IN THE UK COVID-19 INQUIRY
MODULE 8

SUBMISSIONS ON BEHALF OF
CLINICALLY VULNERABLE FAMILIES ('CVF')
FOR THE FIRST PRELIMINARY HEARING ON 6th SEPTEMBER 2024

AND SUBMISSIONS ON KEY LINES OF INQUIRY

A. Introduction

1. These submissions are made on behalf of Clinically Vulnerable Families ('**CVF**'). On 7 August 2024 the Chair designated the group as a Core Participant ('**CP'**) for Module 8.

2. As the Chair knows, CVF was granted CP status shortly before the First Preliminary Hearing. Moreover, as a CP in Module 3, CVF and its legal team have been preparing for the final hearings which are due to begin one working day after this preliminary hearing. As such, the below submissions have been prepared at speed, and will be supplemented in oral submissions at the hearing.

(i) A brief introduction to CVF

3. CVF is known to the Chair and the Inquiry as a group which currently has CP status in Modules 3 and 4 of the inquiry, has provided evidence to Modules 1 and 2 and has been asked to provide a Rule 9 witness statement in Module 7.

4. CVF represents a group of vulnerable individuals who have underlying conditions, many of whom are immunosuppressed, who are at high risk of severe outcomes from the disease, such as greater mortality (x9.2 more likely compared to those who are healthy) and long covid (x5.4 more likely compared to those who are healthy), than the greater population In many cases, they continue to shield to this day. For many vulnerable individuals, the pandemic is by no means over and indeed they still face as significant a risk – and in some respects a higher one, because of the removal of mitigation measures – from contracting Covid-19 as they did in early 2020.

5. CVF was founded in August 2020 and currently represents those who are Clinically Vulnerable ('**CV'**), Clinically Extremely Vulnerable ('**CEV'**) and the Severely Immunosuppressed, as well as their households, across all four nations. CVF initially concentrated on issues relating to education but very quickly broadened its focus to other issues such as healthcare, risk mitigation at work and the provision of accurate scientific information. CVF is a grassroots organisation; it is not a legal entity, and it does not have charitable status.

6. CVF is keen to ensure that the Inquiry considers the full impact of the pandemic on the Clinically Vulnerable (CV), the Clinically Extremely Vulnerable (CEV) 'the shielded', and the severely immunosuppressed (SI), their families and households. Such individuals not only faced but continue to face greater risks to their lives than any other category of person. As such, any planning for future pandemics and/or consideration of the effectiveness of public health services needs to do so with the impact on the Clinically Vulnerable as a key group at the forefront of such planning. Moreover, mitigations are required now for new Covid-19 variants.

7. CVF looks forward to assisting the Inquiry in relation to children and young people who were Clinically Vulnerable, Clinically Extremely Vulnerable and Severely Immunosuppressed, or were part of clinically vulnerable families.

(ii) CVF's work with children and young people

8. CVF actively supported its members, many of whom faced threats of fines, legal action, or prosecution due to COVID-19 related absences from school. CVF worked, and continue to work, collaboratively with various other charities and organisations pursuing shared goals. Some of CVF's key interventions were:

   (a) fighting for cleaner air in schools,

   (b) advocating for children in CV families who had not been vaccinated,

   (c) advocating for young carers and a new type of young carer where children in Clinically Vulnerable families had protect the lives of themselves of a loved one,

   (d) campaigning for masking in schools and supporting children in vulnerable households to do so,

(e) highlighting inequalities for children forced out of schools due to Covid, and who could not return or had lost highly contested school places,

(f) helping families to locate appropriate educational resources when their children were not supported through the formal education system,

(g) advising families on how to mitigate risks so that their children could attend school more safely,

(h) raising awareness on behalf of 'Covid orphans' – children who lost a primary carer to a Covid infection (many of whom would have been Clinically Vulnerable),

(i) campaigning for safer exam conditions to minimise the risk of infection and addressing inequalities faced by children and young people in Clinically Vulnerable households,

(j) supporting and assisting Clinically Vulnerable families as they navigated attendance pressures from schools and local educational authorities, which often resulted in the unwilling removal of children from their school rolls,

(k) highlighting problems faced by 'ghost children'[1] who were locked out of education due to clinical risks (although this is a term that CVF finds particularly offensive given the context), and

(l) advocating for access to the National Tutoring Programme.

9. CVF also attend the Children and Young People's Forum of the Inquiry and have inputted into various discussions.

B. Clinically Vulnerable children and young people must not be sidelined - again

10. One of CVF's primary focusses in this module is to ensure that CV children and young people, and those who lived in CV households are not forgotten, as they were during the height of the pandemic and in pandemic planning.

[1] A name given by the Chair of the Education Select Committee, Robert Halfon MP, to describe children missing from education since the onset of the pandemic.

11. Children and young people in Clinically Vulnerable families are defined by their own, or their household member's, risks to Covid-19. They faced, and continue to face, unique challenges.

12. For example, the UK government first identified certain children and families as CEV and subsequently sent them shielding letters to inform them of the need to take stringent protective measures, even within their own households.

13. Meanwhile, those who were CV but not classified as CEV were provided with formal but not direct guidance, which was made available on government websites and communicated during regular news briefings.

14. Even before there was a formal definition of this group, there was a general understanding among the population that certain individuals faced much higher risks. Early news articles invariably reported the deaths of individuals as having "u*nderlying health conditions*". According to the Telegraph, 89% of the 185 children who died in the first two years of the pandemic had "*underlying health conditions*" so the vast majority of children who died, and continue to die, are known to be Clinically Vulnerable children[2].

15. CVF also submit that decisions concerning children and Covid-19 have been problematic often because they often overlooked the fact that children do not exist in isolation in a pandemic involving a highly-infectious virus; the risks include to those in their household. The Inquiry risks repeating these mistakes if it doesn't take into account the specific impacts on children in CV households, whether or not that child is themselves CV.

C. <u>Provisional outline of scope</u>

16. CVF submit that the scope should explicitly recognise the unique circumstances faced by children in Clinically Vulnerable households. CVF propose the following additional text (in red):

> *those with special educational needs and/or disabilities*[3]*, those who were Clinically Vulnerable (CV) and/or Clinically Extremely Vulnerable (CEV) and/or who were*

[2] https://www.telegraph.co.uk/news/2022/11/08/covid-caused-death-20-healthy-children-teens-uk-first-two-years/

part of families of CV/CEV people, and those from a diverse range of ethnic and socio-economic backgrounds.

17. CVF requests that the Inquiry include consideration of children who were removed from the school roll[3] whilst also recognising the significant impact on nearly half of CVF's families who were told to withdraw their children from school under the threat of fines and prosecutions. Only a small number went to court, but many withdrew (mostly temporarily) or felt compelled to take unnecessary risks.

D. <u>Expert Witnesses</u>

18. Paragraph 44 of CTI's note refers to:

"The experience of children with special educational needs and disabilities during the pandemic and the impact of the pandemic on them."

19. CVF are keen that the experience of CV/CEV children and also children who lived in CV households are considered by the experts in this module. CV children are different from children with SEN and disabilities and will have experienced specific and different impacts compared to all other children and young people. CVF accordingly request that there is an expert allocated to:

"*The experience of children with clinical vulnerabilities and children in clinically vulnerable households since the emergence of Covid*."

20. Experts that could report on this should be from a range of disciplines but some suggestions for the Inquiry include:

(a) <u>Professor David Taylor-Robinson</u> is a distinguished expert in public health, particularly focused on health inequalities, with a strong academic and practical background. Holding the H. Duncan Chair in Health Inequalities at Liverpool University, he is also a Professor of Public Health and Policy and an Honorary Consultant in Child Public Health. His expertise in child public health makes him highly qualified to consider the specific challenges faced by children in Clinically

[3] *What is off-rolling, and how does Ofsted look at it on inspection?* Dan Owen, 10 May 2019: https://educationinspection.blog.gov.uk/2019/05/10/what-is-off-rolling-and-how-does-ofsted-look-at-it-on-inspection/ "Off-rolling is the practice of removing a pupil from the school roll without using a permanent exclusion, when the removal is primarily in the best interests of the school, rather than the best interests of the pupil. This includes pressuring a parent to remove their child from the school roll".

Vulnerable families, particularly regarding health disparities and systemic inequalities.

(b) Professor Tamsin Ford. Professor of Child and Adolescent Psychiatry at the University of Cambridge. Her research focuses on the mental health of children and adolescents, particularly in how social factors and healthcare systems affect mental well-being.

(c) Professor Becky Francis, Chief Executive of the Education Endowment Foundation, has been involved in assessing the educational impact of the pandemic, particularly on disadvantaged pupils. She has contributed to many reports and articles focusing on how the pandemic exacerbated educational inequalities, the widening attainment gap, and the effectiveness of various catch-up strategies.

21. CVF also submit that the experts should also consider how Covid-19 compares to other vaccine-preventable diseases in terms of severe acute and long-term disease in children and young people. CVF respectfully submits that Professor Kate Brown (UCL / GOSH) Paediatric Cardiac Intensive Care consultant could be a suitable expert to approach in this area.

22. CVF are also concerned, as they have raised in other modules, that "during the pandemic" is intended in the past tense when the Covid-19 pandemic is still ongoing.

E. Key Lines of Inquiry ('KLOE')

23. To assist the Inquiry, we have listed here the five main KLOE and then have proposed additions in red:

1. **The impact of education closures and disruption as a result of the pandemic on children and young people (CYP)**
    a. Remote learning or the lack thereof (including access to online learning, devices, connectivity; online safety; hard copy resources/remote teaching in the event of not being online);
    b. Attendance/engagement (e.g: attendance by children who had the option to attend in-person classes, engagement with remote education) including children in CV households who were excluded due safety issues relating to in-person learning;

c. Participation in pre-school, community and Sure Start activities (where applicable) and the impact of not attending early years and delaying formal education until compulsory school age;
d. Education transitions (e.g. between EY and school, primary and post-primary/secondary school, post-primary/secondary school and further/higher education) including for those who did not attend in summer 2020 or were subsequently formally/informally shielded;
e. Teacher-assessed exam grades and the impacts on children subsequent exam years who were affected by formal/informal shielding and/or ill-health;
f. Covid measures or lack thereof (e.g. social distancing, masks, testing) in education/EY settings (including the experiences of CYP who attended settings while they were closed as well as when CYP returned to in-person education;
g. SEN assessment, diagnosis and support;
h. Identification of risk/safeguarding including whether the invocation of safeguarding (relating to CV families) was appropriate;
i. Access to on-the-job training;
j. Access to meals provided in education and early years settings (to include breakfast clubs and free school meals), including the appropriateness or otherwise of supplied food;
k. Returning to school post pandemic including adjustments made for children's learning and mental health (if applicable), catch-up support and any other issues they may identify;
l. Any positive experiences of education and changes during the pandemic and whether those have continued.
m. Children who were withdrawn from schools since the start of the pandemic due to safety fears and/or CV/CEV status of them or their family.

2. The impact of the pandemic on children and young people's physical, social and emotional wellbeing and development

2(g) Shielding for CYP with underlying health conditions, disabilities and other health vulnerabilities.

24. CVF point out that disability of a child would not in itself be a reason to shield, but rather their level of clinical vulnerability. CVF suggest that this section is re-written as follows:

> *"Shielding for children with clinical vulnerabilities and children in clinically vulnerable households since the emergence of Covid including issues related to shielding or the lack of shielding."*

25. CVF submit that the impact on the physical and mental health of children who were shielded, or in families of those shielded, including the effect of the guidance on their physical and mental health, should be included as a KLOE. When shielding was withdrawn for children, which was before children under 15 years of age were vaccinated, people were told that children were no longer considered to be CEV. This is a highly sensitive topic and caused a huge amount of upset to CV families. The issues caused by shielding being stopped so abruptly is something CVF would like the Inquiry to consider.

3. The impact of the pandemic on children and young people in relation to their access to and engagement with social care services and other agencies with a role in supporting the safety of children.

a. Covid-related restrictions and containment measures such as

- The increase in risks to Clinically Vulnerable caregivers or household members;

4. The impact of the pandemic on children and young people's access to and the use of the Internet, social media and online resources

5. The impact of the pandemic on children and young people in contact with the criminal justice system including those in the youth custody estate, youth defendants and offenders and those whose parents or primary carers were in custody during the pandemic

Including the challenges that CV families faced when they were taken to court or threatened with fines or prosecutions due to school absences.

26. Further issues that CVF also submit should be added to the KLOE include:

(a) Inconsistencies in government guidance relating to children and Covid-19;

(b) Access to remote healthcare;

(c) Vaccine access (such that it is not covered in Module 4);

(d) Lack of testing for younger children and impacts of excluding children from standard track and trace (such that it is not covered in Module 7);

(e) The impact of the lack of guidance on the differing Covid-19 symptoms and different length of isolation for infected children when compared to adults;

(f) The lack of access to specialist care delivered through schools, such as physiotherapy;

(g) Financial issues and impacts on children (such that it is not covered in Module 9).

F. Conclusion

27. CVF hope that these submissions are of assistance to the Chair.

ADAM WAGNER
Counsel for CVF
Doughty Street Chambers

KIM HARRISON
Solicitor for CVF
Slater and Gordon

20th August 2024