could only manage up to an hour outside in the evening, could not tolerate the sunny weather. Everything is planned around S's needs. His siblings can only invite friends at certain times, only in good weather when they can be in the garden, the noise of people talking is overwhelming and the sitting room is his bedroom now. We are unable to have visitors from abroad, family members. Occasional outings to celebrate the milestones of his siblings are only if S is well enough to tolerate the short journey by car and the noise of the surroundings.
How is your health now – do you continue to suffer health impairment ?	We will be celebrating two years in September 2021 and S is still very poorly. He was recently assessed as CFS Functional ability scale: 20% recovered [note this is recovery of basic function not pre-morbid fitness]. This is defined as severely affected. What does his future holds ?

UK COVID-19 INQUIRY

EXHIBIT SM/8-INQ000000

CHRONOLOGY OF ADVOCACY BY LONG COVID KIDS

Date	Event	Source
September 2020	Long Covid Kids established as a grass roots support and advocacy group	
October 2020	Long Covid Kids publish film "Our Unhappily Ever After"	SM/5 – INQ000000
October 2020	Meeting with Andrew Gwynne MP	
21 December 2020	Email to MP Chris Loder about HofC debate on Long Covid on 7 January 2021	SM/9 – INQ000000
07 January 2021	NHS Long Covid Task force meeting	INQ000238600
07 January 2021	Email to Layla Moran MP introducing Long Covid Kids and offering support.	SM/10 – INQ000000
11 January 2021	Joint briefing from Parents United Against Unsafe Schools (of which LCK was part) sent to MPs regarding debate on Long Covid	SM/11 – INQ000000
26 January 2021	Long Covid Kids members and founders give evidence to the APPG on Coronavirus, published in APPG's Long Covid Report.	SM/13 – INQ000000
29 January 2021	LCK attended Ministerial Roundtable on Long Covid	INQ000238600
4 February 2021	LCK attended NHS Long Covid Task force meeting	INQ000238600
23 February 2021	LCK attended Ministerial Roundtable on Long Covid led by Secretary of State for Health and Social Care Matt Hancock and Lord Bethell	INQ000060080
4 March 2021	Email to Chris Loder MP with LCK's Schools Pack	SM/43 – INQ000000
30 March 2021	LCK attended Ministerial Roundtable on Long Covid	SM/12 – INQ000000
April 2021	Long Covid Kids member Fran Simpson attended the Academy of Medical Sciences and Mental Health joint workshop on 'Progress and priorities for mental health sciences research since Covid-19'. She had the opportunity to ask Chris Whitty about his views on Long Covid in children. He stressed the many unknowns around this condition,	SM/44 – INQ000000

	including the difficulties of knowing where the line is drawn between physical and mental health impacts. He conceded that there may be neurophysiological causes, but also drew attention to the ongoing challenges in the CFS/ME communities, for example, concluding that research and progress will take time.	
12 April 2021	Joint Letter (with Safe Ed for All) to Matt Hancock Secretary of State for Health and Social Care	SM/14 – INQ000000
4 May 2021	Letter to Gavin Williamson Secretary of State for Education	SM/15 – INQ000000
16 June 2021	LCK attended Ministerial Roundtable on Long Covid	INQ000061094
1 July 2021	Meeting arranged with Wera Hobhouse MP to discuss Long Covid in children with along with Safe Ed For All.	SM/45 - INQ000000
3 July 2021	Email to Neil Obrien MP (with Safe Ed for All)	SM/46 - INQ000000
7 July 2021	NHS Long Covid Specialist assessment service subgroup meeting	INQ000238600
9 July 2021	Letter to Sajid Javid MP upon his appointment to DHSC raising concerns about Long Covid data and policy.	SM/16 - INQ000000
15 July 2021	Email from Ian Murray MP to a Long Covid Kids member	SM/47 - INQ000000
21 July 2021	Long Covid Kids attend Ministerial Roundtable on Long Covid	INQ000061418
1 September 2021	NHS Long Covid Taskforce Research subgroup meeting	INQ000238600
14 September 2021	Video published by Long Covid Kids regarding government failure to update the symptoms list on their website.	INQ000231942
23 September 2021	Long Covid Kids Round Table Meeting with Sajid Javid	INQ000067049
29 September 2021	NHS Long Covid Specialist assessment service subgroup meeting	INQ000238600
6 November 2021	Long Covid Kids publish blog post criticizing JCVI vaccination recommendations	SM/18 - INQ000000
17 November 2021	NHS Post Covid National Taskforce Subgroup Your Covid recovery rollout, development and Long Covid rehabilitation	INQ000238600
24 November 2021	NHS Long Covid Specialist assessment service subgroup meeting	INQ000238600

29 November 2021	Long Covid Kids attended a meeting with Rt Hon Jeremy Hunt MP	INQ000249053
7 December 2021	LCK attend Ministerial Roundtable on Long Covid	INQ000067606
7 December 2021	Letter to Sajid Javid raising concerns about numbers of children with Long Covid; response undated December 2021 from Lily Gilder Department of Health and Social Care	SM/48 - INQ000000
10 December 2021	Letter to Dame Rachel Souza, Children's Commissioner.	SM/49 - INQ000000
12 December 2021	Long Covid Kids founder attends ASC PPE and Testing Stakeholder Working Group	INQ000061481
17 December 2021	Long Covid Kids web article responding to JCVI minutes on child vaccines.	INQ000231939
3 February 2022	LCK attend NHS Long Covid Task force meeting	INQ000238600
16 February 2022	NHS post covid specialist services subgroup	INQ000238600
22 February 2022	Long Covid Kids joint statement with Long Covid SOS in response to the Prime Minister's announcement on 21 Feb 2022 removing all Covid measures.	INQ000231928
11 March 2022	Letter to Andrew Gwynne about LCK visit to Downing Street	SM/22 - INQ000000
11 March 2022	Letter to Layla Moran MP about LCK visit to 10 Downing Street	SM/20 - INQ000000
17 March 2022	Email to Damien Hinds MP about LCK visit to 10 Downing Street	SM/21 - INQ000000
1 April 2022	Letter to Boris Johnson enclosing support guide and children's letters, delivered on visit to 10 Downing Street	SM/25 - INQ000000 SM/24 - INQ000000
27 April 2022	Email correspondence with Gavin Robinson MP about LCK in Northern Ireland.	SM/32 - INQ000000
30 May 2022	Email correspondence with the office of Jeremy Miles MS, to arrange a meeting to discuss Long Covid and children.	SM/30 - INQ000000
1 June 2022	Email from Miss A Johnson at DHSC in response to LCK visit to 10 Downing Street on 1 April 2022	SM/26 - INQ000000
1 June 2022	Meeting with Stephen Morgan MP	
28 June 2022	Long Covid Kids publish open letter to Boris Johnson responding to Department of Health and Social care response	SM/27 - INQ000000
2 July 2022	Long Covid Kids write to Mark Drakeford, First Minister of Wales, about Long Covid	SM/31 - INQ000000

6 September 2022	Letter from James Morris MP Department of Health and Social Care on behalf of Prime Minister Boris Johnson responding to Downing Street visit by LCK and their members	SM/28 - INQ000000
26 September 2022	In-person meeting at the Scottish Parliament with Cabinet Secretary for Health	INQ000231997
2 November 2022	Email to Neil O'Brien MP Parliamentary Under Secretary of State for Primary Care and Public Health, reply dated in November	SM/50 - INQ000000
20 November 2022	Long Covid Kids letter titled 'Long Covid Kids Rebuttal Letter to U.K Prime Minister'	INQ000231935

Appendix 4: Brief Summary of LCK work in Scotland [1]

Supporting Scottish families

- Long Covid Kids Scotland Support Group

Representing Scottish families

- Roundtable on Long Covid with Cabinet Secretary for Health and Social Care and the Clinical Priorities Unit
  - 22nd November 2021
  - 21st February 2022
- Cross Party Parliamentary Group for Long Covid
  - 8th September 2021 - presented to the CPG
  - 8th December 2021
  - 9th March 2022
  - 8th June 2022
  - 26th October 2022
- Scottish Parliament Long Covid Debate briefing note to MSPs
  - 19th May 2022

- Updated the SIGN Long Covid Guidelines Implementation Support Note to support paediatric Primary, Secondary and Allied Healthcare professionals in Scotland.
  - March - July 2022

- In-person meeting at the Scottish Parliament with Cabinet Secretary for Health & Social Care, Humza Yousaf with families in Scotland whose children were affected by Long Covid to have the opportunity to speak face-to-face with the Cabinet Secretary.
  - 28th June 2022

- Partnered with and completed many impactful pieces of work with future projects in discussion, with:
  - Children and Young People's Commissioner for Scotland
  - A Place In Childhood
  - The Health and Social Care Alliance Scotland

[1] As stated this information is preliminary to assist the Inquiry; LCK are not yet recognized CP in the Module 2A and an application is being made.

- Long Covid Scotland
- ME Action Scotland

- Engaged with various relevant organisations.
  - Royal College of Paediatrics and Child Health (RCPCH Scotland)
    - Met with Dr Mairi Stark, Dr Eddie Doyle, CabSec Humza Yousef and Clinical Priorities Unit.
    - Raising awareness of Paediatric Long Covid, and the enormous impact on the wider family, and sharing our LCK Support Guide on which they later provided feedback and complimented our work.
  - NHS Scotland National Services Scotland (NSS) Lived Experience Group Stakeholder meetings.
    - This working group feeds directly into the planning, design and implementation of Long Covid services in NHS Scotland.
    - These meetings have so far proved to be an ineffective tick-box exercise, and have yet to lead to meaningful improvements in outcomes for families in Scotland.
  - Social Security Scotland
    - Stakeholder meetings regarding Child Disability Payment applications.
  - Royal College of General Practitioners (RCGP Scotland
    - Meeting with Dr Williams and Dr Shackles on 23rd November 2022 to discuss co-production of Long Covid training for GPs in Scotland.
  - Lanarkshire Covid Rehab Team
    - Meeting with Abi Campbell, Lead Clinician, on 14th November 2022 to discuss how we can support their Rehab programme for children and young people.
    - The meeting will be attended by Helen Goss (LCK) Kirsty Stanley (LCK Occupational Therapist) and Mary Kelly (Long Covid Physio, physiotherapist)