IN THE UK COVID-19 INQUIRY

MODULE 3

SUBMISSIONS ON BEHALF OF
CLINICALLY VULNERABLE FAMILIES ('CVF')
FOR THE PRELIMINARY HEARING ON 28TH FEBRUARY 2023

A. INTRODUCTION

1. These submissions are made on behalf of Clinically Vulnerable Families ('**CVF**'). On 16th January 2023 the Chair designated the group collectively as a Core Participant ('**CP'**) for Module 3 of the Inquiry, stating in her reasons that CVF:

> *"can assist the Inquiry in understanding individuals experiences of healthcare systems from the perspective of a range of those advised to shield, and assist the Inquiry with understanding the perspectives of and impact on those considered to be clinically vulnerable or those who may have been considered to be clinically vulnerable."*

2. 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 (x7.5 more likely compared to those who are healthy) and long covid (x5.2 more likely compared to those who are healthy), than the greater population[1]. 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 from contracting Covid-19 as they did in early 2020.

3. CVF was founded in August 2020 and currently represents those who are Clinically Vulnerable, Clinically Extremely Vulnerable and the Severely Immunosuppressed, as well

[1] Pre-existing conditions of people who died due to coronavirus (COVID-19), England and Wales - Office for National Statistics
Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK - Office for National Statistics (ons.gov.uk)

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.

4. CVF is keen to ensure that the Inquiry considers the full impact of the pandemic on the clinically vulnerable, the clinically extremely vulnerable 'the shielded', and the severely immunosuppressed, 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. Through the lived experiences of CVF and its members, their insight into the impact of public policy decisions and subsequent impact upon the clinically vulnerable, and their intricate knowledge of the practical effect of the pandemic on the public health service places CVF in a unique position to offer assistance during the course of the Inquiry.

B. SUBMISSIONS

(1) Modification of the provisional scope

5. In relation to the provisional outline of scope ('**Provisional Scope**'), CVF supports the inclusion of paragraph 11, "*Shielding and the impact on the clinically vulnerable (including those referred to as "clinically extremely vulnerable".*

6. In relation to terminology: CVF understand why the terms "*clinically vulnerable*" and "*clinically extremely vulnerable*" have been utilised, being terms which have been widely used during the pandemic and are publicly reasonably well understood. We propose, however, that going forward the Inquiry consider whether the terminology is adequate. For example, some of the terms such as "*clinically extremely vulnerable*" have included different groups at different points during the pandemic and has now been replaced by the

government by new categories such as "*severely immunosuppresse*d" and "*people whose immune systems mean they are at higher risk*."[2]

7. CVF further submits that the experience of clinically vulnerable and clinically extremely vulnerable people should be included more explicitly in some of the other paragraphs. Accordingly, we propose the following amendments (amended text has been underlined).

8. The Covid-19 Decision Support Tool was used to determine the treatment pathway of patients with Covid-19 and particularly their level of vulnerability. The adequacy or otherwise of this tool, and other tools, is critically important in determining how well clinically vulnerable and clinically extremely vulnerable people were protected when being treated for Covid-19. Therefore, the following amendment to paragraph 6 is proposed:

   Decision-making about the nature of healthcare to be provided for patients with Covid-19, <u>including the use of decision support tools to determine patients' pre-morbid state and their treatment options for Covid-19</u>[3], its escalation and the provision of cardiopulmonary resuscitation, including the use of do not attempt cardiopulmonary resuscitation instructions (DNACPRs).

9. The spread of Covid-19 within healthcare settings posed particularly high risks for clinically vulnerable and clinically extremely vulnerable staff and patients. Paragraph 8 should make clear that the measures to mitigate risk will consider these groups specifically. Additionally, there was in CVF's submission insufficient information provided to clinically vulnerable people about what PPE they should use (for example, what kind of face mask) in order to mitigate the risks to them in healthcare settings. Therefore, the following amendment to paragraph 8 is proposed:

   Preventing the spread of Covid-19 within healthcare settings including infection control, the adequacy of PPE, <u>information given in relation to PPE</u>, and rules about

[2] See e.g. *Guidance: COVID-19 Response: Living with COVID-19* under the heading "Antivirals" https://www.gov.uk/government/publications/covid-19-response-living-with-covid-19/covid-19-response-living-with-covid-19

[3] For example, the Covid-19 Decision Support Tool https://prod-upp-image-read.ft.com/765d3430-7a57-11ea-af44-daa3def9ae03

visiting those in hospital. To include the impact on clinically vulnerable frontline health and social care staff and clinically vulnerable patients including those who were immune compromised.

10. CVF are concerned that there were changes to the policy relating to DNACPRs in relation to patients who were not infected with Covid-19 but were clinically extremely vulnerable. The Provisional Scope as currently drafted would not permit this group to be investigated, but they clearly should fall within Module 3. Therefore, the following amendment to paragraph 9 is proposed:

Communication with patients with Covid-19 and their loved ones about patients' condition and treatment, including discussions about DNACPRs, and also patients who were 'clinically extremely vulnerable' and not infected with Covid-19.

11. Paragraph 11 as currently drafted is potentially misleading as only the 'clinically extremely vulnerable' were told to shield. The larger group of 'clinically vulnerable' were not told to shield unless they fell within the smaller subcategory of clinically extremely vulnerable. Therefore, the following amendment to paragraph 11 is proposed:

Shielding, as it impacted on those referred to as "clinically extremely vulnerable" and the impact of not including all of those referred to as 'clinically vulnerable' in shielding.

(2) The Listening Exercise – and a note on terminology

12. CVF welcomes that the Inquiry is going to listen to the experiences of bereaved families and others who were affected by the pandemic. CVF is willing and able to assist with the design of the Every Story Matters Listening Exercise. In relation to the further detail provided by STI in their notes prior to this hearing, CVF have two submissions.

13. First, in relation to §1.9 of STI's 13th September 2022 note, which states:

"Over time these trials will increase in scale until the listening exercise is running at full capacity next year. The Inquiry wishes to hear from a cross section of society

impacted by the pandemic - including the bereaved and those whose health has suffered from the disease (including long covid sufferers), those living with disability or health problems, the clinically extremely vulnerable, (those shielded), the clinically vulnerable and the immune suppressed, and those whose family life, education, jobs, health and wellbeing and livelihoods have been significantly affected. The Inquiry will test different approaches with affected groups as it plans the listening exercise into the start of 2023."

14. It is important that the Inquiry's Listening Exercise team understands that there are different "*vulnerable*" groups who have had and who continue to have notably different experiences of the pandemic. It would therefore be important in data collection and subsequent thematic analysis that these groups are given due regard. The risk of simply using the "*clinically vulnerable*" category is that within that group there is a very wide range of experience of the pandemic. There are, for example, people who had some risk from their underlying condition and for whom vaccination has been effective, and others, who were shielded due to the severity of their underlying condition and for a smaller group than these, there is a group of immune suppressed who have remained particularly vulnerable despite vaccination. Clearly these categories of individuals would have experienced different levels of risk and government information through the pandemic. CVF therefore recommends that careful thought is given to potential sub-categories of those who are, in the generality, "*clinically vulnerable"*.

15. As stated above, the government has more recently started using different terminology to describe what used to be described as *"clinically vulnerable"* or *"clinically extremely vulnerable persons",* namely persons at "*higher risk of severe disease*" from Covid-19 infection, as well as those at "*greatest risk*". When analysing historic periods during the pandemic it will make sense to use the original terms as this is vital to understanding the effects on the different groups at any particular point in time. Going forward, however, CVF proposes that the terminology of "*higher risk of severe disease from Covid-19*" is considered for use by the Inquiry to match the current government terminology being utilised today.

16. Second, CTI state in their note at §60: "*Specifically in relation to Module 3, the Inquiry is particularly interested to hear from: people who needed primary, secondary and tertiary*

healthcare during the pandemic, including those admitted to hospital; relatives and friends of patients in hospital; the bereaved; and people working in healthcare settings during the pandemic". CVF submits that this indicative list should also include the clinically vulnerable and clinically extremely vulnerable and the severely immunosuppressed, who were, and remain, deeply impacted by their vulnerability to Covid-19 when accessing healthcare settings.

(3) Producing an Interim Report

17. As stated above, for many clinically vulnerable people, there has been no 'Freedom Day', the Covid-19 pandemic is not over and they still remain at serious risk from contracting the virus. One of the key tasks for the Inquiry is to ensure that lessons are learned. However, the focus should not solely be on saving lives during future pandemics or epidemics, however vital that clearly is, but also on urgently addressing the ongoing risk to persons who have higher risk of severe disease from Covid-19, and their families and their reintegration into society. This can be achieved through improved safety and access to health service provisions to mitigate against their increased and ongoing risk arising from Covid-19.

18. In this regard, CVF request that the Chair considers using her power under the Inquiry's Terms of Reference to produce an Interim Report on measures which can be taken to improve the safety of persons who have higher risk of severe disease from Covid-19 in the here and now. For example, CVF have been campaigning and continue to campaign on measures such as air filtration in the workplace, healthcare settings and schools, the reintroduction of face masks in healthcare and the introduction of a legal duty to protect the clinically vulnerable (for example, to make reasonable adjustments under the Equality Act 2010). CVF are willing and able to assist the Inquiry in any way which is useful in considering these recommendations.

(4) Expert material and the instruction of expert witnesses

19. In relation to §§53-58 of CTI's note, CVF appreciate the indication that experts will be appointed by the Inquiry in Module 3 and that CPs will be given an opportunity to provide observations on which specialist areas in relation to which lay and expert witnesses are

likely to be giving evidence (§58) on the identities of experts (§56) and the questions and issues that they will be asked to address (§56). However, for this consultation to be meaningful, CVF make the following requests:

(i) That the "*specialist areas"* which have been provisionally identified by the Inquiry are disclosed as soon as possible so that CVF can comment upon them;

(ii) That the identities of experts who the Inquiry is minded to instruct, and which are relevant to the issues of interest to CVF, are disclosed to CVF in advance of those experts being instructed (§56 of the CTI note is vague as to when this will happen ("*before the expert reports are finalised"*). A consultation on the identity of an expert would be of no or very little use if that expert has already been instructed by the time the consultation takes place. A late consultation with CPs may also lead to problems being identified which lead to an expert being de-instructed, causing unnecessary cost to the Inquiry;

(iii) The questions and issues experts are asked to address are disclosed to the CPs before they are finalised, not before the report itself is finalised. This will allow the CPs to meaningfully input into the questions. Where CPs are subject matter experts – as CVF are – they are in a position to make constructive suggestions, but the earlier this can take place in the process, the better.

(5) The process for applying for public funding

20. In the Chair's decision of 16th January 2023 to designate CVF as a Core Participant, she stated that directions would be given in relation to applications for an award under s.40(1)(b) of the Inquiries Act 2005 of expenses to be incurred in respect of legal representation at the preliminary hearing.

21. Preliminary hearings involve a significant amount of preparation including conference/s with lay clients, drafting submissions, considering the submissions of CTI and other CPs, and attendance at the hearing. The practical effect of not making directions before the preliminary hearing is that where a newly designated CP cannot afford legal representation, a significant obstacle is put in the way of their effective participation. If they cannot afford lawyers, then they will by definition find it difficult or impossible to secure representation for the hearing. This could prevent their effective participation and also lead to inequality

of arms as compared to other CPs such as public authorities which will not require any award under s.40 of the 2005 Act.

22. Although this will make no practical difference in relation to Module 3, CVF propose that going forward, the Inquiry consider making directions for s.40 applications at the point when CP status is granted rather than at the preliminary hearing itself.

C. CONCLUSION

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

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Doughty Street Chambers
21st February 2023