



Questionnaire

UK Covid-19 Inquiry: Module 2 – Request to Long Covid Kids M2/R9R/LCK/TJS

We set out our responses to the Inquiry's request for information below. We have prepared our responses without sight and substantial consideration of the relevant evidence or disclosure. However, in order to assist the Inquiry as much as possible, we have tried to respond to the Inquiry's requests as comprehensively as we could at this early stage. This response is correct to the best of our knowledge given that the organisation was set up by patients who were extremely unwell at the time, many of whom continue to have ongoing health issues. It is provisional information provided without disclosure and to that end we reserve our right to amend or provide further information as necessary.

We would of course be willing to provide a statement to the Inquiry on the issues raised in the Inquiry's Rule 9 questionnaire in more detail.

A brief overview of the history, legal status and aims of the organisation or body. Please explain whether the work of the organisation or body is UK wide, or is instead confined to England, Scotland, Wales or Northern Ireland only.¹

Long Covid Kids (LCK) was founded in September 2020 by people living with Long Covid. In 2021, LCK became the first registered charity advocating for families, children and young people living with Long Covid anywhere in the world. Currently supporting over 11,000 families, LCK's vision is to achieve recognition, support and recovery for Long Covid and related illnesses in children and young people. Our mission is to increase understanding, aid early diagnosis and improve response and intervention. LCK volunteers have worked tirelessly to raise awareness and effect change throughout the pandemic. [Our Annual Report 2021-2022 spotlights our impact.](#)

LCK's award-winning guidebook '[Shining a light on Long Covid in Children. A Guide to Recognition. Support. Recovery](#)' was created in response to the increase in demand for our support services. The guide contains practical and helpful information for health and education professionals, and families, designed to support and inform on recovery alongside our popular resources; [Pacing Penguins](#) and [Cautious Tortoise](#).

¹ Where documents are public links are provided; other documents are referenced and can be provided.

Long Covid Kids is a UK-based international charity. Our headquarters are located in England and we have representatives in Scotland, Wales, Northern Ireland, the Republic of Ireland Europe, Greece, Argentina, the USA, Canada and New Zealand.

In terms of legal status, LCK is a registered charity in England and Wales. LCK is in the process of registering for charitable status in Scotland and is at the final stages of the process.²

2. A brief description of the group(s) which the organisation or body supports or Represents.

We support, represent and advocate for children and young people living with the ongoing symptoms of COVID-19 / Long Covid. This includes the families/caregivers and education and health professionals working with them. We support young carers of parents living with Long Covid. LCK is currently supporting over 11,000 families.

3. A brief overview of the work of the organisation or body in supporting or representing the relevant group(s) between January 2020 and Spring 2022 as it relates to the response to Covid-19 of (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive.

We have set out at Appendix 1 Chronology of the work of Long Covid Kids has undertaken between January 2020 to Spring 2022³. This sets out in broad outline the work of the organisation in supporting and representing children and young people living with Long Covid. It should be apparent from that work that in summary, Long Covid Kids has advocated on behalf of children and young people living with and families affected by Long Covid in the UK by:

1. Writing to the Prime Minister and relevant Government ministers and MPs;
2. Meeting with Government Ministers and MPs;
3. Participating in relevant taskforces and expert panels relevant to Long Covid;
4. Submitting evidence to the APPG
5. Collaboration with other relevant partners
6. Contributing to UK and international research;
7. Undertaking wider advocacy
8. Devolved nations (summary)

1. Writing to the Prime Minister, relevant Government ministers and MPs;

We have made many efforts to engage the government in the risk of Long Covid and infection harm to children.

² Note that LCK is seeking CP status in Module 2A through separate legal representation, Thompsons. Any Rule 9 specific to Module 2A will be provided separately as LCK are not yet Core Participants in Module 2A; a brief summary is provided in Appendix 4.

³ Please note that hyperlinks are provided where the documents are online. Other LCK documents that are not hyperlinked are not online but can be provided.

In the lead up to the first parliamentary debate on Long Covid on 11 January 2021 LCK wrote to MPs raising concerns about infection rates and Long Covid in children and young people. On 23 December 2020 LCK (co-founder Sammie McFarland) wrote to Chris Loder MP 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. On 7 January 2021 LCK wrote to Layla Moran MP (led the APPG on Coronavirus) on 7 January 2021 stating that LCK represented over 400 children and *“almost all the stories are the same”* that was having inadequate healthcare support and response. As part of the Parents United Against Unsafe Schools campaign a briefing was provided to MPs. 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”*

The administrative decision-making around advice to schools is an important aspect of our work. LCK have prepared a schools pack and a Support guide.⁴ On 12 April 2021 with Safe Ed for All LCK wrote to then Secretary of State for Health and Social Care Matt Hancock raising concerns about risks and mitigation measures in schools. 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”

On 4 May 2021 LCK wrote to the Secretary of State for Education: NR (copied to Education Secretaries for the devolved administrations) about mitigation measures in schools. This was part of a campaign by Parents United. The letter stated:

“It is essential that the UK achieves effective suppression of COVID-19, 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*

⁴ Available on the LC website under Support – Support Guide by entering an email address.

- *increased numbers of Long-Covid sufferers, 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.”

On 9 July 2021 LCK wrote to the then Secretary of State for Health and Social Care Sajid Javid 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.”* We raised various concerns that there was no paediatric clinical 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 (reinstatement of face masks in schools and funding for CO2 monitors and HEPA filtration for schools).

In March 2022 LCK wrote to Layla Moran MP, Damien Hinds MP and Andrew Gwynne MP 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 2022⁵.

On 1 April 2022 a cohort of children and young people with Long Covid delivered LCK’s support guide to Downing Street (see “Long Covid: Children affected take fight to Downing Street”). Each child represented 10,000 young people in this country who have been seriously impacted by the condition, and they had come from every corner of the UK with letters describing the toll this illness has taken on their lives.

The visit was planned in coordination with staff at Downing Street, so LCK had to provide the details of the children and adults attending and were given security passes. The children were assured that their individual letters would be received by the Prime Minister’s office. Several of these children have been disabled by a ‘mild’ SARS-CoV-2 infection, to the extent that they must now use wheelchairs. The visit to Downing Street required significant effort. Unfortunately neither the Prime Minister nor anyone from his office met the children and their individual letters were not received.

By letter dated 1 April 2022 LCK briefly wrote to the Prime Minister providing him with the LCK support guide and calling for:

- *Improved indoor air quality in education settings for prevention health and well being*
- *Equitable education for all*
- *High quality co produced pediatric research*

The Department of Health and Social Care responded to the visit in a letter dated 1 June 2022 which implied that Long Covid was caused by mental health issues⁶. By letter dated 28 June

⁵ Emails to MPs dated 11 March 2022

⁶ The letter from A Johnson Department of Health and Social Care dated 21 June 2022 stated *“Thousands of children and young people have had to adapt to the challenges presented by the COVID-19 pandemic. Whilst many children have shown remarkable resilience in difficult*

2022 LCK wrote and explained why this was inappropriate and factually incorrect. On 6 September 2022 James Morris MP Parliamentary Under Secretary responded with an apology.

LCK raised concerns about Long Covid in children by email dated 2 November 2022 to Neil O'Brien Parliamentary Under Secretary for State for Primary Care and Public Health and a meeting was agreed (not yet taken place).

On 21 February 2022 issued a joint statement with LC SOS raising concerns about removing all Covid measures.

2. Meeting with Government Ministers and MPs;

From early 2021 members of LCK attended the Long Covid roundtables, initially chaired by Lord Bethell. At these meeting we raised concerns about the minimization of the risk of serious long term illness in children. LCK attended Ministerial Round Tables on Long Covid on 23 February 2021, 20 April 2021, 16 June 2021, 21 July 2021, 23 September 2021 and 7 December 2021.

LCK raised concerns at these meetings about the risk of Long Covid in children and young people and the experiences of our members. LCK recorded a blog post on 28 September 2021 which sets out the matters we [raised with Sajid Javid](#), then Secretary of State for Health and Social Care. These were:

- “The symptom list on the NHS and Government websites need 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.”

LCK campaigns to reduce children’s risk of infection with SARS-CoV-2 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 and lobbies for adaptations to be made for affected young people in educational establishments.

Long Covid Kids has had meetings with MPs as set out below (please note some of the specific dates are not known as records were not kept). Members would raise concerns with LCK and LCK would advocate for them. At these meetings LCK raised the core issue of significance to

circumstances, the Government know that there are those who have found this period especially difficult for their mental health and wellbeing”

their members these were broadly raising awareness that children were getting sick with COVID-19 and not recovering, raising concerns about the range of symptoms children experience, lack of paediatric definition, the urgent need for health care support, the issues caused by children being on long term sick from school, lack of support and awareness in education settings, the impact on parents of being unable to work due to the need to look after chronically ill children, vaccines and calling for biomedical research.

- Were Hobhouse MP July 2021
- Jeremy Hunt MP Dec 2021
- Stephen Morgan MP 1st June 2022
- Andrew Gwynne MP October 2022
- Richard Drax 29th Nov 2022

3. Participating in relevant taskforces and expert panels relevant to Long Covid;

LCK was a member of the NHS Task force and some sub groups. LCK reported in these meetings the experiences of the children and families that we supported in terms of the devastating impact of Long Covid, the symptoms, difficulties accessing care and all the issues that we have raised publicly.

The families that LCK support found that, particularly in 2020 –2021, despite turning to GPs for help and existing medical knowledge of post-viral illness for the children they were often disbelieved or dismissed.

In the first year of the pandemic LCK had to demonstrate that children and young people also suffered from COVID-19 as there was little information that children and young people could suffer debilitating symptoms and Long Covid. LCK wrote to individual hospitals and to GPs. They would say that they had no information that children suffered from COVID-19. We spent the first year evidencing the impact of COVID-19 infection and Long Covid on children and young people using lived experiences.

On 2 November 2021 LCK [published a statement](#) raising concerns about the decision of the JCVI not to recommend vaccinations for children.

4. Submitting evidence to APPG

On 26 January 2021 Sammie McFarland, Fran Simpson and Charlie Mountford-Hill of LCK gave evidence to the APPG on Coronavirus which was relied upon in [its report on Long Covid](#) in March 2022 (see p.16, 18 and 19). At paragraphs 17 – 23 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 (para 17). The APPG acknowledged the wide range of symptoms experienced by children (para 21); it found that the UK Government had failed to adequately acknowledge the prevalence of Long Covid among children (para 22) and that the UK had failed to establish specialized care pathways for children living with Long Covid (para 23).

5. Collaboration with other relevant partners

LCK work with partner organisations to keep the spotlight on Long Covid in children and young people.

One of our founders attended the first WHO meeting on Long Covid on 21 August 2020. LCK have [also worked](#) with the World Health Organisation on their expert panels, on the nature of COVID-19 and impact on children. As part of this work LCK shared concerns and issues raised by members of their support groups, their surveys on symptoms and other issues relating to Long Covid in children and young people.

LCK stakeholders for NICE and were involved in the consultation process for the NICE Long Covid Guidelines in December 2020.

Other examples of collaboration include presenting at the Education Psychologist Festival of Educational Psychology, POTS UK Long Covid Masterclass, Independent Sage session on 30 September 2022 on Mitigations and Education, Long Covid Physio International Forum, Catherine Peckham Symposium, the Royal College of Occupational Therapists, Network on Cognition, International Severe Acute Respiratory and Emerging Infection Consortium, National Voices webinar, International Webinar of Pediatricians.

6. Contributing to UK and international research

LCK collects and spotlights child-specific infection statistics and analysis for continuous accountability and clear reporting of the impact that SARS-CoV-2 infection has on children. LCK strongly believe child-centered research co-produced with lived experience has the best change of directly benefitting families, children and young people; and directing meaningful changes.

In October 2020 one of our co-founders published an article in the British Medical Journal "[Counting Long Covid in Children](#)." She stated "There is a need for clinicians, at primary and secondary care levels, to be alert and aware of the multisystem symptoms in children through rapid guidelines or continual professional development. There is also a need for parents to be aware that this may explain ongoing issues that may come and go in the aftermath of a covid-19 infection."

LCK are stakeholders on the NIHR Expert Group panel on Long Covid and contributed to the guidelines looking at what should be funded for research

LCK are collaborating with the University of Derby on researching long covid. LCK are working with Post Covid Condition Core Outcome Set in Children Study (PC-COS-C) which is an international collaboration led by Dr Daniel Munblit.

A list of the research that LCK has contributed to is included in Appendix 2. For example LCK developed an online platform to enable parents from all over the world to report their child's experience. The 'Long COVID Kids Rapid Survey 2' was designed as a follow-up to a pilot survey (that established quantity and type of symptoms) as a means to establish clusters of

symptoms rather than the full breadth of symptoms as well as the effects on the mental and physical health of the child as a result of long COVID. The survey was used in a peer reviewed publication in Future Medicine – [Clinical Characteristics, activity levels and mental health problems in children with long coronavirus disease a survey of 150 children.](#)

7. Undertaking wider advocacy

LCK undertakes wider advocacy to raise awareness about Long Covid in children and seek support and improvements for its members. As well as writing to schools directly we would send them our Schools Pack about risk of transmission in schools, mitigation measures to reduce transmission, how to understand Long Covid and how it presents in a child etc.

LCK also advocated for members in relation to individual members' issues with specific schools eg about how best to support a child with Long Covid.

It made a film in September 2020. The film "Our Unhappily Ever After" (October 2020) was put on YouTube <https://www.youtube.com/watch?v=RiIambG8vs0> and shared on social media.

LCK wrote to the Children's Commissioner Rachel de Souza on 10 December 2021 inviting engagement with us and children affected by Long Covid inviting engagement with stakeholders relating to Long Covid.

8. Summary of Information relating to devolved nations.

LCK has not been granted CP status other than in relation to M2. It is applying for CP status in M2A (see below). It has support groups in Wales and Northern Ireland. It represents and supports families affected by Long Covid in the devolved nations.

Scotland

LCK has not yet been granted CP status in Module 2A. However we understand that application is being progressed by Thompson's solicitors. To avoid duplication of work and to best assist the C19 Inquiry Team a summary is provided in Appendix 4 . This is short list of work undertaken in Scotland however a complete and comprehensive answer can be provided in due course upon being granted CP status in Module 2A.

Welsh Government

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

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

On 2 July 2022 LCK representative for Wales Kate Davies wrote to the First Minister of Wales about the expert subgroup on Long Covid in children. On 19 July 2022 LCK received a letter

from Lois Hullen, Women and Children's Health Branch stating that once a final pathway was in place it would be shared with LCK.

Kate Davies LCK lead in Wales wrote to and met on 25 July 2022 the Education Secretary 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.

October 10th 2022 LCK had a discussion with members for the Welsh Government Education department to discuss CO2 monitors in schools, work around improving ventilation, investment and guidance provided. Discussed removing barriers for accessing education, difficulty in accessing Welsh medium education assurances for parents related to fines

Northern Ireland Executive

On 1 April 2022 LCK met with Gavin Robinson MP to discuss the lack of Post-Covid Support for under 16s, lack of mitigation measures in schools and lack of testing.

4. A list of any articles or reports the organisation or body has published or contributed to, and/or evidence it has given (for example to Parliamentary Select Committees) regarding the impact on the group(s) which the organisation or body supports or represents of the response to Covid-19 by (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive. Please include links to those documents where possible.

You are referred to Appendix 2 which sets out a list of publications LCK has contributed to including evidence to APPG and others.

In particular, LCK would highlight the following letters, evidence and papers which they have contributed to:

- i. Counting Long Covid In Children , British Medical Journal 16 October 2020 ([here](#))
- ii. My unhappily ever after October 2020– video testimony of children with Long Covid ([here](#))
- iii. Briefing to Layla Moran and other MPs in advance of debate on Long Covid held on 11 January 2021.
- iv. LCK Support Guide which is provided to MPs, Ministers and was for example emailed to Boris Johnson's office on 1 April 2022.
- v. [LCK Schools guide](#) ⁷
- vi. LCK People with Data Snapshot : Over view, symptoms, diagnosis January 2021.
- vii. Evidence provided to the All Parliamentary Group on Coronavirus on 26 January 2021 raising many concerns about children with Long Covid and those that had not recovered from Covid-19.
- viii. Joint letter with Safe Ed for All to Matt Hancock dated 12 April 2021
- ix. LCK letter to Sajid Javid dated 9 July 2021 (briefly summarised in blog [here](#))

⁷ The Support Guide is available on the Long Covid Kids' website under Support by entering an email address. It currently has over 13,000 views.

- x. “Long Covid In Children”, The Lancet, volume 6 issue 1 published January 2022 ([here](#))
- xi. Visit to Downing Street with children with Long Covid on 1 April 2022 and the associated documents being LCK letters dated 1 April 2022 and 28 June 2022, and the individual children’s letters.
- xii. Supporting children and Young People with Long Covid in the Classroom, British Journal of Child Health April 2022 ([here](#))
- xiii. Clinical Characteristics, activity levels and mental health problems in children with long coronavirus disease: a survey of 150 children, Future Medicine April 2022

5. The view of the organisation or body as to whether the group(s) it supports or represents was adequately considered when decisions about the response to Covid-19 were made by (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive. Please also explain the reasons for the view expressed by the organisation or body in this respect.

We provide these comments to assist the Inquiry with our views which are formed on the basis of our experience and knowledge of events to date. However they are only preliminary comments provided without sight of disclosure or evidence. It is our view that the impact of Long Covid on children and young people was not adequately considered when making decisions about the response to Covid-19 by the UK Government. This applies equally to those children and young people who were already suffering from the condition and those who would potentially be infected in the future. We have come to this view taking into account the following non-exhaustive issues:

1. Long Covid Kids believe the risk of long term illness/disability in children and young people was not adequately considered by the UK government in its pandemic response (see Letter to Matt Hancock 12 April 2021, Letter to Sajid Javid 9 July 2021) including in regard to advice to schools and educational settings about transmission.
2. There appears to have been a lack of planning for post acute sequelae despite long term conditions being evidenced in previous pandemics.
3. There was an apparent failure to produce a public awareness campaign for COVID in children, including COVID-19 and PIMS symptoms; Long Covid in children and COVID-19 outcomes for children. LCK believe that as a consequence, testing of children was not prioritised and the symptoms of covid-19 in children were missed (see APPG report).
4. 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 (see evidence to APPG; symptom survey and article on clinical characteristics in children [here](#)).
5. There are concerns that the high levels of infections among children, particularly in Jan/Feb 2021 and Jan/Feb 2022 resulted in *Child COVID-19 hospital admissions, Long Covid, PIMS-TS cases and child deaths* (see briefing to MPs with Parents United January 2021).
6. 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). We are aware of two separate methods of data collection,

⁸ Paediatric Inflammatory Multisystem Syndrome (PIMS) is a new condition that happens weeks after someone has had the virus that causes coronavirus see [Great Ormond Street guidance](#).

one through the orange card system filled out by pediatricians and the other through PICA net which records PICU admissions.

7. We are concerned that at the outset of the pandemic the Government advisors stated that that children were less likely to contract or transmit Covid-19, without as far as we are aware a conclusive evidential basis for this advice⁹. We are concerned that may have led to inadequate consideration in regard to mitigation measures in schools and inadequate information to parents and members of the public.
8. Vaccination lessens the risk of long COVID in adults and children. However, messaging around juvenile vaccine programmes has, in our view, been poor.

6. Whether the organisation or body raised any concerns about the consideration being given to the group(s) which it supports or represents with (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive when the Government(s) and/or Executive were making decisions about their response to Covid-19. Please provide a list of any such correspondence or meetings with the UK Government, Scottish Government, Welsh Government and/or the Northern Ireland Executive, including the dates on which the body or organisation wrote or such meetings were held, to whom the correspondence was addressed or with whom the meeting was held, and any response received from the UK Government, Scottish Government, Welsh Government and/or Northern Ireland addressing such concerns.

Please see Appendix 1 Overview Chronology; Appendix 2 Articles, Evidence and Publications.

Long Covid Kids has advocated and raised concerns to the UK Government and others arising from our experiences as parents of children with Long Covid and on behalf of our members since the early days of the pandemic.

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.

We have set out above at question 4 the particular advocacy that we draw attention to. Concerns were also raised in direct meetings. For example in a [Roundtable meeting](#) with Sajid Javid on 23 September 2021 we raised concerns that the symptom list on the NHS and Government website needed updating (it only had three symptoms rather than the known and well established multiple symptoms of Covid-19 as identified by the WHO and CDC); that masks should be reinstated in schools; our concerns about children being admitted to hospital with Covid-19 who had no underlying health condition; that children were not able to get referrals to Long Covid Clinics/hubs; that the CMO Chris Whitty had stated that it was inevitable that

⁹ August 2020 ““There is reasonable, but not yet conclusive, evidence that primary school age children have a significantly lower rate of infection than adults (they are less likely to catch it).” <https://www.gov.uk/government/news/statement-from-the-uk-chief-medical-officers-on-schools-and-childcare-reopening>.

unvaccinated children would catch Covid and that prevention must be the focus as there was no cure for Long Covid.

7. A brief summary of the views of the organisation or body as to any lessons, if any, that can be learned from any consideration which was given to the group(s) that the organisation or body supports or represents by (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive when they were making decisions about their response to Covid-19.

We provide these comments to assist the Inquiry to focus its investigations however they are only preliminary comments provided without sight of disclosure or evidence. We will only be in a position to provide detailed submissions on lessons to be learned after receiving disclosure and hearing evidence adduced during the Inquiry. Our preliminary view is that the following lessons could be learnt

- Recognise the risk of chronic illness and disability
- To take children seriously: listen to patient experience and have a child centered approach to diagnosis
- Improve the system for dissemination of crucial health information of novel conditions
- Encourage engagement with parent support groups to ensure they keep up with what is happening on the ground to achieve the best outcomes for children.
- Provide support for parents who had to look after chronically ill children
- Clarify the bodies representative of children's best interests in a pandemic situation
- Assist education settings with mitigation measures
- Improve guidance, policy and deterrents to counter misinformation and disinformation.



Long Covid Kids

Appendix 1:

Overview Chronology of the work of Long Covid Kids regarding Module 2

January 2020 to Spring 2022

Date	Event	Source
September 2020	Long Covid Kids is established as a grass roots support and advocacy group for children and families affected by Long Covid.	
Oct 2020	Meeting with Andrew Gwynne MP	
23/12/2020	Email to MP Chris Loder about HofC debate on Long Covid on 7 January 2021	Email exchange
07/01/2021	NHS Long Covid Task force meeting	
07/01/2021	Email to Layla Moran MP	Email dated 7/01/2021
11/01/2021	Email to Layla Moran MP with briefing from Parents United Against Unsafe Schools (of which LCK was part) regarding debate on Long Covid	Briefing with Parents United
26/01/2021	Long Covid Kids members and founders give evidence to the APPG on Coronavirus	<u>Report pdf p.16, 18, 19</u> Statement from Sammie McFarland, LCK and briefing
29/01/2021	LCK attended Ministerial Roundtable on Long Covid	
04/02/2021	NHS Long Covid Task force meeting	
23/02/2021	LCK attended Ministerial Roundtable on Long Covid led by Secretary of State for Health and Social Care Matt Hancock and Lord Bethell	
04/03/2021	Email to Chris Loder MP with LCK's Schools Pack	Email dated 04/03/2021 Schools Pack March 2021
12/04/2021	Joint Letter (with Safe Ed for All) to Matt Hancock Secretary of State for Health and Social Care	Letter dated 12/04/2021
04/05/2021	Letter to NR Secretary of State for Education	Letter dated 4/05/2021
09/06/2021	NHS Long Covid Specialist assessment service subgroup meeting	
16/06/2021	LCK attended Ministerial Roundtable on Long Covid	

03/07/2021	Email to Neil Obrien MP (with Safe Ed for All)	Email dated 03/07/2021
07/07/2021	NHS Long Covid Specialist assessment service subgroup meeting	
01/09/2021	NHS Long Covid Taskforce Research subgroup meeting NHS Long Covid assessment clinics subgroup meeting	
09/09/2021	Letter to Sajid Javid raising concerns about numbers of children with Long Covid	Letter from LCK with email to Sajid Javid
23/09/2021	Ministerial Round Table on Long Covid chaired by Sajid Javid, Secretary of State for Health and Social Care	https://www.longcovidkids.org/post/round-table-meeting-with-sajid-javid-23-09-21
29/09/2021	NHS Long Covid Specialist assessment service subgroup meeting	
17/11/2021	NHS Post Covid National Taskforce subgroup Your Covid recovery rollout, development and Long Covid rehabilitation	
24/11/2021	NHS Long Covid Specialist assessment service sub group meeting	
December 2021	Meeting with Jeremy Hunt	
07/12/2021	LCK attend Ministerial Roundtable on Long Covid	
07/12/2021	Email to Department of health and social care; response undated December 2021 from NR Department of Health and Social Care	Email 7/12/2021
10/12/2021	Letter to Dame Rachel Souza Children's Commissioner	Letter dated 10/12/2021
03/02/2022	LCK attend NHS Long Covid Task force meeting	
16/02/2022	NHS post covid specialist services sub group	
21/02/2022	Joint press statement with LC SOS	
01/02/2021	Email exchange with Wera Hobhouse MP about Long Covid in children with another group Safe Ed for All	Email exchange dated 01/02/21
04/03/2022	Email from Dr Anne Cox CAMHS Intensive Support Team	Email dated 4/03/2022
11/03/2022	Letter to Andrew Gwynne about LCK visit to Downing Street	Letter dated 11/03/2022
11/03/2022	Letter to Layla Moran MP about LCK visit to Downing Street	Letter dated 11/03/2022
17/03/2022	Email to Damien Hinds MP about LCK visit to Downing Street	Email dated 17/03/2022
01/04/2022	Letter to Boris Johnson enclosing support guide	Letter dated 1/04/2022

30/05/2022	Email from Jeremy Miles office, Member of Senedd re effects of Long Covid on children and education	Email exchange with Kate Davies Lead LCK representative in Wales
01/06/2022	Email from NR Department of Health and Social Care in response to LCK letter dated 1/04/2022 delivered with LCK visit to Downing Street	Email dated 1/06/22
01/06/2022	Meeting with Stephen Morgan MP	
28/06/2022	Letter to Prime Minister Boris Johnson responding to Department of Health and Social care response	Letter dated 28/06/2022
06/09/2022	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	Letter from MP dated 6.9.22
02/11/2022	Email to Neil Obrien Parliamentary Under Secretary of State for Primary Care and Public Health	Email dated 2/11/22
11/2022	Response from Neil Obrien Parliamentary Under Secretary of State for Primary Care and Public Health	Letter dated November 2022



Long Covid Kids

Appendix 2: List of Articles, Publications and Evidence to Committees that Long Covid Kids has contributed to

Date	Publication	Title	Quote/comments
Ongoing	Surveys and statistics on LCK website	<u>LCK UK Child Specific Covid-19 Infection Analysis</u>	LCK Review of child-specific official statistics with the aim to evidence the impact of Covid-19 infection on the child population and present charts to illustrate that data.
September 2020	LCK video	<u>My unhappily ever after</u>	Video testimony from member of Long Covid Kids' support group
16/10/2020	British Medical Journal	<u>Counting Long Covid in Children</u>	"There is a need for clinicians, at primary and secondary care levels, to be alert and aware of the multisystem symptoms in children through rapid guidelines or continual professional development. There is also a need for parents to be aware that this may explain ongoing issues that may come and go in the aftermath of a covid-19 infection. <u>Existing data show</u> that severe covid-19 is less likely in children. As the pandemic continues to evolve, we must continue to collect and analyse more data and <u>listen to patient narratives</u> to help inform the management of long covid and any policy implications that arise from these findings."
January 2021	LCK	People with Data Snapshot	Survey on symptoms in children
26/01/2021	APPG on Coronavirus	LCK give evidence to the APPG on Coronavirus	The report was published in March 2022. https://www.appgcoronavirus.uk/home/long-covid-report-march-2022 See pages 16, 18 and 19.
23/02/2021	British Journal of General Practice - Life	<u>Long-COVID in Children – Parents and families' perspectives need to be heard</u>	"The lack of GP awareness has led to some parents whose children have long-COVID feeling that their children's symptoms were minimised or even 'gaslighted'"

March 2021	LCK	Support Guide	Support Guide for children and young people and families affected by Long Covid
April 2021	LCK Survey on Symptoms	Survey here	
02/10/2021	Website	Long Covid Recovery for Children a Cautious Tortoise	This is an “easy to follow flow chart that aims to gently guide parents and caregivers through the early steps of their child's recovery while supporting them to preserve energy to aid ongoing recovery”.
November 2021	LCK and LC Support	Joint Leaflet	To educate the public on the symptoms of Long Covid, signpost to our support group and to seek medical help where necessary. The leaflet was produced by people with lived experience of Long Covid, including GP's and reviewed by the Patient Information Forum. Long Covid can be difficult to diagnose, and some people might not realise their symptoms could be linked to prior COVID-19 infection.
18/11/2021	Authorea	ONS Data on COVID-19 deaths in children is reliable, and increasingly of concern (Re: "Deaths in children and young people in England after SARS-CoV-2 infection during the first pandemic year")	The recently published “Deaths in children and young people in England after SARS-CoV-2 infection during the first pandemic year” ¹ attempts to unpick the issue of paediatric deaths “with” versus “from” COVID-19, additionally reporting on pre-existing comorbidities of the children and young people (CYP) who died after a COVID-19 diagnosis
10/12/2021	Nature Medicine	Promotion of non-evidence based therapeutics within patient led Long Covid Support groups	LCK raised concerns that patient-led support groups are vulnerable to people joining the group who then use their access to promote experimental, unproven or ineffective therapeutics and treatments
23/12/2021	Website	Supporting Children Living with Long Covid to Manage Their Energy with Pacing Penguins	This blog discusses how Long Covid affects energy use, how children describe their fatigue and then uses our Pacing Penguins poster to share tips on how pacing can support recovery.
January 2022	The Lancet	Long COVID in children	Recent analysis of Zoe application (app) data (launched jointly by Zoe Limited and King's College London) by Erika Molteni and colleagues ¹ assessed the symptom profile and duration in children with a confirmed positive SARS-CoV-2 test. The study provides important information about symptomology but probably underestimates the true prevalence of long COVID in children.

29/03/2022	SecEd	<u>Exhausting Painful, Lonely: The Impact of Long Covid on Children</u>	Considers the impact of Long Covid on pupils, their wellbeing and their education
02/04/2022	British Journal of Child Health	<u>Supporting children and young people with Long Covid in the classroom</u>	Dr Sue Peter provides some practical guidance aimed at school health professionals, educationalists and school leaders, to help them support children and young people once they are able to start attending school again
04/04/2022	Edpsych	<u>How I became the mother of a child with Long Covid</u>	Dr Sue Peters explains she is “keen to awareness for educational professionals such as EPs, teachers, ELSAs as well as to support parents and school staff to support children”
05/04/2022	SecEd	<u>How can we support pupils with Long Covid</u>	The strategies below are for when a child is well enough to be able to begin attending school again
1/04/2022	Future Medicine	<u>Clinical Characteristics, activity levels and mental health problems in children with long coronavirus disease: a survey of 150 children</u>	The authors performed a survey in children suffering from persistent symptoms since initial infection. A total of 510 children infected between January 2020 and January 2021 were included. Results: Symptoms such as fatigue, headache, muscle and joint pain, rashes and heart palpitations and issues such as lack of concentration and short-term memory problems were particularly frequent and confirm previous observations, suggesting that they may characterize this condition
12/07/2022	British Journal of Child Health	<u>Long COVID: new guide to recognition support and recovery</u>	New guidance has been published to help the recognition, support and recovery of long COVID in children and young people. Sammie Mcfarland explains
August 2022	Pre print	<u>Long Covid active case finding: co produced community based pilot within STIMULATE-ICP study (Symptoms, Trajectory, Inequalities and Management: Understanding Long Covid to address and transform existing integrated care pathways.</u>	A pilot study in a defined geographical area (Camden, London, UK) to test the feasibility of a community-based approach of identifying Long Covid cases that have not been formally clinically diagnosed and have not been referred to Long Covid Specialist services. We will explore the barriers to accessing recognition, care and support, as well as experiences of stigma and perceived discrimination.

28/08/2022	Evidence based Nursing	<u>Supporting Children Living with Long Covid to return to school</u>	Returning to school with Long Covid might be difficult, especially if the child is still feeling ill or if they missed school the previous academic year, have gaps in their learning, have missed social events or endings in their previous setting or are 'out of the routine' of being at school.
30/08/2022	WHO	<u>Life as a young person with long COVID: you go through so many phases of up and down its like being on a roller coaster for ever."</u>	"I mainly felt dizzy and exhausted. I would faint a lot and get heart palpitations; I could be just sitting around, and my heart would suddenly leap to 190 beats a minute"
08/09/2022	Science	<u>Covid-19 and Children</u>	Although most children recover fully from COVID-19, some will have persistent symptoms. Children with Long Covid can be divided into those unable to return to normal life because of symptoms such as (but not limited to) pain, fatigue, post-exertional symptom exacerbation, headaches, and cognitive difficulties, and those who have additional postinfectious complications, such as pediatric multisystem inflammatory syndrome (PIMS), acute neurological disease, myocarditis, and other potential acute or subacute illnesses
22/09/2022	WHO	<u>An absolute tsunami of need</u>	LCK funds post COVID-19 condition research, in which its members also participate. It also campaigns to reduce children's risk of infection with SARS-CoV-2 through better ventilation and masking in schools, and lobbies for adaptations to be made for affected young people in educational establishments.



Appendix 3: List of Media Long Covid Kids has contributed to January 2020 – Spring 2022 (this includes interviews with members of Long Covid Kids' support group)

Date	Publication	Title	Explanation of content if necessary
23/09/2020	I News	<u>Covid Symptoms: Government update on common signs of coronavirus in process as calls for new guidance grows</u>	Expansion of symptom list to better reflect the experience of patients and open up PCR testing to sick children and adults. Featuring - Sammie Mcfarland - LCK CEO
31/10/2020	Daily Mail	<u>Its not just adults, now children are being hit by long term Covid too – despite experts' mantra that they're more likely to get hit by a bus than suffer severely from the virus</u>	Experiences of 3 families demonstrating a range of Long Covid symptoms Featuring - Lois Benson (Toby and Josh), Frances Simpson (Co-Founder) and son Magnus and daughter Saskia, Sammie and Kitty Mcfarland

18/11/2020	BBC Look East	<u>BBC's Nicola Haseler speaks to members of Long Covid Kids and highlights the need for the NHS to provide Long Covid clinics for children</u>	Video References BMJ article but lack of recognition by Drs that LC even exists in children. Announcement of adult Long Covid clinics but none for children Featuring - Charlie Mountford-Hill and 5 children and Susie Horwood and her 3 children, Sammie Mcfarland
20/11/2020	5 News	<u>Not just adults now children are being hit by long covid</u>	Video Featuring - Variety of LCK with their signs, Elizabeth Pangbourne and daughter Isabel, Sammie and Kitty Mcfarland
25/11/2020	BBC Radio	<u>Members of Long Covid Kids talk to BBC 3 Counties</u>	"Discussing Long Covid in children, our reality" Featuring - Sammie
15/12/2020	Vox	<u>The many strange long-term symptoms of Covid-19 explained</u>	Mentions new allergies and MCAS Featuring - Frances Simpson co-founder and 2 children
13/01/2021	ITV News	<u>Long Covid: Mum warns about protecting children as family suffering 10 months on</u>	Featuring - Susie Horwood and 3 daughters
14/01/2021	Planet Radio	<u>Hundreds of children suffering with Long Covid</u>	Radio A leading paediatrician tells us it's a 'growing concern' as MPs prepare to debate the issue in Parliament." Featuring - Sammie and Kitty, Liliana and Gail Jackson

15/01/2021	The Sun	<u>Our kids were left unable to eat or walk by Long Covid and treatment was 'torture' but docs don't know how to help</u>	<p>"Our children aren't being recognised as Long Covid sufferers because doctors aren't joining the dots between a <u>wide range of symptoms</u>."</p> <p>Featuring - Sammie and Kitty, Frances and 2 children, Gracie Hayes (Mum Claire), Nichola Careless - Mani and Eleni</p>
19/01/2021	West Country Bylines	<u>Long Covid Kids</u>	<p>Co-founder Sammie McFarland interview</p> <p>Featuring - Sammie and Kitty</p>
22/01/2021	ITV News	<u>Long covid leaves mum and teenage daughter bed ridden for almost a year</u>	<p>Mentions LCK has 600 families</p> <p>Featuring - Sammie and Kitty</p>
25/01/2021	Channel 4 News	<u>Long Covid Kids</u>	<p>Debate about schools re-opening and mitigation measures</p> <p>Molly Kingsley and LCK CEO</p> <p>Featuring - Sammie and Kitty</p>
25/01/2021	Metro	<u>Children battling symptoms of Covid months after being infected</u>	<p>Discusses delayed onset of symptoms following acute infection. Dr Clare Rayner and Dr Strain (LCK Champions) talking about children. LCK quotes too.</p> <p>Featuring - Melissa Duvall and daughter Emily, Rifkah Cohen and children Isaac and David, Sammie and Kitty, Claire Hastie and 3 children</p>
28/1/2021	BBC Look East	<u>It's a national scandal" -Nicola Haseler BBC Look East</u>	<p>Video</p> <p>Featuring - Charlie Montford-Hill</p>

05/02/2021	BBC News	<u>Long Covid kids: Mum's 'heartbreak over children's illness.</u>	Featuring - Nichola Careless and Eleni and Mani and Sammie
05/02/2021	Byline Times	<u>The Hidden Plight of Long Covid in Children.</u>	Featuring Sammie McFarland
05/02/2021	BBC Radio Newcastle	<u>Mum, they don't believe me</u>	Radio Featuring - Nichola Careless and Eleni and Mani
05/02/2021	Byline Times	<u>The Hidden Plight of Long COVID children</u>	Quotes from LCK Featuring - Statement from Charity as an entity
6/02/2021	BBC News	<u>Long Covid in children 'not recognised' says Milton Keynes mum</u>	Video Featuring - Charlie Mountford-Hill and 5 children and Sammie
15/02/2021	Sky Times	<u>The 'ongoing battle' of long COVID: what it's like living with debilitating after-effects for nearly a year.</u>	Mentions LCK up to 1k families and survey results Featuring - Sammie and Kitty
18/02/2021	Channel 4 News	<u>A year of living with long Covid</u>	Video - Interview with Long Covid Kids family Featuring - Nichola Careless and Eleni and Mani

24/02/2021	By Line Times	<u>The Big COVID Leap of Faith the Government wants us all to make</u>	<p>“The advocacy group Long COVID Kids now has more than 1,700 children as members, and it is growing fast. If we are to assess risk on behalf of children, surely we need to know the prevalence of Long COVID in them and whether it has any detrimental impact on their long-term health.”</p> <p>Featuring - Statement from Charity as an entity</p>
02/03/2021	The Guardian	<u>Data on long Covid in UK Children is a cause for concern, scientist say</u>	Featuring - Sammie and Kitty and Frances
03/03/2021	The Irish Times	<u>Long Covid in Children: New data is cause for concern, scientists say</u>	<p>Duplicate of above in different paper</p> <p>Featuring - Sammie and Kitty and Frances</p>
09/03/2021	ITV News	<u>Care After Covid: How many children are suffering with Long Covid?</u>	<p>Video</p> <p>Featuring - Izzy Bolton and Sammie and Kitty</p>
11/03/2021	The Telegraph	<u>My 16-year old daughter has had long Covid for five months and I don't know how to fix it.</u>	Featuring - Liliana and Gail Jackson
13/03/2021	The Times	<u>Forgotten children living with long Covid</u>	Featuring - Isabel Walton and mum Catherine
16/02/2021	Metro	<u>Children suffer with long Covid for over eight months on average study suggests</u>	<p>Appropriate mitigation measures in schools.</p> <p>Featuring -</p>

18/03/2021	Doncaster Free Press	<u>Seriously ill Doncaster Girl 10 had to wait five months before her long Covid diagnosis</u>	Featuring - Isabel Walton and mum Catherine
26/03/2021	RTE	<u>What we know so far about long Covid in children</u>	Featuring - Sammie as CEO
31/03/2021	BBC South News	<u>Why Every School Needs a CO2 Monitor</u>	Video Featuring - LCK (on our YouTube)
01/04/2021	Advertiser and Times	<u>Pupils evacuated as school installs air quality alarms to stop spread of covid</u>	LCK supplied air monitors Featuring - Samuel Awesome , Frances Simpson,
01/04/2021	The Scarborough News	<u>Scarborough Mum campaigning for more research into long Covid in children</u>	Mentions the awareness pack newsletter Featuring - Frances Simpson co-founder, Marcus and Saskia
11/04/2021	WSW	<u>Staggering 10-15 percent of infected children suffer from Long Covid</u>	Mentions two surveys LCK completed and the notes campaign Featuring - Frances Simpson co-founder, Delaney, Seren, Itai,
12/04/2021	Manchester Evening News	<u>The kids who have had Covid for a year and the war against a sickness time bomb</u>	Interviews with children and families who are members of LCK support group Featuring - Susannah Horwood and 3 daughters, Sammie and Kitty,
27/04/2021	The Guardian	<u>Children may be at risk from Long Covid symptoms study finds</u>	Featuring - Frances Simpson

03/05/2021	The Guardian	<u>Its terrifying: parents struggle to get help for children with Long Covid</u>	Interview with co-founder and children and families who are members of LCK's support group Featuring - Gail Jackson and Liliana
11/05/2021	TRT World	<u>Children worldwide still suffer from Covid-19 after diagnosis</u>	Interview with child and family members of LCK support group Featuring - Tilly and Lorraine Orange
15/06/2021	ITV News	<u>'The doctor told me there was no such thing': The children living with Long Covid every day</u>	Interviews with children and families who are members of LCK support group Featuring - Liliana Jackson, Heidi and Dylan (both mentioned as member of support services)
18/06/2021	CNN	<u>Teen is one of few kids vaccinated in the UK</u>	Video "The United Kingdom is taking a cautious approach toward vaccinating young people, a stark contrast from the United States, where more than 5 million children under 18 are fully vaccinated". Featuring - Thomas Crone - Claire Hastie,

19/06/2021	Grimsby	<u>Schoolboy 10 too weak to walk after developing long covid type illness</u>	Video Interview with child and family member of LCK support group Featuring - Jake Parish and family
20/06/2021	The Herald	<u>Long Covid and children what to do if you are a worried parent</u>	Featuring - Long Covid Kids as a charity
24/06/2021	Clinical Trial Arena	<u>Drug Development for long covid-19 in children warrants unique focus on how mechanisms prevalence differ from adults</u>	Featuring - Frances Simpson Co-Founder
25/06/2021	The Press and Journal	<u>Suffering in Silence: Calls for Scottish Government to create long Covid clinics for kids</u>	Featuring - Anna and Helen - Scotland focus
28/06/2021	News Stv	<u>Mum of child with long covid calls for specialist clinics</u>	Video - Scotland Focus Featuring - Anna and Helen
29/06/2021	BBC Look East	<u>Long Covid clinics in children – 8% who get the virus affected – NHS sets up paediatrics hubs</u>	Video Featuring - LCK video, Charlie Mountford-Hill, Sammie,
30/06/2021	BBC	<u>Long Covid: Teenage was so ill she thought she might die</u>	Interview with child and family members of LCK support group Featuring - Liliana Jackson

30/06/2021	National Geographic	<u>Long COVID affects kids too. Here's what we know so far.</u>	<p>"Many children can also experience lingering symptoms after getting COVID-19. But scientists are struggling for answers, so parents are banding together to find treatments and warn others of the risks."</p> <p>Featuring - Wednesday Lynch and Mum Melissa and Sammie</p>
6/7/2021	BBC News	<u>Sammie McFarland CEO & Founder BBC News Scrapping School Bubbles, Ventilation & Vaccination</u>	<p>Video</p> <p>Featuring - Sammie</p>
10/08/2021	Guardian	<u>What is happening to me? The teenagers trying to make sense of Long Covid</u>	<p>Featuring - Sammie, Dr Danilo Buonsenso (LCK Champion) James and Emma and Tom (no surnames)</p>
22/08/2021	The Sunday Post	<u>Despite ministers advice and extra millions some councils fail to buy air monitors to test classrooms.</u>	<p>Scotland Focus</p> <p>Featuring - Helen Goss and Dr Jeremy Rossman (Head of Trustees)</p>
30/09/2021	The Press and Journal	<u>Parent Groups demand immediate action to protect schoolchildren from COVID</u>	<p>Scotland Focus</p> <p>Featuring - Helen Goss</p>
20/10/2021	Fortune	<u>Long COVID in kids is worrying the experts: 'it affects everybody different and at different timescales.'</u>	<p>Behind paywall</p> <p>Featuring - Kitty and Sammie</p>

11/11/2021	The Courier	<u>Air Quality in Schools: Long Covid Mum says CO2 Monitors Must Prompt Action to Tackle virus</u>	Scotland Focus Featuring - Helen Goss
22/12/2021	Sky News	<u>Founder & CEO Sammie McFarland Sky News Vaccines for 5-11 year olds 22.12.2021</u>	Video Featuring - Sammie Mcfarland
4/1/2022	BBC Radio Solent	<u>Sammie McFarland on Radio Solent with Alun Newman 4th Jan 2022</u>	Video Featuring - Sammie Mcfarland
5/1/2022	BBC Northern Ireland	<u>Lived Experience of Long Covid in Children Rosie speaks to BBC Northern Ireland 5th Jan 2022</u>	Video Northern Ireland Focus Featuring - Rosie and Colin Pigeon
?	BBC Newsline	<u>Lived Experience of Long Covid in Children</u>	Video Northern Ireland Focus Featuring - Rosie and Colin Pigeon
05/02/2022	5 News	<u>Nearly 120,000 children in the UK are living with Long Covid</u>	Video Featuring - Emily and Louise Saville, and Sammie

21/2/2022	Sky News	<u>"Protections not Restrictions" - Long Covid Kids response to removing isolation.</u>	Video Featuring - Sammie
1/04/2022	BBC	<u>Long Covid: Children affected take the fight to Downing Street</u>	"Children affected by long Covid have travelled to 10 Downing Street to ask the government for more support." Featuring - LCK Team Ten
1/04/2022	Daily Mail	<u>Nine year old girl was forced to learn how to walk again after getting Covid</u>	Featuring - Emily Saville
1/04/2022	Daily Express	<u>Long Covid Campaigners descend on Downing Street as 119,000 UK kids suffer horror symptoms</u>	Featuring - LCK Team Ten
1/4/2022	Good Morning Britain	9-Year-Old Forced To Learn To Walk Again After Catching Covid Raises Over £7,000 For NHS GMB	Video Featuring - Emily and Louise Saville and Michael Rosen (LCK Patron)
1/4/2022	BBC News South	Long Covid Kids visit 10 Downing Street	Video Featuring - LCK Team Ten and Lou, Eva and Corbin
02/04/2022	ITV News	<u>Dad says Long Covid has 'drained colour' out of 17 year old daughter's life</u>	Northern Ireland Focus Featuring - Rosie and Colin Pigeon

05/04/2022	I News	<u>New Covid Symptoms list should include rashes and bloating to protect school children, campaigners say.</u>	Behind a paywall Featuring - picture of LCK Team Ten included
05/04/2022	Press and Journal	<u>'We need help': Nine year old girl battling long Covid in plea to prime minister.</u>	Featuring - Anna and Helen



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)