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On behalf of Clinically Vulnerable Families
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**IN THE PUBLIC INQUIRY INTO THE
COVID-19 PANDEMIC**

WITNESS STATEMENT OF
Dr Catherine Finnis
On behalf of Clinically Vulnerable Families

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I, Dr Catherine Finnis, will say as follows: -

A. Introduction to Clinically Vulnerable Families

1. I am writing this statement in response to the UK Covid 19 Inquiry's request dated 9th March 2023, for evidence under Rule 9 of the Inquiry Rules 2006 in respect of Module 3. I provide this written response on behalf of Clinically Vulnerable Families ['CVF'] led by myself and Lara Wong, the founder of CVF. Throughout the statement I have provided case studies and quotes from many of our members to assist the Inquiry in understanding their real life lived experience.
2. CVF is a grassroots organisation; it is not a legal entity, and it does not have Charity status. It was founded in August 2020 before children returned to schools for the first time following their closure towards the start of the pandemic in late March 2020. At that time, parents were told that schools were safe and that "*all children must be in school*". We were repeatedly told that children did not catch or spread Covid-19 infections but despite that CVF remained concerned due to the risks posed to clinically vulnerable staff and children in schools and to other clinically vulnerable close contacts lived in households with children who were attending school. This was pre-vaccination.
3. Clinically extremely vulnerable persons had been shielded between 21st March 2020 and 1st August 2020, including many clinically vulnerable persons more informally. To these families, nothing had really changed in the pandemic; their unaddressed risks remained and consequently they felt exposed with limited options available to them or the protections in place to mitigate their vulnerability. For them, Covid-19 still represented a significant and serious threat to their life and the health of their families and communities' wider connections.
4. After shielding was paused in April 2021 and never resumed, CVF extended the offer of support to all clinically vulnerable persons and those who could be considered at high risk by living live in clinically vulnerable households, therefore widened its membership and strategy to incorporate the concerns and needs of all clinically vulnerable families in the UK and their many concerns.
5. CVF currently represents those who are Clinically Vulnerable, those identified as Clinically Extremely Vulnerable (before this terminology was retired) and the Severely Immunosuppressed; and those in their households across all four nations with its

concentration initially on education but very quickly broadened its focus to other wide-ranging issues such as healthcare.

6. Our support group is limited exclusively to those in Clinically Vulnerable households. Entry questions are used to determine whether applicants / household members meet the criteria as outlined in "Covid-19: the green book, chapter 14a" **[Exhibit CF/1 - INQ000408795]** (or those with household members who have qualifying conditions). At present, the combined membership and following of CVF is approximately at 45,987 and is continuing to grow. The group have a significant online presence, through which most of their work is achieved, and there are approximately 2,406 members of CVF's private Facebook group, 11,762 Twitter followers and 1,161 Mastodon followers. Each member/follower tends to represent a family/household and we can therefore reasonably assume that CVF's reach is at least three times the number of actual members and followers to account for multiple occupancy households.
7. CVF's mission is to support, inform and advocate for those in clinically vulnerable households as they face an ongoing threat posed by Covid-19. Our vision is that one day we will have sufficient protections to restore the freedoms of society's most vulnerable.
8. CVF has multiple purposes, and these have evolved since its foundation. CVF primarily aims to support, educate, assist, advocate and campaign for clinically vulnerable families in the United Kingdom due to the risks posed by COVID-19. To further understand the work of the group I have set out how CVF fulfils its functions below:
 - a. Support
CVF's social media presence grew and was firmly rooted in our 4 core principles:
 - I. To be scientific and evidence based.
 - II. To provide peer support and practical assistance (i.e drafting letters, helping with other correspondence and communications for their members);
 - III. To address mental health needs of members by offering weekly check-ins with members; and
 - IV. To operate exclusively for the clinically vulnerable and their households. Through communication with their members, CVF are able to identify and address any additional needs that arise

from a member's circumstances, such as the need for legal advice and advocacy.

b. Education

- I. Due to my background and that of Mrs Wong, the group are able to offer a variety of resources to help its members and actively share good quality scientific publications, with possible interpretations, to help assist members to access the information, including, but not limited to: sharing how to assess individual risk and advice on how to reduce risk of Covid-19 infection; providing information on eligibility for additional vaccines and antiviral treatment including advice on any processes involved and commonly experienced difficulties; and regular updates on government policy documents relating to clinically vulnerable families.

c. Assist

- I. CVF aims to identify those members with urgent needs and help them by offering peer support. For example, we have helped members access antiviral treatments within the tight timescales of 5 days by providing basic explanations of how to apply as well as helping to make representations to members MPs in some exceptionally challenging cases.
- II. The group try to support members who have been fined and/or prosecuted for Covid-19 related absences in school, those who are losing their jobs or being made redundant for Covid-19 related reasons.
- III. CVF have supported people in making requests for risk assessments and reasonable adjustments within school and employment settings.

d. Advocacy and Campaign

CVF is working collaboratively with various other charities and organisations pursuing shared and unique goals. Our key issues include:

- I. Clean indoor air;
- II. Reasonable adjustments in schools and in workplaces;
- III. Improved access to treatments;

- IV. Removing barriers to living 'in' society through improving Covid-19 safety protections;
- V. Access to antivirals;
- VI. End to isolation rules;
- VII. Masks in schools;
- VIII. Masks in healthcare;
- IX. Freedom Day concerns including mask wearing;
- X. Safe access to Healthcare;
- XI. Inequalities for children forced out of schools;
- XII. Access to Covid testing;
- XIII. Safe shopping / food deliveries;
- XIV. Raising awareness on behalf of Covid Orphans;
- XV. Job losses;
- XVI. Choice between education and lives;
- XVII. Stopping the spread (reducing transmission);
- XVIII. Masked carriages on trains and buses;
- XIX. Exam conditions risking infections;
- XX. Inequalities for CV families in exams;
- XXI. Pressure from school and education authorities on CV families which resulted in the removal of children from the school roll;
- XXII. The general need for reasonable adjustments for CV people;
- XXIII. Access to the National Tutoring Programme;
- XXIV. 'Ghost Children'¹; and
- XXV. Risks posed by warm rooms.

9. To date, CVF have driven policy change through various methods. CVF have:
- a) Shared members' case studies with the local and national media;
 - b) Developed and maintained strong links with Parliamentarians who have asked questions in Parliament on behalf of CVF;
 - c) Taken part in relevant All-Party Parliamentary Groups ['APPGs'], for example, members of the group were invited to take part in the Coronavirus APPG chaired by Ms Layla Moran. This led to a question being asked in the House of Commons about clinically vulnerable people and schools;

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.

- d) Joined forces with other campaign and educational groups, such as Covid-19 Bereaved Families for Justice, Independent SAGE (for example, in relation to 'The Covid-19 Pledge' where as a signatory to the pledge we have advocated for the needs of our members and have worked to raise awareness of the pledge directly with companies and by encouraging our members to raise with their employers and other businesses.), Clean Air Classrooms and Long Covid groups. CVF has brought its unique perspective to these collaborations, a perspective which is not available from any other organisation;
- e) Made connections, established awareness, and raised CVF's profile through social media platforms, aiming always for a better future for the clinically vulnerable and their families;
- f) CVF are stakeholders of the NICE appraisal for Evusheld and have gathered information to contributed to their recent call for evidence as set out in the exhibited submissions. [Exhibit CF/2 - INQ000408806 is demonstrative of the submissions made by CVF to NICE].

10. More information about the group and the work that we do can be found by accessing CVF's website, images of which can be found at [Exhibit CF/3 - INQ000408817].

11. In order to prepare this statement, I have drawn on my own knowledge, including from my professional training in research methods, as well as the knowledge and experience of CVF members. CVF is a volunteer group with a primarily online membership base, as set out above. I am aware of many members' experiences and perspectives because CVF has sought to advocate for members' rights, has provided peer support for members and we routinely discuss the challenges faced both individually and as a group.

B. Introduction: Clinically Extremely Vulnerable People and Clinically Vulnerable, including the Severely Immune Suppressed.

12. The names of these groups were created by the government during the pandemic, along with the term 'shielding'. These terms have continued to be removed and changed by the government over the period of the pandemic to the current day. Although the term Clinically Extremely Vulnerable ('CEV') stopped being used by the government, many who were designated CEV continue to describe themselves as such.

13. The term Clinically Vulnerable ('CV') remains in active use today. It covers all of those who remain at higher clinical risk to Covid-19 and qualify for vaccines based on those

risks. The UK Health Security Agency's "Covid-19: Green book, Chapter 14a" **[Exhibit CF/1 - INQ000408795]** p20 states:

"Those clinically vulnerable to COVID-19 are defined by the JCVI priority groups as:

a) children of any age with severe neuro-disability, severe or profound and multiple learning disabilities (including Down's syndrome and those on the learning disability register) or immunosuppression (as defined in table 4);

b) adults who have underlying health conditions leading to greater risk of disease or mortality as defined in table 3; and

c) those of advanced age."

a) These individuals have always been at highest risk of poorer outcomes from Covid-19 infection and continue to be into the fifth year of the pandemic **[Exhibit CF/4 - INQ000408828, page 60]** as noted on 31st December 2023 by Dr. Maria Van Kerkhove (Infectious Disease Epidemiologist; COVID-19 Technical Lead, Director of Epidemic & Pandemic Preparedness & Prevention, WHO, WHE) **[Exhibit CF/5 - INQ000408839]**

b) It is difficult to calculate how many CV people in the UK qualify for vaccines, however, we do know that:

I. In March 2022, *The State of Ageing 2022 Summary* by the Centre for Ageing Better **[Exhibit CF/6 - INQ000408850]** estimated that 19% of the population were aged 65 and over. Therefore, for those clinically vulnerable due to age (aged 65 and over) the figure is almost 11 million people.

II. NICE released guidance, published on 14th June 2023 **[Exhibit CF/7 - INQ000339319]** in which it is claimed that the number of severely immunosuppressed people eligible for Evusheld as 1.8 million. Over the period of the pandemic, the various government lists of CEV/CV and Severely Immunosuppressed have changed. Some people may not be aware of their risk or status.

III. As stated by the BBC News, 'England on track for vaccinating Covid priority groups' dated 12 February 2021 **[Exhibit CF/8 - INQ000408872]**, the total number of persons identified in the top priority groups in 2020/2021, excluding care home workers, health and social care workers, and those aged 64 and under, but including those aged 16-64 with underlying health conditions, totalled approximately 20.5 million. It is important to note that these figures exclude CV young people under the age of 16.

- c) For many within these groups, they remain at higher risk despite vaccination.
- d) This is especially true for immune suppressed individuals, some of whom may not mount a response, or an effective response, to Covid-19 vaccination and therefore remain at incredibly high risk Covid-19.
- e) From the final Office of National Statistics (ONS) dataset, **[Exhibit CF/9 - INQ000408875]** people who have 'underlying conditions' versus 'healthy people' have a **9.2 times increase in death** from Covid-19. People who identify as 'activity limited by health a lot by health conditions' versus 'healthy people' **have a 5.4 times increase in developing Long Covid [Exhibit CF/10 - INQ000408796]**.
- f) CVF was forged from these new clinically vulnerable groups of people as identified by the government during the pandemic. Shielding had never happened to people, and neither had being grouped into national categories designating your vulnerability to a virus. This was a totally new experience.

(Q1) Diary entry dated 24th March 2020 by a CVF Member.

“So, here we are. It’s a very odd, surreal and strange feeling. We are in the ‘shielded group’. That means we can’t leave the house for 12 weeks! Well, ‘a minimum of 12 weeks.’ This is impossible to perceive at the moment. The world has felt an odd and alien place. Food has become a big issue. It’s hard to get any deliveries from supermarkets are virtually impossible to get. I’ve been ‘panic-buying’ toys.

I don’t want X, who’s 19 months to not have a fun, stimulating year. I feel worried about the fact we’re all on lockdown but then as Mr T says it’s the same for all the kids. Anyway, enough for now, it’s shattering being in this situation.

I spent 400+ attempted calls to get a Sainsbury Priority Delivery List today. Finally, I got onto a holding line which took 1.5 hours but finally I registered. Or, at least I think I did because I haven’t yet had an email confirmation. Hopefully I’ll get the email tomorrow. To receive that will be a big relief. Not knowing where or how to source food for the family is a huge anxiety.”

Anon

C. Shielding, identification and information, and experiences.

14. Shielded / ‘Clinically Extremely Vulnerable’ were identified according to a list of higher risk conditions and people were initially identified through an algorithm and through GP identification lists, this was not always accurate. This list, ‘Caring for people at highest clinical risk from Covid-19, Background and FAQs for patients, published 1 April 2020’ is exhibited as **[Exhibit CF/11** **INQ000068624**

15. As at 1st April 2020, people falling to the highest clinical risk group included:

- a). Solid organ transplant recipients.
- b). People with specific cancers:
 - people with cancer and are having chemotherapy.
 - people with lung cancer and are having radical radiotherapy.
 - people with cancers of the blood or bone marrow such as leukaemia, lymphoma or myeloma who are at any stage of treatment.

- people having immunotherapy or other continuing antibody treatments for cancer.
 - people having other targeted cancer treatments which can affect the immune system, such as protein kinase inhibitors or PARP inhibitors.
 - people who have had bone marrow or stem cell transplants in the last 6 months, or who are still taking immunosuppression drugs.
- c). People with severe respiratory conditions including all cystic fibrosis, severe asthma and severe COPD.
- d). People with rare diseases and inborn errors of metabolism that significantly increase the risk of infections (such as SCID, homozygous sickle cell).
- e). People on immunosuppression therapies sufficient to significantly increase risk of infection.
- f). Women who are pregnant with significant heart disease, congenital or acquired.

16. Some people were left off the list who should have been on it, and indeed vice versa. This caused a lot of confusion and upset as people were unsure whether they should or should not be on the list. For people who should have been on the shielded list, and yet were not, this could mean they were put at extra unnecessary risk due to a delay (or indeed, the complete lack of shielding protections). Not being on the shielding list was problematic as it meant people could not seek the available protections, such as working from home, and accessing priority supermarket home delivery or the free government food parcels. For those exposed via high-risk frontline roles, it posed a considerable threat to life.

(Q2) Quote from CVF Member

“We started shielding a couple of weeks prior to lockdown as it was obvious what was going to happen, and I knew I was highly vulnerable. I was happy to shield but I was not happy to be erroneously missed off the shielding list. It took me about 3 weeks and many emails to the GP and consultants to finally get on it, despite an absolutely cut and dried reason.”

Catharine, aged 55

17. The timescale to shielding was that the first lockdown was announced to start on 23rd March 2020, and GPs were officially asked to identify vulnerable ‘shielded’ patients two days previously on 21st March 2020, which was already fairly late in the trajectory of

climbing case numbers. This was important as the later people started to shield, the more chance there was they would be infected. This means that the people with the highest risk may not have been identified in time and so became very sick and sadly, some may have died.

18. People who were known to be very vulnerable to the virus (through medical studies already undertaken around the world) were not protected at a time when the virus was spreading widely in early March. The World Health Organisation ['WHO'] declared a PHEIC ['Public Health Emergency of International Concern'] on 30th January 2020. The WHO, at this time, were clear that governments should be preparing for the pandemic. CVF do not think that there was sufficient planning before the pandemic for how to protect the clinically vulnerable during the pandemic, and all the concurrent issues relating to this. Even in the first few months of 2020, the clinically vulnerable could have been prepared but this did not happen.

19. Many more privileged clinically vulnerable people were able to shield informally from an earlier date. A poll in the CVF group of 370 members **[Exhibit CF/12 - INQ000408798]** (some of whom were not classified as CEV but were CV) demonstrated that 63% of those started to informally shield before 15th March 2020, with a further 28% starting to shield between 16th – 22nd March 2020 and the remainder on 23rd March 2020 with the official national 'lockdown'.

(Q3) Quote from CVF Member

"I was being cautious by mid-February, but not with any real understanding, just an unease about crowds and being on the bus etc. A combination of the news of the virus in other places and having watched films like Contagion was making me very aware of how vulnerable we all were. I began full 'shielding' on 13th March 2020, when I began to understand how specifically vulnerable, I was. I thought it would be for a couple of weeks."

Lisa, aged early 50s

20. Some employers were particularly understanding and people who knew they were at higher risk were able to work from home earlier than the formal shielding guidance or lockdown.

(Q4) Quote from CVF Member

“I was lucky that I was able to start working full time from home by about 12th March, and that felt quite ‘late’ as it was. My team were still booking team training events in London for May 2020. I really strongly suspected we wouldn’t be going. As it happened, we were all locked down anyway.”

Katie, aged 45

21. People who started to informally shield early gained the information they needed to do so from various sources. Many people explain hearing the risks around Covid-19 through the media and especially from international comparisons e.g. Italy.

(Q5) Quote from CVF Member

“We locked down in February 2020, as I was watching Italy and Spain and knew it was coming here. The schools thought I was nuts at the time. I still remember the conversation with the primary school. She said it wasn’t coming here, it’s not gonna happen. Seems I wasn’t nuts in the end.”

Anon

22. Several people report that their clinician contacted them to tell them to ‘stay at home’; both adult and paediatric teams have been reported as offering this advice early. There are also reports of school headteachers advising parents to remove their children from school (either where the child was CV, or the parent was known to be clinically vulnerable).

(Q6) Quote from CVF Member

“It was the week before lockdown when my kids headteacher advised me to pull the kids out of school until things felt safe (kids are healthy, I’m immunosuppressed) as he was worried about me being vulnerable – we just assumed they would go back after the Easter break ...”

Anne

23. However, this disadvantaged people, particularly those who were in public facing job roles such as shop employees, health and social care workers and education workers in

early years, schools, colleges, and universities. Some people were unable to shield until it was officially begun by the government. This was because their places of work did not allow it prior to that. Some people were required to travel on public transport to attend work and this continued until the official date for shielding (and depended on someone being correctly identified and sent proof). This put many people who should have been protected at risk for a longer period than necessary, and at risk of catching Covid and suffering severe illness and sadly, for some, death. The sense of this period pre-official lockdown is that many CVF members knew of the impending risk. However, very much depended on the individual's circumstances whether they were allowed to informally shield or not.

24. There was a lot of confusion around the shielded list originally. Our members reported that they were initially contacted telling them to shield, via email or text message. For example, one CVF member shared with us the text message they received on or around 24 March 2020, which purported to give guidance on what to do while staying at home on the shielding list and which was the first official contact she received about shielding **[Exhibit CF/13 - INQ000408799]**. Also, our members recall that official shielding letters were sent and repeatedly sent, as well as texts and emails. CVF members feel that this approach excluded people suffering from digital poverty, which logically will especially affect older people, people living in deprived areas and those for whom English is their second language. People were also able to directly refer themselves to be added to the shielded list and this was then agreed or not by their GP. Many patients tried to contact their GPs and they could be added via this route to the shielded list. As set out in '*Covid-19: GP's opt to prioritise all patients with learning disabilities for vaccination, by Gareth Lacobucci published 19 February 2021*' *BMJ* 2021;372:n510, **[Exhibit CF/14 - INQ000408800]**, the original number who were identified as being at the highest risk was around 1.3 million people which rose eventually to 2.2 million people. Clearly for many people there were delays in identifying them as needing to shield. This could negatively affect them in terms of receiving support such as not being able to work from home nor claim appropriate benefits nor accessing food and medicine safely.
25. People who were officially asked to shield were on the 'shielded patients list'. Letters were sent directly to people telling them to stay at home and avoid all face-to-face contact, initially for 12 weeks, including working from home. Some shielded people were able to work from home, but others could not work. On 16th April 2020 new regulations came into effect that if people were classed as CEV/shielded and who had been advised to follow 'rigorously shielding measures' then they were deemed incapable of work for the period.

This meant they were entitled to receive Statutory Sick Pay ['SSP'] for every day they were unable to work and for the whole shielding period. This is set out in 'UK: Statutory Sick Pay (SSP) Extended to Employees Who Are 'Shielding' published on 17th April 2020 **[Exhibit CF/15 - INQ000408801]** and at Q15 of 'Caring for people at highest clinical risk from Covid-19, Background and FAQs for patients, published 1 April 2020' **[Exhibit CF/11 - INQ000408797]**.

26. The shielding information given was very frightening and unachievable for many. There was an early emphasis on handwashing, there was no information on the airborne or droplet spread of Covid-19. There was no information on good ventilation or on masks that could help reduce Covid-19 infection. The text message sent advising shielded people to be ready to attend hospital was very worrying for those who received it. People were confused, they had initially been told to only open a window and not to go outdoors at all. Text messages were sent to those on the shielding list from the NHS Coronavirus Service on or around 25 March 2020 saying, 'Be prepared in case you need to go into hospital, get a single bag ready with your key health information and essentials for an overnight stay'. We exhibit one such message received by a CVF member **[Exhibit CF/16 - INQ000408802]**. From the experience of our members, we understand that this was sent to all people on the shielding list.

(Q7) Quote from CVF Member

"Pretty worried originally having received the first text message telling us to open the window to get fresh air..."

Amos, aged 43

27. This information later changed and you were able to visit your garden if you had one. We exhibit the letter sent to one CVF member advising them of the rules as **[Exhibit CF/17 - INQ000408803]**. It should be noted that CVF is an informal, member-based organisation originating as a support group before moving into an advocacy role. As a result, its records of communications with shielded people are derived entirely from what its members have saved and continue to have access to and are not intended to form a comprehensive record of all communication with shielding people (which will be held by relevant authorities). We appreciate the date of this letter pre-dates what we claim to be the initial text message, however, we cannot explain why that is but would think that NHSE would be able to provide an accurate chronology of communications sent to those considered CEV at the time.

28. In summary, CVF's experience of the communication on shielding was that it was confusing and disjointed. CVF as a group was only formed (in response to the ongoing difficulties suffered by the clinically vulnerable) in August 2020 so could not play a role at the time in improving the guidance. However, it ought to have been obvious to decision-makers that vulnerable persons like CVF's members required clear and consistent messaging. Research from G. Lasseter et al [Exhibit **CF/26 INQ000408813**] showed the:

'importance of sharing tailored and timely advice to inform shielding decisions.'
In addition, it also showed that *'messages that reinforce self-determined action and assistance from support services could reduce the negative impact of shielding on mental health and feelings of social isolation.'*

29. The shielded faced multiple problems in terms of accessing their usual medicines, food, and other necessary items. Many people could not get access to supermarket delivery slots which were supposed to be prioritised for the clinically vulnerable. If you did not have access to the internet, getting specific information was difficult. It took a little while for the community hubs to be established. People who were shielding often had to take risks to get essential food or medicines especially in the early days of the pandemic.

30. On 23rd March 2020, two days after the first lockdown was announced, Sainsbury's opened a helpline for vulnerable customers (0800 328 1700). However, the phones were extremely busy including waiting for many hours on phonelines and then being unsuccessful in gaining a slot. Many of the shops provided vulnerable delivery time slots which proved very difficult and time-consuming to get onto. There was also a potential cost implication for people needing to spend many hours on telephones. We exhibit documentation from just one CVF member showing her efforts to access food delivery [Exhibit **CF/19 - INQ000408805**]

31. At the outset, the information given to shielding people was incomplete. The first letter CVF members received identifying them as a shielding person contained guidance on how to protect themselves, which effectively meant staying apart from others [Exhibit **CF/17 - INQ000408803**]. There was no advice on masking. Vulnerable people who had to go outside their house despite all the advice were simply advised to wash their hands and distance.

32. When CVF formed in August 2020, it initially served as a support group, emerging partly in response to the risks faced by CV, particularly as schools reopened in 2020. It therefore

tried to remedy the gaps in information given to shielding people with a particular focus on information regarding mitigating risks in challenging situations, particularly for teachers and pupils. Other critical information shared with all group members, and which was not contained in widespread information shared by the Government, included issues such as:

- a. **Use of Respirator Masks (FFP2/3):** Emphasis on their importance, correct fit, and guidance on caring for reusable masks.
- b. **NDIR (Non-Dispersive Infrared) CO₂ Monitors:** Information about types of CO₂ monitors and their use.
- c. **CO₂ Levels as a Proxy for COVID-19 Risk:** Educating about safe levels of CO₂ as an indicator of indoor air quality (IAQ) and the percentage of rebreathed air in an environment.
- d. **Ventilation:** Guidance on the importance of ventilation and how it affects transmission risk.
- e. **Air Filtration:** Information on the use and benefits of air filtration systems particularly in poorly ventilated enclosed spaces with high occupancy.
- f. **Quarantining at Home:** Advice on best practices for quarantining at home to reduce or prevent the spread of the virus within a household.
- g. **Access to COVID-19 Tests:** Providing updates and information on how to access COVID-19 testing. PCRs, priority PCRs and latterly LFTs.
- h. **COVID-19 Symptoms:** Regular updates on the symptoms associated with different COVID-19 variants.

33. The incomplete patchwork of support offered to shielding people continued throughout the pandemic. In January 2021, all CEV or those in residential or nursing homes were offered a free supply of Vitamin D tablets through the post. The Government's guidance, '*Vitamin D and clinically extremely vulnerable (CEV) updated 24 February 2021*' on this is set out [Exhibit CF/20 - INQ000408807]. We understood this is because there was some evidence that showed that if people had a lower Vitamin D level they were at higher risk of Covid 19 illness. CVF are perplexed why Vitamin D tablets were distributed but not masks. At no point during the pandemic have CV/CEV or severely immune suppressed been given advice on FFP2/3 masks or given masks to protect them.

34. Shielding itself was stopped and started, this was very confusing for people. The referenced document from the University of Sheffield '*A (brief) history of shielding, by Katherine Runswick-Cole, published 4th November 2020*' details how confusing the guidance was, and in constant flux [Exhibit CF/21 - INQ000408808]. It outlines the timing

of the various iterations of shielding guidance and how the term 'shielding' itself was not used consistently over time (up until 4 November 2020, the date of the blog).

35. The blog shows how the term "shielding" can and was being used in various ways, demonstrating its multifaceted nature in the context of the pandemic. 'Shielding' has been used both as a verb and a noun, each carrying different and significant implications in public policy and personal experience.
- a. **"To Shield"**: When used as a verb, 'shielding' refers to the action of protecting oneself, particularly but not exclusively by the clinically extremely vulnerable, from exposure to COVID-19. This involves staying at home and avoiding face-to-face interactions. The use of 'shielding' as a verb implies an active, ongoing process, one that individuals had to continually manage and reassess as circumstances and guidelines changed.
 - b. **"The Shielded"**: As a noun, 'shielding' refers to the group of people who were following these protective measures. This group, often termed 'the shielded', represents a specific demographic that was identified by public health policy as needing extra precautions due to their heightened risk from COVID-19.
 - c. **In Relation to Resources or the Law**: The term also extends to encompass the resources and legal frameworks put in place to support 'shielding' individuals. This includes government guidelines supporting the ability to work from home and came with funding for assistance programs such as food boxes or volunteer led support.
 - d. **Voluntary Shielding**: The document also touches on people choosing to shield of their own accord, even when official measures were lifted or perhaps not strictly required. This highlights a divergence between government policy and individual choices, showing how people redefined 'shielding' for themselves based on their personal or household health and risk assessments.

- e. **Evolution of Shielding:** The concept of 'shielding' evolved over the course of the pandemic, with individuals and communities often applying it differently from official government guidelines.
36. Overall, the language of 'shielding', as set out in the blog, is complex, reflecting both a set of government policies and a range of personal responses and interpretations by individuals, employers, schools and communities.
37. Shielding was stopped on 1st August 2020, as demonstrated in the Government's press release, '*Plans to ease guidance for over 2 million shielding*' published 22 June 2020 [Exhibit CF/22 - INQ000408809], and people lost their protections to work from home. At this point, however, there had been no vaccination and there were no available antivirals. Potentially even worse than this was that the public, including those who were CEV, were given false confidence that the coronavirus pandemic was no longer a threat to their health, or life. It was this summer that '*Eat Out to Help Out*' was also open, between 3rd-31st August 2020, coinciding with the end of shielding.
38. CVF are of the strong view that stopping shielding completely in August 2020 was too early. As the University of Sheffield blog notes, by 5 November 2020, shielding was not formally reintroduced but CEV individuals had been once again told to stay at home. However, children who were not identified as CEV but were living in the same household with a CV person were told they must attend school. Many families were threatened with fines and prosecutions or had pressure in the form of phone calls or visit from school staff, School Attendance Officers and Children's Services.
39. Ultimately, shielding had to be reintroduced in January 2021 (from 1st April 2021 the advice to shield was paused, and from 15th September 2021 the shielding programme ended), which was probably again too late in the context of rapidly rising case numbers. CEV people were put at greater risk by the 'stop-start' of shielding and in the absence of explaining the ongoing risks to people.
40. Each time shielding ended, frontline keyworkers were expected to return to the workplace and Covid-19 cases once again started to rise. This disproportionately affected people in specific professions such as education, healthcare, hospitality and retail and those working in higher risk, indoor, busy environments such as factories.

(Q8) Quote from CVF Member

"I started to have anxiety. But as I work in a school I had to go back between lockdowns and each period of shielding. After shielding stopped I had to go back properly as I could not afford not to. Got full pay for times I had to shield though."

Karen, aged 62

41. A further issue found by some CEV people was that their employers did not understand and therefore agree with their CEV/Shielded status and carried out their own risk assessments and put pressure on employees to return to an, often unsafe, workplace. This put very vulnerable and high-risk persons under great stress. Some even felt forced to decide between returning to work or leaving work.

(Q9) Quote from CVF Member

"When I was told to shield, my school (employer) said that on their risk assessment, that as I was only CV, that I had to work."

Karen, aged 62

42. Some employers demanded evidence that people were CEV/shielded and even the government letters detailing this were not sufficient.

(Q10) Quote from CVF Member

"When my work refused allowing me to shield (note: I had the Government CEV letter, which employer wouldn't accept), and I was battling them, I asked my GP to write me a letter to tell my employer that I was vulnerable, and they wanted to charge me £65 for the letter to allow me to shield. My employer wouldn't and still won't allow reasonable adjustments even with Occupational Health report advising non face to face as a reasonable adjustment. Currently off sick . ." May 2023.

Kerry, aged 43

43. Some things were better for shielded/'CEV'; they could legitimately be given alternative work from home which protected them from infection, at least when their employer agreed

to this. This may also have benefitted their general underlying condition and managing certain symptoms such as fatigue, and pain.

44. Shielding was, despite all its challenges as detailed here, often a reassurance and practical help to clinically extremely vulnerable people. It is a fact that CEV people and CV people were at higher risk of severe outcomes from Covid. In fact, in an analysis by The Health Foundation published an article, *'Research reveals devastating and lasting impact of the pandemic on those asked to shield'* on 20th October 2021 [Exhibit CF/23 - INQ000408810] they found that:

"Clinically extremely vulnerable people experienced a higher rate of deaths compared to the general population over the pandemic. At the peak of the first wave (2 April 2020), the rate of deaths among the clinically vulnerable population was over two and half times that in the general population (1 in 2,500 or 0.039% compared to 1 in 7,000 or 0.014%). Furthermore, by the end of August 2020, the clinically extremely vulnerable population accounted for 19% of all deaths while only making up 4% of the total population in England."

(Q11) Quote from CVF Member

"Absolutely petrified, isolated, long and sad but at the same time, safe, it was the only safe option." May 2023.

Becky, aged 41

45. Unfortunately, the protection that shielding afforded has become diluted during the pandemic. The government guidance, *'Covid-19: guidance for people whose immune system means they are at higher risk, updated 21 September 2023'*, for people now states [Exhibit CF/24 - INQ000408811]:

Guidance as of 14 March 2023

You are advised to try and avoid contact with people who have symptoms of COVID-19 or other respiratory infections. If you have visitors to your home, consider ventilating your rooms by opening windows and door to let fresh air in. Consider asking visitors to your home to take additional precautions, such as keeping their distance. COVID-19 tests are no longer free for the general public, but you may wish to ask visitors to take a lateral flow device (LFD) test before visiting. You might also consider asking them to wear a face covering and you may want to wear a face covering yourself.

46. Clearly this government advice (updated 14th March 2023) whilst wholly sensible and that which, in principle CVF agrees with, is not currently possible for many people who at higher risk of Covid-19 and specifically the immune suppressed. One of the main places people with underlying conditions need to frequent is healthcare.
47. In healthcare there has been a continual reduction in Covid-19 protections. CVF agree with healthcare professionals who expressed concerns about the relaxation of COVID-19 prevention such as: respiratory hygiene including the use of facemasks; reduced testing for asymptomatic patients; isolation of positive patients as set out in '*Covid-19: NHS relaxes infection prevention and control measures by Gareth Lacobucci, published 22 April 2022, BMJ 2022; 377:o1029 [Exhibit CF/25 - INQ000408812]*. Without testing for Covid-19, levels of hospital acquired infections can now increase without being detected, which CVF believes poses a risk to patient safety. CVF feel that the NHS's lack of clarity on COVID-19's airborne transmission, contrasts with more rigorous infection control measures used for other pathogens such as MRSA.
48. Moreover, the approach is a postcode lottery due to a void in government guidance on the matter. Currently, as outlined throughout this statement, many of our members do not feel they can attend medical appointments safely.

(Q12) Quote from CVF Member

"As a household we are now in our 4th year of shielding, it's been the only option for us. The main problems we've faced have been caused by the attitudes and behaviours of other people toward us. We've been bullied, harassed and gas lit relentlessly by the school, council and my employer. They have stopped me sleeping at night, made me live in constant fear due to their threats and made me physically ill through the stress and worry they've caused me. Due to lack of safety mitigations in hospitals, we are not even given the privilege of being able to attend our urgent medical appointments safely anymore. Seeking medical attention has become a truly terrifying ordeal, that I would liken to a game of Russian Roulette with our lives. The UK no longer feels like my home, it is not a safe, tolerant or kind place for a person with disabilities to try and live." May 2023

Amanda, aged 43

49. In addition, our members cannot attend many other environments safely such as workplaces, schools, places of worship, community pharmacies, community hospitals, social places such as village and town halls, exercise classes, theatres or cinemas. The government guidance, as set out above, is impossible for people in the context of 'personal responsibility'. Moreover, the generally prevalent social culture now within the UK is against mask wearing, even to the extent that our members have suffered 'mask abuse', which means people have suffered from name-calling, spitting, coughing over or physical removal of our masks. It could be said that our members now face a 'hostile environment' in terms of trying to keep themselves safe from harm from Covid-19 infection.

(Q13) Quote from CVF Member

"I was taking my child to an appointment at Great Ormond Street, had just parked the car and was approached by a man and women who were shouting at me. They were really 'in my face' and swearing. The man threatened to 'punch me up' and then that 'he hoped our car would be alright' whilst we left it to go to our appointment. We were all wearing masks. The woman told us there was no need as we were all outside. I called 999 as I felt under physical threat. After escorting me and my child to the hospital, my husband returned alone to move the car. I reported this to the MET Police but I was informed that it was not a case of discrimination as masks 'are not covered'. This is despite my having a disability."

Maria, aged 39

50. People who were shielded who also needed daily care, were left vulnerable as PPE for carers who were employed through social services 'direct payments' was not given out until sometime later. This means people who were very clinically vulnerable and who needed care in their own homes were potentially put at risk.

51. Some people who need daily care felt they had to cancel their care. For some, there was someone available to help fulfil the caring duties, but for others they either had no care or had to take the risks of carers coming into their homes daily.

(Q14) Quote from CVF Member

One of our members Philip King, cancelled carer visits for his partner, due to the Covid risk on March 12th 2020. At the time, his partner, who is severely disabled, was having professional carers a few hours a week. He wrote to the carers company on 12th March: *“This is just to confirm our decision to suspend ██████’s care service effective immediately due to the risks to him from coronavirus. As explained, the care service is only to provide respite for myself, I am therefore able to provide full time care for ██████, and I should stay at home more to avoid infection myself anyway. In addition, it seems sensible to limit the number of visitors to the house . . .”*

Philip King

52. Shielding was challenging, especially for people who lived alone, or who lived in multi-generational or overcrowded households or who had no outside space.

(Q15) Quote from CVF Member

I panicked at first as on my own now and felt very isolated but accepted it as sensible to stay safe, especially when I heard of people I knew locally dying from Covid.’

Maggie, retired

53. People’s psychological health was affected by shielding. There is evidence that shielding created new mental health problems in some people. Indeed, research by Lasseter et al (22 November 2022) [Exhibit CF/26 - INQ000408813] has shown that; *‘Since shielding had begun physical and mental health reportedly worsened for 35% and 42% of survey respondents respectively.’* It had potential adverse effects on mental well-being causing feelings of loneliness, anxiety, and depression. CVF addresses below the trade-off of these experiences against the protection provided by shielding.

(Q16) Quote from CVF Member

'Initially terrified at the thought of leaving my kids without a mum. Then when restrictions were lifted, I felt like a massive burden to my family and wondering if they'd be better off if I died. I felt excluded from society, friends, and family. The only place where I still had value as my work where I could work from home. I'm still cautious but finding is so hard now that Covid is over'

Hannah, aged 44

54. For some people shielding also impacted on their physical health, both in terms of a reduction in physical activity and access to healthcare services. There was no offer from the government to support people during shielding or when shielding was stopped.
55. However, shielding also created feelings of safety and protection.

(Q17) Quote from CVF Member

"Protected and safe. When we were forced out of shielding, I and my children, were terrified. One week after mitigations were got rid of in schools our family, including me, caught Covid. I now have Long Covid and my existing health condition (severe asthma) is much worse."

Nikki, aged 52

56. There was clearly a tension experienced by CVF members as to the benefits and risks of shielding. Overall, CVF consider that the guidance given did not strike the right balance in terms of protecting people from Covid-19 versus the potential negative physical and mental health impacts on those shielding.
57. Our view is that the negative effects were at least in part because of the poor quality of the guidance rather than necessarily the need to shield. The content of the guidance was sometimes scary and was constantly changed. The advice was often unachievable and certainly was insufficiently reassuring that shielded people were being protected. Additionally, the guidance:

- a. Failed to ensure complete household protection, focusing on the CEV individual but often neglecting the risk posed by non-shielded household members.
- b. Lacked support for CV individuals, including elderly people without specific health conditions, leaving them more exposed to the virus.
- c. Contributed to significant mental health challenges due to isolation, an impact that could have been mitigated with more thoughtful guidance.
- d. Suffered from inconsistencies as it didn't protect all people and possible transmission risks, leading to confusion and a sense of inequality.
- e. Struggled to adapt quickly as understanding of COVID-19 evolved, sometimes misaligning with the current risk level.
- f. Did not address other mitigations like FFP3 masks and instead gave a blanket instruction to people to retreat from society.
- g. Neglected non-COVID healthcare needs, causing delays in treatment for other conditions.
- h. Overlooked the economic and occupational risks for those needing to shield, forcing difficult choices between health and financial stability.

58. The mental health impacts of shielding might have been mitigated had the guidance been carefully considered. As stated above, CVF think the shielding guidance was withdrawn too quickly. Most importantly, when it was finally withdrawn there was no offer of rehabilitation back into society 'safely' or to overcome the psychological effects of the frightening communications received during shielding.

(Q18) Quote from CVF Member

“Terrified, excluded, lonely, suicidal . . . images of ICU haunt me still. Shielding still.” (May 2023)

Jan, aged 71

59. Being shielded affected people's finances, often significantly.

(Q19) Quote from CVF Member

"I had to give up my business, as I had a small B&B, and my husband also had to put his plastering business on hold. We had to sell our home, and have lost all our money to be able to keep a roof over our heads, rental, and food etc."

Amanda, aged 53

60. Many relied on benefits if they were unable to work in publicly facing roles. However, this support ran out when shielding stopped and people were left with the difficult decision about whether to risk working in a potentially unsafe way or leave their job (and therefore their income). Some people were hounded out of the workplace due to their inability to work in the way they had prior to the pandemic. Some were targeted for redundancy and others for 'capability'.

(Q20) Quote from CVF Member

"I was selected as part of a job pool for redundancy in the summer of 2020. I was given an opportunity to apply for voluntary enhanced redundancy but as I had been there for over ten years and was doing a good job, I did not consider it. I was a teacher in the independent sector. The criteria for redundancy to my surprise focussed on the period of the early pandemic. I was marked down as I hadn't 'offered' to go in-person to face to face events. I was actually shielded but no one had checked that with me at any point. Ultimately, I felt targeted as I was shielded. I was selected for compulsory redundancy."

Jim, aged 49

61. This is an ongoing issue throughout the whole pandemic for many CEV/CV and severely immune suppressed. The government guidance continues to recommend working from home but often there is a tension between this and an employer's requirement. It needs to be properly recognised that for people at higher risk of Covid-19 disease and at risk of severe illness and even death that they are eligible for reasonable adjustments to work from home. This includes offering hybrid options, where people at higher risk can join in virtually. Currently this is very patchy in the workplace.

62. When shielding was withdrawn (as it was, and then reinstated, multiple times), it was a blanket decision which applied to all CEV with no consideration of individual ongoing risks. Particularly in the case of those who are severely immunosuppressed, and those who are CV but could not be vaccinated, it left those vulnerable people at risk because their employers, schools and public services were potentially given the false belief that nobody was at risk. However, all CV people remain at greater risk from Covid-19 and are exposed to further risk as the most prevalent strains are constantly shifting and evolving away from vaccine protection – which now remains the only line of defence. It has to be recognised that for us, stopping shielding was like falling off a cliff. People who had been able to work from home or get statutory sick pay were suddenly unable to do so in mid-August 2020, but they were still un-vaccinated, and still at risk. Most of our members knew their risk, which is why they were engaged with us, but other people may have relied on the Government guiding them. CVF therefore played an advocacy role by, for example, explaining the risks and assisting members to advocate for themselves on risk assessments and seeking reasonable adjustments from their workplaces. That is consistent with our role as a peer support organisation.
63. Of course, shielded people often don't live alone. Many of our group are working age adults with families who live with them.

(Q21) Quote from CVF Member

“My husband shielded with me until August 2022, when he had no choice but to go back in person work – we have decimated his pension pot trying to survive financially.”

Amanda, aged 54

64. Partners and sometimes children, shielded with them. This created many different issues including some very difficult circumstances.

(Q22) Quote from CVF Member

“Partner and I both immunocompromised and don't respond to vaccines . . . Daughter turns 18 tomorrow. We've spent three years shielding from her in our home so she can lead a relatively normal life. Heart-breaking for us all.”

Sally, aged 55.

65. Some CEV/shielded people needed family carers. However, these carers were not shielded alongside their shielded family members causing challenging situations, where the family member had to attend an in-person workplace and in distress. This was very much left to employer's discretion.

(Q23) Quote from CVF Member

"I was also a carer for somebody with stage four cancer during COVID. If I had COVID I would not have been able to care for them or would have risked giving it to them. I have always taken a high level of precautions anyway and time proved I was right to do so. I am very fortunate to have had an understanding employer."

Tracy, aged 53.

66. As additional protections have been dropped ever since 'Freedom Day' on 19 July 2021, such as masks in healthcare and the Covid-19 Infection Survey (which allowed an understanding of the relative prevalence of those with Covid-19 at any given time)² people at higher risk of Covid-19 infection feel increasingly vulnerable and as though they are trying to assess their risks completely 'in the dark'. A report published in the British Medical Journal of Science in July 2022 highlighted the way that, after Freedom Day, the Government has failed to ensure that behaviours which manage the risk of Covid-19 infections were implemented, even if those were not mandatory. These included basic steps like use of high-grade face masks, opening windows and the reintroduction of free testing for the CEV as set out in 'Covid-19: One year on from 'Freedom Day,' what have we learnt? By Simon Williams and Susan Michie, published 19 July 2022 BMJ 2022; 378:o1803 [Exhibit CF/27 - INQ000408814].

(Q24) Quote from CVF Member

"Initially I felt well protected in those first twelve weeks but what has been scary is watching all public health protections be dropped. My daughter caught Covid a week after 'freedom day'. I'm still living very cautiously as I don't want to get Covid, and it's harder now to assess risks since the prevalence survey was dropped." May 2023.

Imogen, aged 44.

² The Coronavirus (COVID-19) Infection Survey was an ongoing survey that mapped the percentage of people testing positive for coronavirus (COVID-19) in private residential households in England, Wales, Northern Ireland and Scotland, including regional and age breakdowns. It ran from April 2022 to March 2023.

D. Children who were CEV/Shielded and those who were CV.

67. Some children were shielded too, based on their medical conditions. It was especially challenging for some families when in July 2020 they were told that in general children were no longer consider clinically extremely vulnerable and *“the majority of children currently considered extremely clinical vulnerable to coronavirus (Covid-19) will be removed from the shielded patient list”* as quoted from the Government’s Press Release *‘Majority of children no longer need to shield’ published 6th July 2020 [Exhibit CF/28 - INQ000408815]*.
68. This was before vaccination and at a time when prevalence of Covid-19 had substantially fallen. These children were then expected to return to school in September 2020. There was, again, no general offer of psychological support to these families. CVF have a lot more evidence relating to children, young people, schools and education which we hope to assist the Inquiry with in a future education module.
69. The smaller number of children who were still shielded after this date, were completely removed from shielding finally in August 2021. At this time, vaccination was now available to limited cohorts and no primary aged children. However, in August 2021 many clinically vulnerable 12–15-year-olds hadn’t been vaccinated yet. Even the CEV children who were not fully vaccinated or, had not even received once dose, were made to return to school in September 2021. There was still no offer of psychological support for these families. There was also no advice on better masks or other mitigations to reduce the recognised high transmission risks posed by schools.
70. For some children, they were not recognised as CEV or shielded and so were not offered that protection. This was despite having significant risks of infection. Adults and children with learning disabilities were not initially added onto the shielding list.
71. Some families with children who were shielded often struggled to get access to basic support such as supermarket delivery. There appeared to be an absence of clear guidance on supermarket access for shielded people.
72. Although theoretically, parents may have been able to go to the supermarket or other public places for their vulnerable child, in reality, parents often shielded alongside their children to protect them.

73. CVF parents also describe a concern that they were unable to take their children outside of the home for fear of being reported to social services for not properly shielding their child.

(Q25) Quote from CVF Member

“Was my daughter (age 11 at the time) who was on the shielding list. System was not set up for accessing supermarket delivery slots as she was under 18 – got it sorted in the end and local council support offered too, but system said we had to shield, but wasn’t set up for an under 18 to be supported.”

Anon

E. Learning Disabled Adults and Children

74. In November 2020, a report by the government (*‘Covid 19 deaths of people identified as having learning disabilities: summary’* report published 12 November 2020) **[Exhibit CF/29 - INQ000408816]**. showed that the death rate for people with learning disabilities (‘LD’) with COVID-19, adjusted for under-reporting, was 369 per 100,000 adults, which is 3.6 times the rate in the general population. Deaths in hospital settings, which the report noted were likely to be an under-estimate, were 3.1 times adults without disabilities. The government delayed recognition (by being slow to acknowledge and formally identify) people with LD as a group at increased risk from COVID-19 and who thus required specific protective measures. In particular, CVF understand that the disparity in deaths between the LD and wider public was known before Christmas 2020 but that LD people were only added to shielding list on 19 February 2021 and thus were not initially prioritised for vaccination in early 2021.
75. In February 2021, it was announced by the BMJ that *‘local groups of GPs have decided to deviate from national guidance and said they will prioritise all patients with learning disabilities for vaccination given the disproportionate impact on them’*, and suddenly added LD onto the priority list at the time of vaccination. In fact, it was only in the week of 19th February 2021 that an extra 1.7 million people in England, including some with severe learning disabilities were added to list of CEV people, as evidenced within the BMJ article, *‘Covid-19: GPs opt to prioritise all patients with learning disabilities for vaccination’* by Gareth Lacobucci, published 19 February 2021, *BMJ 2021;372:n510* **[Exhibit CF/14 - INQ000408800]**.

76. Children with LD were also affected, it was often left to the discretion of the GP whether they were offered any shielding protections.

(Q26) Quote from CVF Member

"I had to fight to get my son identified as vulnerable during the early days of Covid. He never received an official shielding letter initially but thankfully my GP gave me one as he could see that he was vulnerable. Eventually learning-disabled people were seen to be vulnerable . . . We have shielded since a week before the official lockdown but trying to get schoolwork for both of my children was a battle."

Laura, aged 45 years and son aged 12.

F. The Clinically Vulnerable (who were not shielded)

77. The Clinically Vulnerable ('CV') were another group defined early in the pandemic by the government as having increased risk to Covid-19 infection with worse outcomes. This is detailed in the referenced NHS England document **[Exhibit CF/11 - INQ000068624]**, dated 1 April 2020, pages 3-4, which defines the 'wider vulnerable group has been identified to the public as:

- a) Aged 70 or older (regardless of medical conditions)
- b) Under 70 with an underlying health condition listed below (ie. For adults this usually is anyone instructed to get a flu jab as an adult each year on medical grounds);
 - I. Chronic (long term) respiratory diseases, such as asthma, chronic obstructive pulmonary disease (COPD), emphysema or bronchitis
 - II. Chronic heart disease, such as heart failure
 - III. Chronic kidney disease
 - IV. Chronic liver disease, such as hepatitis
 - V. Chronic neurological conditions, such as Parkinson's disease, motor neurone disease, multiple sclerosis (MS), a learning disability or cerebral palsy
 - VI. Diabetes
 - VII. Problems with your spleen – for example, sickle cell disease, or if you have had your spleen removed

- VIII. A weakened immune system as a result of conditions such as HIV and AIDS, or medicines such as steroid tablets or chemotherapy
- IX. Being serious overweight (a BMI of 40 or above)
- X. Those who are pregnant'

78. Yet this group were not afforded the protections of the shielded group. They immediately had to return to front line roles even during the wider 'lockdowns'. That was despite evidence that people with these conditions have a higher chance of death from Covid-19 e.g., diabetics, COPD, and people aged over 70 years. For example:

- a. A pivotal study by Public Health England, released in August 2020, revealed a striking statistic: out of 23,698 COVID-19 hospital deaths in England until 11 May 2020, a third were people with diabetes. This finding aligned with early pandemic reports highlighting diabetes as a major risk factor, contributing significantly to deaths. However, a notable and unexpected discovery was the heightened risk of mortality associated with type 1 diabetes, which was greater than that of type 2. The study found that people with type 1 had a 3.5x increased risk, and type 2 diabetics had a 2x increased risk of mortality when compared to those without diabetes. The study is summarised in **[Exhibit CF/30 - INQ000408818]**.
- b. In England and Wales in 2020, the ONS identified that the most common pre-existing condition in COVID-19 deaths was dementia and Alzheimer's disease (18,420 deaths), especially among those aged 65 and over. Diabetes was the second most common condition (14,658 deaths) and the most prevalent in people under 65. This data is set out within the ONS '*Deaths due to Covid-19, registered in England and Wales: 2020*' **[Exhibit CF/31 - INQ000408819]**.
- c. Early UK data found that 17.7% of the 20,133 COVID-19 hospitalised patients had COPD as set out in the *European Respiratory Journal*, Leung J et al 2020 56: 2002108; DOI: 10.1183/13993003.02108-2020 **[Exhibit CF/32 - INQ000408820]**.
- d. Age was also widely known to be a significant risk factor. People over 80 years old have a 70x higher risk of dying from COVID-19 compared to those under 40, while individuals aged 70-79 face a 50x increased risk as set out in Public

Health England's report on 'Disparities in the risk and outcomes of Covid-19' published in August 2020 [Exhibit CF/4 - INQ000408828].

79. This caused a lot of stress and concern for people who fell into these categories, who were known to be at a higher risk but were not given appropriate support or advice on how to protect themselves in order to reduce their risk of infection.

(Q27) Quote from CVF Member

"Initially I didn't fall into a shielding category. My asthma deteriorated over time and due to needing more and more oral steroids I ended up being eligible for antivirals after shielding officially ended. I also have a blood clotting disorder . . . it has never made sense to me why people with blood clotting disorders were never on the shielding list."

Tracy, 53 years

80. Some CV people were confused as to their risk, felt unsupported and were unclear on how they should protect themselves, as unlike the CEV, they were not afforded any specific protections. They too were not offered any advice on masks and were not offered any specific support beyond what would later become known as 'personal responsibility'. e.g. I&S Council advice (pre-vaccines, in November 2020) based on government guidance as seen through their social media [Exhibit CF/33 - INQ000408821]:

"If you are over 60 or clinically vulnerable you could be at higher risk of illness from Coronavirus. Please minimise your contacts with others and wash your hands more frequently whilst maintaining thorough cleaning of frequently touched areas."

81. It was very difficult for this group being told they were at higher risk, especially with constant reminders on the news of people who had 'underlying conditions', such as theirs, who were dying. They were not offered any practical ways to reduce their risks. This was especially difficult for keyworkers and people at work outside of lockdowns as their clinical risks were frequently dismissed by employers and colleagues because they were "just" CV, not CEV. All of the resources for supporting at risk groups seemed to have been allocated to the CEV and, at this stage, seemingly none to the CV group.

82. Many CV people left their place of work rather than return to a workplace that they did not consider protected them sufficiently from the risk of Covid-19 infection. This had a substantial consequence for this group in terms of financial loss, especially in terms of income. It has also likely reduced the number of CV people in the workplace, especially amongst older and high-risk keyworkers. Some members of CVF reported that they took early retirement.
83. Some people who continued to work found that their employers did not recognise the need to offer 'reasonable adjustments' despite a known threat to life and some of them being recognised under the law as disabled. This highlights the need for all CV people to be recognised under the Equality Act 2010 as a new and distinct group with new and distinct needs.
84. Some CV workers were discouraged from masking, particularly those who were working with children. CVF believes that masking must be a protected right, especially in the case of CV people, under the law.
85. Many CV people who were unable to work in high-risk situations could not access the same provision for Statutory Sick Pay as the CEV ('the shielded'). This created an inequality as often the wait for Universal Credit was long and left people at financial risk.

(Q28) Quote from CVF Member

“Being a clinically vulnerable teacher who was not officially shielded during the pandemic was an incredibly stressful experience. It had a significant impact on my life in terms of work opportunities. I had to prioritise my health and leave education, relying on Universal Credit because as a keyworker I was not automatically considered for furlough. The lack of specific guidance and support made the situation challenging. I believe there was. Need for comprehensive assistance and clearer guidelines for individuals in small circumstances. The government’s emphasis on CEV individuals sometimes led the public to respond with dismissive remarks such as ‘You are only CV, what are you worried about?’ The Inquiry must reflect on what level of increased risk of death should be acceptable to anyone.”

Carla, aged 44.

86. The CV were not on the supermarket 'list' and so had to enter into negotiations to try and to try to arrange supermarket deliveries, or they took risks to attend supermarkets in person. On 19th March 2020, some supermarkets implemented a 'vulnerable hour' with the aim to protect clinically vulnerable people, however, with only self-identification and no enforcement. These did not have the desired effect and rapidly became unsafe environments as healthy members of the general public scrambled to gain priority access to these essential resources as can be seen from the newspaper article 'Sainsbury's dedicated shopping hours for vulnerable people 'chaotic and crowded' [Exhibit CF/34 - INQ000408822].

(Q29) Quote from CVF Member

"My husband was not officially shielded but it was not a problem for us as we are retired and could afford to pay a bit extra for food delivery from unusual sources in the first period – early March 2020."

Gillian, aged 66 years

87. It was noted in an article by Pulse Today on 3 July 2020 [Exhibit CF/35 - INQ000408823], that experts said that '*Patients with diabetes, hypertension and cardiovascular disease should be added to the list of Clinically Extremely Vulnerable patients who should shield during a second Covid spike*'. CVF agree that this should have been seriously considered as there is a significant increased risk of severe illness for these conditions. CVF also wish to note that these conditions still aren't eligible in 2024 for booster vaccination or antivirals. Back in February 2023 NICE made recommendations that people with "*heart disease, respiratory disease, diabetes, or neurological conditions*" should be offered antiviral treatments [Exhibit CF/36 - INQ000408824]. CVF feels this recommendation demonstrates the inequity to the CV/CEV group. The Pulse article also mentioned that the impact of adding these people to the shielding list could increase GP workload. CVF question the reasons for not protecting these additional groups more strongly during the pandemic.

88. As the pandemic progressed, some of the CV were brought into the shielded group. For example, by February 2021 the BMJ [Exhibit CF/37 - INQ000408825] reported that an extra 1.7 million people were added to the shielding list. Most of these will have come from the wider CV list yet they were left without the added protections for nearly a year (March 2020 – February 2021).

89. From August 2020 onwards, CVF provided support to those in CV households. CVF has been asked to explain what steps it took to support people who were wrongly not added to the shielding list. These measures included:

- (a) Recognising the critical concerns surrounding schools during the pandemic, Lara Wong, the founder of CVF, starting in August 2020 drew on her expertise in Microbiology, Pathology and Science teaching, to create a set of practical mitigations aimed at reducing risks for both children and school staff. She noticed there was a critical gap in the members' understanding of protective measures, particularly the effectiveness of FFP2/3 masks. Members were very keen to learn about better masks available for different aged children and women, as many of the masks on the market were designed for men.
- (b) To ensure this gap was also bridged for any newer members, CVF added an easily accessible pinned post at the top of the group's Facebook page. This post was regularly updated to reflect the evolving scientific understanding of COVID-19. Another task was educating the group members on various topics, including clinical risks associated with various health conditions, COVID-19 transmission, and the scientific reasoning behind mitigations.
- (c) The initial idea behind the group was to share accurate information with other CV people, particularly those whose households were exposed. CVF therefore identified and shared articles from reputable scientific journals. Group members quickly developed an understanding of many key issues and the importance of adopting effective safety measures.
- (d) In order to address the significant mental health challenges faced by those in CVF, CVF initiated a dedicated mental health post. This allowed members to express their emotions, by posting a coloured heart or a comment. CVF, particularly led by Lara, then always tried to encourage those who posted these hearts to elaborate, fostering a supportive environment where members felt they could openly discuss their struggles. This approach not only created a sense of community but also enabled CVF to identify, provide individual support, and attempt to address the key issues affecting the group.
- (e) As the group evolved, its efforts extended beyond Facebook and onto Twitter to grow the network and reached out to the media, thereby enabling some CVF members to

share their personal stories. This helped to increase public awareness and empathy regarding some of the challenges faced by CV families at the height of the pandemic.

(f) As the group's advocacy efforts continued, they partnered with the Good Law Project to support families experiencing pressure to attend unsafe schools. Unfortunately, the changes CVF hoped for and needed in schools did not come. Despite the challenges in effecting change, the group has written many letters and campaigning to raise awareness on various issues.

(g) Additionally, CVF (led by Lara) was able to negotiate group discounts on essential products such as masks and air filtration units, which was vital due to the financial burden that purchasing these necessities placed on our families. CVF's leadership arranged meetings with MPs to highlight the group's needs and has assisted various members with legal cases, or employment tribunals, when necessary.

(h) CVF hopes that by providing information individuals can advocate for themselves, or are more equipped to do so with the help of peer support. Members frequently have to self-advocate for their own protection, and risk assess individual to reduce their chances of COVID-19 infection. CVF have also assisted CV members to make requests for formal workplace risk assessments and reasonable adjustments within healthcare, school and employment settings.

(i) Today, CVF has developed into a hugely supportive network of well-informed people that can guide new or confused members to quality advice or information including NHS and government policy documents. Any misinformation within the group has always been challenged scientifically, rather than removed, and this has been incredibly effective method to inform members.

90. People who were clinically vulnerable, but not classified as CEV, faced considerable challenges in accessing essential medicines. Whilst local authorities set up networks of volunteers to support CEV people, those who were CV were very much left to fend for themselves. This was a serious problem for those who relied on life giving treatments, such as those who were high-risk insulin dependent T1 diabetics. They had to rely on their own support networks, but as the media attention began to diminish those who were CV, as their only focus was on those designated by the government as CEV, those who were CV found it increasingly difficult to ask or find healthy people willing to put themselves in harms way.

91. Due to the lack of availability of pharmacy deliveries or external support, many CV people (or their household contacts) were forced to make incredibly difficult decisions between essential medicine and an attending high exposure risk locations such as pharmacies or supermarkets.
92. The pandemic's impact on the supply chains further compounded their issues, affecting manufacturing, procurement, and availability as can be seen in the World Health Organisation's article, 'Covid-19 pandemic significantly impacted access to medicines for noncommunicable diseases' published 22 March 2023 [Exhibit CF/38 - INQ000408826]. These factors, in combination, put people at considerable and frequently wholly unnecessary risk. This situation highlights the necessity for inclusive healthcare strategies that consider all at-risk CV populations and the need to ensure resilient supply chains during crises.
93. The current position is that those identified as severely immunosuppressed are eligible for antivirals if they test positive for Covid-19. Some of the "severely immunosuppressed" group would previously have been identified as CEV and others as CV. CVF believe that, as in other European countries and the USA, it would be very beneficial to the wider CV group to have access to antivirals. The Panoramic trial has been ongoing since November 2022 offering treatments to all over 50s and clinically vulnerable people as confirmed on their website [Exhibit CF/39 - INQ000408827], and this is considered in further detail within Module 4.

(Q30) Quote from CVF Member

"I felt very afraid and confused. I'm a working epidemiologist who takes immunosuppressants for my autoimmune arthritis, so I knew I was at higher risk than average, but not high enough to get onto the shielding list. For a time, it was a struggle to get food after I suddenly lost my longstanding supermarket delivery slot (Sainsbury changed to only delivering to CEV people, so I wasn't eligible). I knew how to protect myself and my workplace helped but the wait for my first vaccine shot (group 5/6) felt never-ending. . . . I've recently become eligible for antiviral treatments and booster shots. I feel vindicated that my understanding of my risk was correct but concerned how people like me were forgotten at the beginning."

Alison Dunning, aged 60

G. Impact of Shielding on the Welfare of Shielded Individuals.

94. The instructions shielding people were given, particularly the instruction not to leave their homes, had a serious and detrimental impact on their health and welfare. That included an inability to easily access food which caused many CVF members serious health and welfare concerns. There was a lack of attention given to how shielded people would access both sufficient and appropriate food. The detrimental impact on the shielded, as set out below, was a direct result of the Government's shielding policy.
95. There was a lot of confusion around options to access food deliveries. Some older people could not access the internet for food deliveries and continued to shop in person, even if clinically or extremely clinically vulnerable. Some supermarkets only would accept those who had previously had an account with them, for example, Sainsburys and Ocado. Local food services such as Milk Delivery Companies were overwhelmed and some evidence of this is provided in [Exhibit CF/19 - INQ000408805] showing that one of CVF's members was caller 27,005 in the queue for placing orders and evidences the several attempts by telephone and online platforms to access food.

(Q31) Quote from CVF Member

“ . . . 15th March (2020) or before as I'd returned from York with an injury from a seizure which had me signed off for two weeks rather than go to hospital to keep me safe from Covid-19 whilst healing. Then lockdown and shielding officially began. I was stuck indoors when others were stockpiling and panic buying and unable to get a singly online delivery slot.”

Katie

96. For those who were successful at obtaining a delivery often there were many omissions or substitutions. It was a particularly difficult time for people suffering from food allergies or conditions that require a specific diet, e.g., coeliacs or people with dairy allergy, kidney patients etc. In addition, supermarkets were limiting numbers of food and other items as there had been issues with panic-buying evidenced in [Exhibit CF/40 - INQ000408829] which shows food items being substituted for other items for one particular CVF member. Coeliacs, for example were substituted with non-Gluten Free food or not available, meaning available food could be very limited.

97. As CEV / shielded people were advised to not go into supermarkets, and many clinically vulnerable people were shielding without any government support, they could not go to different shops to get what they needed but rather had to rely on one delivery per week if they were lucky. This caused a lot of additional stress.
98. Some people were delayed being added to the shielding list which gave them additional concerns accessing food, they were unable to secure a supermarket priority slot.

(Q32) Quote from CVF Member

“Thankfully we had the foresight to stock up a bit on pasta, dried and tinned food, long life milk etc. I was unable to access the priority slots (as I was delayed being added to the shielding list) or the shielding food deliveries for several weeks which was a big issue. Neither of us have any family in the area, mine are over 100 miles away and my partners over 200 miles away.”

Catharine, aged 55

99. Supermarkets were given shielded persons details to match with their current records. However, many members spent hours on phone lines trying to ascertain their supermarket status. Some CVF members despite being on the shielded list could not access a supermarket delivery slot.

(Q33) Quote from CVF Member

“Background – CLL leukaemia, on CEV list but Waitrose couldn’t put me on their deliveries list because I didn’t show”.

Peter, aged 60

100. At this point, no other advice was given to this group on how to stay safe if they had to go outside their home. All the advice was centred around staying at home as demonstrated by text messages sent to those in this group. **[Exhibit CF/16 - INQ000408802]**.
101. There was no advice on the use of high-grade medical respirator masks, FFP2/3 which could have assisted people who needed to attend appointments or get food. In fact, at no point during the pandemic has there been any public education on which mask to

choose or how to wear it. This is a difference to other countries. For example, Germany made it mandatory that the public must wear at least FFP2 masks on public transport and in healthcare settings.

(Q34) Quote from CVF Member

"In Germany in August 2022, things were very different to in England. In the shops FFP2 masks were available in single plastic packets at the tills so that people could buy them at very affordable prices easily. There was generally much more mask wearing in shops (and mostly FFP2s) and on public transport and in healthcare it was 100% of people wearing FFP2, including children of all ages (right down to 2-3 years old). They even had different colour FFP2s and they were clearly easily available. In the UK it was virtually impossible to source FFP2 masks for children and people generally either weren't wearing masks on public transport and in shops and if they were, it was the much less effective blue masks. Even then, they often wore them down under their nose. This particularly concerned me, as I realised by then that those who chose to wear masks were generally clinically vulnerable."

Catherine, aged 45

102. Many shielded people were working age and who often were parents or workers in the communities in which they lived. They did not necessarily see themselves as vulnerable and therefore were not 'plugged' into any existing community networks.

(Q35) Quote from CVF Member

"I found it incredibly difficult as it was the extreme opposite of my life before. It was hard on my partner and my small son too. We made the decision to all shield so I wouldn't need to distance from them, naturally my son needed his Mum. We got through it together with zooms to family. Getting food was hard and the support from the government came late and was poor. At that time we knew it was a necessary action and we hoped for a better future. We were scared and it was new. I reminded myself daily it was temporary. Things actually got worse from the point after the initial shielding as people went 'back to normal'. Despite the fact we go for walks, our lives have never gone back to normal. There is no care left towards CEV and now nowhere is safe including, hospitals, dentists, GPs, nothing is safe. I've had Covid twice despite my best efforts, once caught at a booster jab appointment where I was the only one wearing a mask. I now have Long Covid on top of my pre-existing conditions. I don't go to the doctors as I don't want to get Covid again and I cancel all hospital appointments for the same reason. I've never been more broken in my life than I am now".

Amy, aged 41

103. At some point after 28th March 2020, and it really varied across different areas, some shielded people started to receive food packages. Whilst they offered some relief, they were not specific to people's diets and so many people with food allergies could not eat the food given. It is important to note, that CV people were not offered food packages and many were still struggling to access food deliveries at this time often trying to survive on any store of foods that they may have had.

(Q36) Quote from CVF Member

“Given the issues we were having generally sourcing food, the government food packages offered some relief. However, in my family we have a coeliac and someone who is dairy-allergic and we weren’t asked about this. We were therefore very limited in what we could use. It wasn’t consistent either, sometimes, the food included would not have been enough for few days and didn’t offer any fresh fruit or vegetables. Not that we weren’t grateful, it was just very limited.”

Tina, aged 37

104. In the experience of CVF members we consulted with and supported, access to medication in the community varied. Through peer support conversations and discussions amongst CVF members through shared social media channels which CVF facilitates, it is clear that some people were able to get their prescription medication delivered directly from community pharmacies but others were not. As noted above, the NHS Coronavirus Service on 24th March 2020 sent text messages with advice to the CEV/shielded, telling them to ask their family, friends or neighbours to collect their prescription items as demonstrated in these texts [**Exhibit CF/13 - INQ000408799 and Exhibit CF/41 - INQ000408830**]. This advice was not practical, as the reporting of CVF members in shared peer support discussions indicated sometimes this was not possible due to people’s varied personal circumstances.

(Q37) Quote from CVF Member

“I felt relieved at first as I made the decision before the government. I knew what was happening overseas. I had food delivered. We were safe at home with no contact with the outside world. Then the government locked down. Couldn’t get a food shop or chemist delivery etc. and then I felt panic and scared! I had to go out to get them. Once it settled I felt safe again ...”

Anon

105. Some people did not have anyone they were able to ask. Others had to try and negotiate with their neighbours for the first time to collect sensitive medication. For some people their friends and family were also shielded or older. People were also often

reluctant to ask others to do things for them as they saw it as a risk. What if something happened to that person whilst doing a chore for them?

(Q38) Quote from CVF Member

“Both my husband and I were shielded. Our parents were all over 70 years and ‘at risk’ all with underlying conditions. We were not sure who we could ask to help us out. The community hubs were not established early on. We felt that anyone we asked we could be putting them at risk of infection. I did finally ask someone to help, and I paid her. I also bought her masks to try to protect herself. I did not want to be responsible for her becoming infected.

Thankfully she did not catch Covid.”

Petra, aged 49

106. On June 21st 2021 the government decided to remove the support for CEV people to access priority delivery slots for supermarkets. An example of the Government’s communication to a member of CVF is evidenced here **[Exhibit CF/42 - INQ000408831]**. It is CVF’s view that this was too early. Indeed, not all the ‘at risk’ groups were fully vaccinated by this date, and as the pandemic continued to evolve, so new variants appeared, creating new risks for the higher risk group. In addition, for the Severely Immunosuppressed, vaccination has not been effective, and so remain at higher risk. Once again, clinically extremely vulnerable people were left to manage their own risks without any support.

H. Covid-19 Decision Support Tool

107. The Covid-19 Decision Support Tool **[Exhibit CF/43 - INQ000408832]** was a tool not used to identify people who were vulnerable and who needed to shield, but rather a tool to identify people who had Covid-19 and underlying conditions. This tool accessed their pre-existing conditions and gave people a ‘score’. It was on this score, people could access different levels of treatment.

108. There was a strong chance that people who were already CEV or CV, as well as people with neurodivergence and learning disabilities would be likely to easily reach a high level of points.

109. This tool therefore felt very discriminatory and yet another 'blanket policy' against people with pre-existing conditions yet lumped them into a homogenous group without a view on their individual quality of life and abilities.
110. This made people with long term conditions feel very anxious as this was released into the media. At a time when they needed to rely on the healthcare system (and had been told to pack a bag ready if they were shielded) they were now being led to believe that they were not worth 'saving'.

(Q39) Quote from CVF Member

"I saw it on the web and was shocked and particularly worried that an innocent mention of being slower or of walking rather than, say sport for exercise, might gain an extra 3 or 4 points. I felt I would have to be very careful in what I said. It reduced trust."

Derek, aged 70

111. CVF are of the view that no tool should be used in such a way that encourages and/or results in blanket discrimination against individuals based on any pre-existing medical condition. We are also concerned about the long-term effects of this tool and its potential to prejudice the views of those in healthcare, and how this might impact on our care during other times of pressure in the NHS.

I. DNACPRs

112. CVF understands that there was guidance released in 2020, to General Practice for doctors to ask their patients with underlying conditions whether they wanted to be resuscitated. i.e. to consider Do Not Attempt Cardiopulmonary Resuscitation ('DNACPR').

(Q40) Quote from CVF Member

"I got asked about whether I'd want to be resuscitated early in pandemic when I was admitted to hospital after anaphylaxis. My response was 'I've fought too blooming hard to stay alive for you to give up on me'. It's now noted on every hospital discharge that my preference is full resuscitation, which I still find odd though they are at least respecting my wishes, but at the time I was outraged they'd even ask."

Kira, aged 30s

(Q41) Quote from CVF Member

“I received a phone call and this letter asking about DNACPR amongst other things from my GP. It really scared me and upset me at the time. I honestly thought that is it, I’m going to die.”

Helen, aged 45

113. In CVF, this has affected many of our members. It is a traumatising subject. (see above quotes 40 and 41). The quotes above, and the example provided of correspondence from a GP about DNACPRs [Exhibit CF/44 - INQ000408833], show the way CVF members were unexpectedly confronted with messages that they needed to think about whether they would be resuscitated if something happened to them, regardless of their background.

114. In fact, the Care Quality Commission (CQC) of the UK, undertook a report entitled *‘Protect, respect, connect – decisions about living and dying well during Covid-19’* [Exhibit CF/45 - INQ000235492], published 18th March 2021 in which it said:

“From the beginning of the Covid-19 pandemic, there were concerns that ‘do not attempt cardiopulmonary resuscitation’ (DNACPR) decisions were being made without involving people, or their families and/or carers if so wishes, and were being applied to groups of people, rather than taken into account each person’s individual circumstances.’

115. Indeed, the CQC found that *‘Once DNACPR decisions were in place, it varied whether providers and local systems reviewed them.’*

116. Moreover, some of our members have anecdotally reported to us that they have had DNACPR orders placed on their records without discussion, something that is deeply distressing and concerning. As set out above, CVF are aware of this through peer support conversations with members, hosted online through its social media and support groups, and the ‘focus group style’ thematic analysis we carried out, rather than through quantitative analysis. Our members’ feedback is consistent with the findings of the CQC report above, which involved consulting with 50 external stakeholders, surveying 2,048 adult social care providers, 613 patients with a DNACPR and/or their families, reviewing 166 DNACPR records, and 156 interviews or focus groups with clinicians, and clearly found up to 30 per cent of people were not aware of DNACPRs placed on them. The CQC

guidance on decisions on DNACPR states these must never be dictated by blanket policies, must be free from discrimination, and not made on a clinician's 'subjective view of a person's quality of life. One of our members, Jennifer was shocked to discover the DNACPR on her discharge summary, nobody had discussed it with her at all.

(Q42) Quote from CVF Member

"I have just been discharged today (*June 2023*) and discovered that I have a DNACPR on my notes. Not happy at all, don't remember being asked. It was in my discharge note.'

Jennifer, aged 47

117. **CVF suggest that there should be a new order to relay every patient's DNACPR status so that they know if something was added without consent, from 2020 onwards, with full open discussion and psychological support.**

118. The CQC was reported by the BBC [**Exhibit CF/46 - INQ000408835**] ('Covid-19: 'Do not resuscitate' decisions complaints up', 3 December 2020), as saying '*Inappropriate DNARs may still be on people's files*'.

119. CVF agree with the CQC, however CVF's members' experiences in shared group discussions indicates this was continuing into 2023, three years after the CQC made its concerning report. Many people were not informed of the DNACPR on their notes. We strongly suspect that some of these remain, and people are not aware of them since there has been (to CVF's knowledge) no systematic review of DNACPRs despite the CQC findings. There was a concerning story published in a newspaper about a woman in Scotland with atrial fibrillation who unknowingly had a DNACPR placed on her in February 2020, indicating that these deeply concerning problems persist [**Exhibit CF/47 - INQ000408836**]

120. Again, the approach to DNACPRs was treating people who had very different conditions and very different ages and premorbid states but who belonged to the 'shielded category' as being not worth 'saving'. Any such 'blanket' policy is unlawful. The CQC heard widespread denials of blanket policies from healthcare professionals but identified consistent concerns from those in the community that such blanket decision-making was made and evidence from fieldwork that some blanket decisions were made and quickly

revoked after advocacy (p 22). CVF fear that without a robust review, blanket policies may have been imposed and not quickly identified, especially in communities without active advocates.

121. The BBC on 18th March 2021 reported that *'individuals' human rights may have been breached in more than 500 cases where 'do not resuscitate decisions were made during the Covid pandemic'* (BBC, Covid-19: Concern over 'do not resuscitate' decisions during pandemic, 18 March 2021) **[Exhibit CF/48 - INQ000408837]** The CQC's research, referred to above, was carried out due to a report in the 'jump in complaints between March and September 2020', the first 6 months of the pandemic.

122. Both the use of the Covid-19 Decision Support Tool and DNACPR have traumatised the Clinically Extremely Vulnerable especially and have left them less trusting of healthcare. There has been no psychological support for any of these decisions that people have had to make, thrust upon them, or learnt of by accident or in the media, with the realisation that it applies to them.

(Q43) Quote from CVF Member

"GP rang me and said I'd have the do not resuscitate added to my file. I was in shock, didn't argue, quietly agreed to it. It's affected me mentally. I'm not OK. I feel I was, and am, disposable. I was 53 at the time of the call"

Melissa

123. CVF also wish to note that it is not just the matter of the risk of 'blanket DNRs' on extremely clinically vulnerable persons but also the concerning matter of mission creep. There are cases widely reported in the press where DNACPRs stop other life-saving treatment, such as for choking which is not what the DNACPR is intended for. CVF are therefore **very concerned** about:

- a) the discriminatory nature of the blanket approach to the CEV/shielded community in terms of DNACPRs;
- b) the ongoing nature of this problem; how many people aren't aware of this in their medical records;
- c) potential mission creep on people who inadvertently have had these orders wrongly slapped onto their notes during the pandemic and who may now

- not be treated for other life-saving therapies, without even being aware of the DNACPR in the first place; and
- d) the psychological trauma of discovering this in your medical records, or being asked abruptly and only relating to the Covid-19 pandemic with no psychological support offered at any time.

(Q44) Quote from CVF Member

"I also received a phone call and a letter asking about DNACPR from my GP surgery. I was told to get my affairs in order, to make a will, would I prefer to go into a home or remain at home if I contracted Covid-19 because I wouldn't be admitted to hospital because of the 'threat of overwhelming the NHS!' It really scared and upset me enough to tell the caller that I wanted time to decide and couldn't give them an instant reply over the phone! It scared me so much that I have been shielding from February 2020 until today!! I was 65 years old at the time. It was traumatising. I complained to my GP during a telephone appointment. He apologised and admitted it was to prevent the NHS being overwhelmed. He didn't offer me any psychological support through any of this. He didn't consider me to be vulnerable enough to be CEV or shielding despite multiple health issues'.

Glynis, aged 65

J. QCovid – high risk identification tool.

124. Qcovid [**Exhibit CF/49 - INQ000408838**] was developed by University of Oxford and was used for identifying high risk people for early vaccination, as well as other targeted protection and interventions. It provided a data-driven approach to risk assessment which CVF welcomed.

125. It enabled individuals to have a clearer understanding of their own vulnerability to severe Covid-19 outcomes and potentially take appropriate precautions. However, this was not a well-known tool in the general population and was potentially under-used. CVF find that a common issue with members and people who are CV, CEV and severely immunosuppressed is their general lack of understanding of risk assessment. It is hard to assess a risk for yourself without training and education and where possible CVF offer support to its members in respect to some of this. We did share Qcovid with our members

but it did cause a degree of confusion and upset and CVF were concerned to note that many known risk factors were missing from this tool.

126. Qcovid was limited in the discrete variables and so offered a generalised approach, possibly over-generalised and not person specific enough. CVF think that for people with rare disease the tool was unhelpful as it did not cover individuals with rarer conditions. It relied on available data and clinical factors at the time of its development, as stated in the NHS Digital website '*Coronavirus (Covid-19) risk assessment. How Qcovid was developed*' [Exhibit CF/50 - INQ000408840]

K. The Use of Masks, Especially in Healthcare

127. Many hospitals and other healthcare facilities only used surgical masks which are not protective against Covid-19 as it has airborne spread. Evidence from, inter alia, the European Centre for Disease Prevention and Control indicated that FFP2 and FFP3 masks were much more effective than surgical masks, evidenced in the exhibited article, '*Considerations for the use of face masks in the community in the context of the SARS-CoV-2 Omicron variant of concern*', Baka A et al, published 7 February 2022 [Exhibit CF/51 - INQ000408841]. However, CVF's members' experience was that FFP2 and FFP3 masks were not widely used in general healthcare, by staff or patients. CVF members were very aware (because they were higher risk) that FFP2/FFP3 masks are more effective protections against aerosols and Covid infections, if properly fitted. Members were therefore concerned and shared their experiences where they attended hospital and could see that healthcare assistants weren't wearing the best quality masks available.
128. Moreover, many hospitals required CVF members to remove their higher quality respirator masks and replace with a IIR surgical blue mask that is dramatically less protective against an airborne virus. This problem was written about by Trisha Greenhalgh in BMJ 'Opinion' in August 2022 [Exhibit CF/52 - INQ000408842], she states, "*Downgrading masks is an issue for everyone. ... However, it has particular impact on those who are clinically extremely vulnerable.*" CVF agree with Greenhalgh that this practice "*puts us [CEV] at greater risk of infection.*"

(Q45) Quote from CVF Member

“Twice when entering into hospital (once in 2020 and once in 2021) requested at entrance to remove my mask and use basic blue surgical masks. First time, I was wearing my own (standard white) FFP3, second time wearing Cambridge Mask. Thankfully, I had spare FFP3s with me, individually sealed in plastic wrappers, on both occasions. They challenged me using my own but I showed them me unwrapping it from scratch and got away with it. The receptionists didn’t understand at all that the blue ones weren’t superior! I had to convince them, and a senior nurse was called over the first time to give consent”.

Zoe, aged 48

129. A study carried out by Cambridge University showed that FFP3 masks were highly effective in reducing Covid-19 infection in healthcare workers. In fact, *“Healthcare workers working on red wards faced an approximately 31-fold (and at least fivefold) increased risk of direct, ward-based infections. Conversely, after changing to FFP3 respirators, this risk was significantly reduced (52-100% protection)”* [Exhibit CF/53 - INQ000408843].

130. The removal of masks in healthcare on 27th May 2022 has been especially concerning for CVF and our vulnerable members. On this date, English and Welsh governments removed the requirement for face masks in healthcare settings unless there is a risk of splashing or known Covid-19 infection. This was the last Covid-19 measure to be removed. The experience and self-reporting of CVF members is that removal of masks was not consistent even across England, with some acute Trusts keeping masks for longer than others or have reimplement them during times of pressure.

a. England

In a letter sent out on 1st June 2022, NHS England updated its guidance to indicate that patients entering general practices no longer need to wear a face mask unless they have respiratory symptoms. This guidance underscored the importance of local risk assessments, allowing for increased measures when deemed necessary. Health and care staff were advised to continue wearing face masks as part of personal protective equipment when dealing with patients with suspected or confirmed COVID-19. This guidance also noted that

universal masking should be applied in situations like a known or suspected cluster of COVID-19 or during an outbreak or if new variants of concern emerge.

b. Subsequently, mask wearing and enforcement in healthcare was almost uniformly dropped, this was despite evidence showing that staff wearing upgraded face masks cut ward based infections to zero as seen at Addenbrooke's Hospital **[Exhibit CF/54 - INQ000408844]**. However, below are examples from across England where mask use was reinstated at different times:

- I. Winchester Today online confirmed that Hampshire Hospitals NHS Trust insisted that current Covid-19 restrictions will remain in place within its hospitals despite the Government lifting restrictions **[Exhibit CF/55 - INQ000408845]**.
- II. Chelsea and Westminster NHS Trust confirmed on 28 December 2022 that in light of significant rising numbers of Covid-19 they have taken the decision to reinstate mask-wearing in all areas **[Exhibit CF/56 - INQ000408846]**.
- III. University Hospitals of Derby and Burton saw mandatory face masks return to Derbyshire hospitals just weeks after rules eased, as discussed in this article in the Derby Telegraph **[Exhibit CF/57 - INQ000408847]**.
- IV. An article in Stoke on Trent Live dated 6 July 2022 talks about the Royal Stoke University Hospital and Stafford's County Hospital where face masks became mandatory again in all areas, including non-clinical areas, amid concerns about rising Covid-19 cases **[Exhibit CF/58 - INQ000408848]**.

c. **Scotland**

Unlike England, Scotland retained the use of fluid resistant face masks (FRSM) until May 2023 when they moved to risk assessments for PPE, as can be read in this article from The Pulse **[Exhibit CF/59 - INQ000408849]**. This change followed the World Health Organization's declaration on 5th May 2023, that the COVID-19 global health emergency was over. CVP members are concerned that despite calls to reinstate masks this winter, as of mid-January 2024, NHS Scotland have not done so, as demonstrated in this article in The Scotman,

'NHS Scotland winter crisis: Calls to reintroduce Covid 'pandemic-style' measures, including mask wearing, to save NHS' published 3rd November 2022
[Exhibit CF/60 - INQ000408851].

d. Wales

In Wales, the mandatory requirement to wear face masks in health and social care settings was removed on 30th May 2022. The decision to lift this mandate was part of the Welsh Government's response to an improving situation regarding COVID-19 infection figures and hospitalisations at the time. However since then mask mandates have been reimplemented across Wales at different times.

- I. An article in Wales Online published on 11 November 2022 demonstrates that mandatory facemasks were reintroduced to hospitals and GP surgeries in one part of Wales by the Betsi Cadwaladr University Health Board **[Exhibit CF/61 - INQ000408852].**
- II. An article published on 8th July 2022 evidences that mask wearing was reinstated at Glangwili Hospital as confirmed by the Hywel Dda University Health Board **[Exhibit CF/62 - INQ000408853]**

e. Northern Ireland

In Northern Ireland (NI), the legal requirement for wearing face coverings in healthcare settings was revoked on 15th February 2022 as set out in the Statutory Rules of Northern Ireland 2022 No.47 Public Health, The Health Protection (Coronavirus, Restrictions, Wearing of Face Coverings)(Revocation) Regulations (Northern Ireland) 2022 **[Exhibit CF/63 - INQ000408854].** This change was part of the broader lifting of COVID-19 legal restrictions in the region, shifting from mandatory requirements to guidance. CVF are not aware of masks ever being reinstated at any of the six Health and Social Care Trusts to date, which has made CVF members in NI particularly anxious when cases rise.

(Q46) Quote from CVF Member

“At one point, when masks were inconsistently applied across different hospitals, I realised that masks were withdrawn from my child’s paediatric department which is an immunology department. I was so worried about this, that I actually made enquiries about another hospital which still had masks in place. When I talked to this other hospital, they could not believe that our current hospital had removed masks. The nurse gave me the impression that they actually thought it was reckless.”

Cassandra, aged 34 years

131. Clinically Vulnerable Families polled our membership on 28th June 2022; with a response of over 500 members with 54% saying they had already delayed or cancelled a healthcare appointment due to high Covid-19 risks. In October 2022, we again polled our membership with a response of over 450 members with 91% saying they have or would delay or cancel a healthcare appointment due to high Covid-19 risks. In our November 2023 poll, which surveyed 827 CV people, 90% reported they have or would delay or cancel medical appointments due to high Covid risks. This percentage has remained remarkably stable when compared to the previous year’s poll, where 91% of 450 respondents indicated the same concerns.

(Q47) Quote from CVF Member

“I feel healthcare is no longer safe, now that masking has been removed, I find every visit stressful. I spend a week before and after feeling very anxious and worried. I can’t cancel appointments, I need my treatments, I still need facial surgery for my skin cancer, but I have delayed having a minor surgery to have my port removed. It seemed safer in 2020 because everyone was masked, there were more virtual appointments available, and the hospitals were much quieter.”

Juliet, aged 59

132. The consistently high percentage of CV people delaying or cancelling healthcare is clearly concerning as it can have serious consequences. This group often have more serious underlying conditions to begin with. The degree of those postponing or cancelling shows how risky the CEV/CV consider healthcare. CVF believe there is a need for

enhanced protective measures in healthcare settings which disproportionately serve more vulnerable people. Alternative healthcare delivery, such as telephone and online appointments, or increased precautions can ensure safe care for this high-risk population during pandemics or other periods of high-risk.

L. The Use of Clean Air, Especially in Healthcare

133. Covid-19 is an airborne virus, and the use of clean air and good ventilation has long been agreed upon. The government says it agrees with this in its Research Briefing on *'Building Ventilation and Covid-19'* on 18th May 2022 [Exhibit CF/64 - INQ000408855]. Despite this, as outlined above, many CVF members feel they cannot access healthcare and other public indoor spaces due to the lack of clean air. CVF is aware of this through the peer support conversations and informal 'focus group' style information gathering with its members, as set out above hosted online through its social media and support groups, rather than through quantitative analysis.

(Q48) Quote from CVF Member

"I haven't been for an in-person asthma review since 2019. I don't consider it safe to remove my FFP3 mask in a healthcare setting – even more so now that masks are no longer required for staff or patients and there's no guidance on clean air or filtration."

Jo, aged 47

134. There has been new NHS England guidance [Exhibit CF/65 - INQ000408856] on the use of cleaning air with HEPA just released on 9th May 2023. CVF strongly support this guidance. We completely agree with the statement from the document that: *'Ventilation* is an important line of defence for infection control in the healthcare environment.*

135. HEPA, 'high efficiency particulate air' (filter) are the recommended air cleaning filters. According to smartairfilters.com [Exhibit CF/66 - INQ000408857] they were *'invented back in the 1940s'*. 'They can capture viruses, bacteria, pollen, PM2.5, allergens, and more. HEPA air filters are the most important component of any air purifier'.

136. CVF has recently given a presentation to the Covid-19 Inquiry staff and are grateful for this opportunity [Exhibit CF/67 - INQ000408858].

137. CVF would support the use of HEPA filtration which removes Covid-19 and other respiratory pathogens, including for a future respiratory epidemic or pandemic, in all indoor public places, including but not limited to; hospital and GP waiting rooms, all hospital and GP consultation and treatment rooms, dentists and ortho-dentists, and community health providers such as podiatrists. We would like to see them in shops and pharmacies as well as theatres and schools. Some organisations already have good HEPA filtration which CVF welcomes.
138. The Houses of Parliament have installed a system that *'vastly improved upon the indoor air quality, ensuring that airborne viruses and bacteria were kept to an absolute minimum within the space'* as stated on their website **[Exhibit CF/68 - INQ000408859]**.
139. The Ministry of Defence has also insured it has clean indoor air: *'Towards the end of 2020, Purified Air was commissioned to supply the Ministry of Defence with our mobile virus irradiation units (VIU Mobile) to help reduce the spread of airborne Covid-19 the indoor environment'* as stated on their website **[Exhibit CF/69 - INQ000408860]**.
140. Other Government agencies also appear to be soon benefiting from clean air: *"Purified Air start year 2 of a national rollout: Purified Air are proud to be supplying, via a close partner, an arm of HM Government with virus control air filtration solutions. At the end of the first year, Purified Air provided over 1000 VIU Mobile Units alongside over 1000 Fan Coil UVGI 2L/4L units. These units were implemented to reduce the spread of viruses to both the public and employees within the space"* as stated on their website **[Exhibit CF/70 - INQ000408862]**.
141. CVF is pleased that the Houses of Parliament and some Government agencies and ministries have clean air installations but are sorry that the same technology has not been afforded to places that clinically vulnerable people attend, especially healthcare, workplaces, and schools.
142. Some parents have been able to purchase HEPA units out of their own budgets for their children at school. The issues with schools CVF hope to be able to share with the Inquiry in a later module. However, it is important to note there, that despite the government offering HEPA filters to schools, some schools have refused parents being able to provide HEPA filters for their child's class or school. This is hugely problematic for CV families, as this is one easy non-invasive way that infection risk can be substantially reduced.

(Q49) Quote from CVF Member

"I have bought one large unit, a 'Mini-Blast' as well as seven smaller units for use in my child's school. This is because it is an old building. It also helps to reduce viral and bacterial particles in the air to reduce infection for my clinically vulnerable child. Of course, it also helps to reduce infections, hay fever and pollution in the other children in the class as well as the education staff."

Kayleigh, aged 35

M. Access to Healthcare (with the risk of Covid-19 infection)

143. Ideally, CVF believe that it is important to protect vulnerable people in healthcare settings. We would therefore strongly advocate for the return of face masks in all high-risk healthcare settings, for both patients and staff.
144. CVF would like to see an improvement in indoor air quality especially in healthcare settings. CVF welcomes the new guidance from NHS England regarding improving ventilation in healthcare spaces. CVF would like to see both HEPA and mechanical ventilation improved (with HEPA added if possible).
145. Interim measures, as reasonable adjustments for Clinically Vulnerable People:
- a) Allow people to wear their own FFP3/FFP2.
 - b) Enable people at higher risk a way to easily request staff to wear masks (before their appointment).
 - c) Allow higher risk patients to wait in a different setting, e.g., in the car or in another room.
 - d) Monitor CO2 as a proxy for rebreathed air and respiratory virus risk in all healthcare settings. Make CO2 readings readily available to patients and their families.
 - e) Improve the waiting rooms – consider mechanical or natural ventilation and where not possible or where CO2 remains too high (over 1000ppm CO2), add a HEPA filtration machine.
 - f) Improve the consultation rooms – consider mechanical or natural ventilation and HEPA filtration.

- g) Staff working in setting with clinically vulnerable patients all wear FFP2 masks or if symptomatic, or not symptomatic and at the request of a patient does a LFT.
- h) Offer higher risk people the first or early appointment in the day.
- i) Offer a digital option to people who prefer it and for whom it is acceptable on a clinical basis.

CVF Member V – Case Study

A severely immunocompromised patient, due to blood cancer and chemotherapy, who also suffers from severe asthma has had various healthcare experiences that they wanted to share with the inquiry.

Prior to the pandemic their GP proactively treated infections and asthma which avoided severe outcomes including hospitalisation. In May 2020, their asthma deteriorated and since they were too frightened to attend A&E and GP would only offer telephone advice. This culminated in an emergency hospital admission where the patient requested protection, which would not have been automatic, they were able to be treated in a side room with mask-wearing staff.

In June 2022, they collapsed with a suspected stroke. An ambulance was called but took more than 4 hrs to arrive. At the hospital there were 8 ambulances waiting to offload patients, but due to the severity of their situation they were prioritised. On arrival in resus there were a number of people without masks due to a change in hospital policy. The patient was alarmed and due to their condition was initially unable to communicate their fear and was instead labelled 'uncooperative'. Only on the intervention of the ambulance driver were they moved to a side room due to their high Covid risks. Subsequently it was suggested that they would be admitted to the hospital and treated on an open ward. The patient was able to use their one functioning hand to type on their phone:

"You will kill me if you give me covid. I refuse to consent to be put at risk in an open ward. I need a side room to keep me safe. I would rather die at home from a stroke than in hospital from covid."

Only when the staff were made to make the choice between sending them home to potentially die and offering appropriate protections did they make alternative arrangements. The patient was left feeling unsupported by the NHS due to the ambulance delay and the lack of any policies to protect their vulnerable patient which they feel has compromised their ability to access the care they require in an ongoing way. They now feel traumatised by any visit to hospital since there is no certainty that protections are in place for airborne infections such as Covid. They are not confident that they can reasonably expect to be kept safe. Previous experiences of being left in waiting rooms, unable to move themselves independently, surrounded by unmasked symptomatic patients with poor ventilation have only heightened their anxiety.

They have been refused face to face appointments when both they and the doctor felt it was needed and also been require to attend hospital when face to face was not necessary. It seems these decisions are being made by managers rather than on based on needs and risks. Since the 'Learning to live with Covid' policy the burden has shifted onto each individual patient to manage their own risk, even in a healthcare environment. Their experiences in both acutes setting and outpatients have highlighted the lack of public health measures to prevent airborne infections. They feel that patients must not have to constantly request that each professional wears a mask or have to consider aspects such as ventilation in these settings.

146. Again, CVF draws the following input to the Inquiry from its peer support conversations and consulting with members hosted online through its social media and support groups rather than through quantitative analysis. CVF stress that its members' experiences are representative of the wider CV/CEV population (as indicated in the similarities of the CVF membership with the CV/CEV experience disclosed in the CQC report) but that it has not attempted to carry out a population-wide survey of CV/CEV experiences. Indeed, we consider that this is something that the Government ought to have been doing in order to understand our experiences. We have however attempted to consolidate our groups' experience as much as possible in order to assist the Inquiry, as set out at the outset of this statement.
147. Broadly, CVF members reported difficulties with accessing their usual care for their underlying conditions, especially during the early part of the pandemic. This was, in part, because some clinicians were re-directed to alternative departments. Later, general accessibility to medical appointments has become more challenging, with lack of access reported widely to primary care (General Practitioner (GP)) appointments as well as significant waiting lists for hospital treatments.
148. Some CVF members, particularly those with significant underlying conditions report preferring the 'digital first' approach to healthcare consultations, preferring video and phone calls. This is not true for everyone however, underlying the importance of the personalised approach to healthcare.
149. For some CEV/CV people within the CVF membership their usual care was developed into a more convenient, accessible form during the pandemic. For example, some CVF members reported that injections that could only be given in a hospital setting were now able to be given at home by themselves.
150. Many CVF members simply did not access healthcare and that continues up until today. The quotes below (Q50, Q51) is indicative of the type of feedback our members gave us about avoiding healthcare due to fear of Covid-19. Hospitals and other healthcare establishments remain one of the locations with the greatest risk for Covid-19 infection because, for obvious reasons, they are populated with potentially ill people.

(Q50) Quote from CVF Member

"I put off going to the GP about my sinusitis for a whole year and had been using over the counter decongestants to manage my symptoms. Things got really bad, and I had constant nose bleeds and sinus infection so I eventually had to go. I needed to be examined and had to remove my mask. I was in absolute terror leading up to the appointment and for the whole ten days after, scared I'd caught Covid. . . . I have to go hospital appointments and the pharmacy regularly and each time I do this I'm the only one in a mask. It's terrifying and frustrating. This shouldn't be my responsibility to be making sure these settings are safe to breathe air in, but no one else cares so I have to do this."

Hannah, aged 27 (diagnosed with type 1 diabetes)

151. Some CVF members, such as the experience of the anonymous member quoted below at Q51, indicate that concerning, they have been discharged from both medical and dental clinics due to the period of shielding and non-attendance and, in some cases, their ongoing concerns at attending in-person healthcare. CVF would encourage all healthcare providers to put into place infection control for CEV/CV and Severely Immunosuppressed people and also to consider employing alternative solutions such as digital before discharging the person.

(Q51) Quote from CVF Member

"Accessing healthcare has been and continues to be an utterly terrifying experience, which has now become considerably worse (with the increased lack of masking or any sensible precautions in place). We have had to postpone multiple appointments and balance up the risk of attending and being exposed to Covid versus our need to see a consultant. We have been thrown off clinic lists, because by us delaying attending we were affecting the hospital's statistics. Totally unforgivable to force someone with a serious and complex medical condition out of healthcare".

Anon, aged 40

152. People who are at higher risk of Covid-19 infection have been traumatised both by the effects of shielding / not being shielded (for both CV and also the CEV outside of the times of shielding) especially for those working in the front lines, (and the other issues

mentioned in this statement) and potentially, for some, the lack of response to vaccination. To add to this, there is now significant trauma faced by this population that many of them feel they can no longer access safe healthcare.

(Q52) Quote from CVF Member

“Frightened to attend appointments. Do all I can to have via telephone. Am anxious about them and have had awful experiences with staff attitudes to wearing masks. Avoid and delay appointments that I don’t think are urgent. Illnesses are bad enough but attending healthcare settings is causing great distress for weeks before and days after.”

Karen

153. CVF have carried out multiple polls on clinically vulnerable people delaying medical appointments. These polls were conducted via social media and are not the subject of separate CVF reports.

- a. a poll of over 500 CVF members on 28th June 2022, showed 54% had already delayed or cancelled medical appointments due to Covid risks.
- b. The same poll showed that 86% had or would delay medical appointments due to Covid-19 risks.
- c. In October 2022 a poll of 450 CVF members showed that 91% have or would delay or cancel medical appointments due to Covid risks.

154. With the final removal of masks from healthcare, in May 2022 in both England and Wales, persons who remain at higher risk are understandably concerned that by entering a hospital, which is, after all, a high volume indoor and potentially poorly ventilated space, they may become infected with Covid-19 and suffer the poorer outcomes. In fact, for many people this has been their experience. At all points during the pandemic the clinically extremely vulnerable and clinically vulnerable are more likely to need healthcare than the general population.

(Q53) Quote from CVF Member

“Accessing healthcare in the present, as opposed to before the pandemic, is extremely precarious. I contracted Covid-19 during a hospital appointment despite diligently wearing an FFP2 mask, primarily due to the government’s policy on mask removal and the emphasis on personal responsibility. The individual sitting next to me was not wearing a mask and unbeknownst to me, was Covid positive. Subsequently, my consultant intervened and requested the Covid positive person to relocate to a separate room, expressing profound apologies for the situation. The consultant was aware of my compromised immune system and the high likelihood of me contracting the virus. Unfortunately, two days later, I tested positive for Covid-19 and eventually had to be hospitalised due to complications arising from the infection. Currently, my approach to attending medical appointments involves making phone calls beforehand to ensure that the medical staff will be wearing masks . . . To further safeguard myself I rely on products like Viraleze and imported VirX nasal sprays, along with upgraded FFP3 masks. I also carry a portable HEPA air filtration system for added protection.”

Lee-Anne Kohli, aged 47

N. Inequalities experienced by the CV and CEV in accessing healthcare during the pandemic

155. As we set out below, there have been multiple inequalities experienced by the CEV and CV during Covid-19 and ongoing in healthcare as these groups have been treated differently to non-CEV and CV people. This group, who already are likely to have poorer health and need relatively more healthcare, are particularly vulnerable to changes in healthcare policy.

156. People who have certain underlying conditions such as asthma or COPD, or inflammatory illnesses such as lupus or bacterial infections are likely to have an associated cough or a fever. However, due to the rules in force at the time, often these vulnerable people with those symptoms were co-located with Covid-19 positive ward areas in case they had Covid-19. This unfortunately, meant that many of them then subsequently caught Covid-19. As indicated in the quote below (Q54), CVF members

have experienced this. It is difficult to estimate a number of CVF members who caught Covid-19 in these circumstances, as CVF have not put this specific question to its membership, but CVF understand from self-reporting that it was not an uncommon experience.

(Q54) Quote from CVF Member

Attended A&E March 2022 with chest infection/severe asthma and was placed in COVID positive resus despite testing negative 3 times that day (LFT and PCR). Tested positive a week later, remained in hospital for the next 3 months. Had lots of complications due to Covid. Tested positive for Covid for the following 10 weeks, and was consequently in isolation for the whole of the time, which had a huge knock on effect on my family. Finally made it home, but not been the same health wise since.”

Michelle, aged 47

157. By mid-March there was evidence that 111 was already stretched. Some vulnerable people were waiting a long time on 111 with no evidence of prioritising people at higher risk of poorer outcomes to Covid-19. Indeed, the Health Services Safety Identification Body, as confirmed by their website [**Exhibit CF/71 - INQ000408863**], have carried out an investigation into some of the issues and delays from March-June 2020. This investigation highlighted that some of the advice for patients had the alternative effect and prevented them from seeking help early enough. They also found that by redirecting the public call NHS 111 rather than access healthcare in other ways (for example, through GPs), *“increased capacity in the wider healthcare system, but risked disrupting continuity of care for patients with complex health needs”*.

158. There was also a risk that people who were trying to access treatment for another illness were assumed to have Covid-19 yet it was actually another infection, e.g., bacterial. In some cases, this delayed or blocked the correct timely treatment. The quote below (Q55) exemplifies this point. Again, CVF did not conduct polling of its membership on this point but heard self-reports of a number of similar cases.

(Q55) Quote from CVF Member

“Both my husband and I had been shielded for a few weeks when my husband got a high temperature of over 39 degrees. He is prone to sinusitis and he looked like he had that. We had not been outside the house or seen anyone else since we’d shielded. He phoned 111 and was immediately triaged as having Covid-19. This was despite him explaining the situation multiple times. He is immune suppressed so more prone to severe bacterial infections. I was so worried he wasn’t going to get any antibiotics at this rate. Eventually we managed to get through to someone who seemed to listen. He said he was going ‘off protocol’ as everything was Covid-19 but we got some antibiotics, it felt we might not for a while. My husband recovered within 48 hours”.

Sarah, aged 50

159. CVF members’ experience was that people attending hospital who had a fever for any reason (including their usual long term condition flare up) were immediately put with other feverish patients many of whom had Covid-19. This was obviously very risky for people who were shielding/CV who did not have Covid-19 but were cohorted with patients who did have Covid-19 on the basis that they had a fever of a different cause.
160. Private hospitals, were, and still are, offering some relief to some shielded people especially for outpatient appointments and procedures and planned care such as operations but were not taking people with fevers as inpatients even if Covid-19 negative on PCR. We discuss the use of private hospitals and reasons for this further below.
161. Vulnerable children who needed to access healthcare had many of the same issues. It often felt unsafe especially after masks in healthcare were withdrawn in May 2022. Young children generally cannot wear masks and so have greater risks of infection. There is the added issue with children who are admitted to hospital of their parents being able to stay with them. This was a concerning situation for both parents who were at higher risk and children. It often meant that CVF members tried to delay, postpone, or cancel these appointments.

O. Private Healthcare – no longer a choice?

162. Many CVF members feel they've had no choice but to access healthcare through private hospitals as they believe the NHS is unsafe due to risks of nosocomial infection.

(Q56) Quote from CVF Member

"I had to go private. I collapsed at home with severe jaundice, itching and pain. GP sent me to A&E where I was sat in the main waiting room with people with Covid etc. Scans showed gallbladder problems. Weeks later and getting worse my husband decided we needed a referral to go private as the NHS were leaving me to die. My new private doctor pulled me in urgently to prevent further catastrophic incident. This was in June 2022. Further treatment November 2022 and self paid for cholecystectomy in January. Still no support from NHS. The financial burden is that we have no savings left, at all."

Andrea

163. Often the choice to use private healthcare is at the risk of a large financial outlay. Given many CEV/CV and severely immunosuppressed cannot work, not least because of the of the ongoing risks of Covid-19 in workplaces and the lack of reasonable adjustments. This, therefore, was not an option available to most people,

(Q57) Quote from CVF Member

"I took early retirement, so my private health insurance stopped. I decided to pay myself, which this year was over £6k, which is a very heavy financial burden. In 2021 I had to have a new heart valve and pacemaker and I simply would not risk an NHS hospital. The special measures the hospital took were brilliant. I've also recently had hand surgery too and the limited contact, private room and personalised treatment, i.e.; they wear masks on request, no crowded waiting rooms, makes it worth it to me. Of course, private health does not cover chronic conditions and NHS hospitals and waiting rooms continue to frighten me, so I minimise attendance.'

Sarah, aged 56

164. Some CVF members have accessed Evusheld privately as well as private antibody tests to check their immunity to vaccination.

P. The Devolved Nations

165. CVF have members across the four nations. All of our members' experiences broadly reflected the themes we have set out above in this statement. Although the precise timings of lockdowns, shielding and other non-pharmaceutical interventions may have differed slightly, the overall themes and fundamental lack of consideration for the clinically vulnerable remained sadly consistent. We do not hold the best expertise about the precise timing of the transitions of guidance and policy across the four nations and therefore have not attempted to set this out here.³

Q. Vaccination

Access to vaccination

166. CVF have been designated as Core Participants for Module 4 of the Covid Inquiry. We will therefore submit the evidence of our lived experience of vaccination for that module. However, for this module, we have covered what we think pertains to CV / CEV and severely immune suppressed people specifically in the context of healthcare specifically. We have much more to share on this subject in due course.

167. Some people, despite being on all the correct NHS lists were/are not invited for vaccination. This causes a lot of distress and confusion, and the person often then must spend many hours trying to sort it out, just to enable them to access a vaccine.

(Q58) Quote from CVF Member

"My husband is supposed to be red flagged for vaccinations. He hasn't once been called by our GP, not even for 'flu jabs, when others with no health issues, have. They can't explain their system."

Norma, aged 75.

168. People at high risk of Covid-19 infection felt that they had a high risk of becoming infected with Covid-19 during vaccination in vaccination hubs as demonstrated by this email between a member of CVF and a hospital's Patient Advice & Liaison Service sharing such concerns [**Exhibit CF/72 - INQ000408864**].

³ We note that, following the Inquiry's requests, we have created devolved nations focus groups within our membership to draw on and may be able to add more specific information about these groups in the future.

169. People often reported early vaccine hubs as being over-crowded, and not properly distanced. In recent times, with subsequent vaccination booster offers, there has been the dilution or complete removal, of all protective measures. There is often now inconsistent or absent mask wearing. Some geographical areas have no staff or patients wearing masks, whilst others are still asking staff and patients to mask.
170. By May 2023 and the Spring Booster Campaign, most areas are now no longer masking and people at high risk of Covid-19, and especially the Severely Immunosuppressed, who are the exact people who need to access vaccination, feel they are being put at additional risk. There is often no requirements for staff or patients to mask with FFP2 / 3 respirator masks or enhanced ventilation and air filtration with HEPA. Communication was poor, and some people chose not to be vaccinated who are eligible due to the risks of catching Covid-19, with clear potential negative consequences for this high-risk group.
171. In the initial vaccination campaign in early 2021, it was apparent that some geographical areas were much slower than others, demonstrated in this email from a member of CVF to the Clinical Commissioning Group re vaccinations [**Exhibit CF/73 - INQ000408865**]. Some shielded people had to travel a substantial distance in order to receive a vaccination. One of our members had to travel over 140 miles round trip in January 2021 whilst still shielded to be able to access a vaccine. This created additional stress and transport issues, and clear inequalities.
172. Many CV/CEV and severely immune suppressed people have various underlying conditions and medication that can interact with vaccinations. Some people are unable to take the vaccination due to previous anaphylaxis to vaccination and this leaves them in a very precarious position. These people need a prophylactic treatment such as Evusheld as well as many non-pharmaceutical protections as possible, especially in indoor settings, such as healthcare, education and workplaces.
173. Quite often there isn't very much information available to people which vaccination is available, where and when. This can make it difficult for people to book.
174. One of the greatest difficulties with the vaccination programme for CVF have been the changes to the eligibility criteria. The data shows that some people who are at higher risk of mortality and severe illness, such as diabetics, hypertensives etc are not eligible for vaccination in some booster campaigns, meaning they only have boosters less often and

when immunity may have waned. People who are severely immunosuppressed are also concerned that their family members who live with them, cannot always access booster vaccinations.

Vaccination for Children

175. CVF are aware that vaccination will be covered fully in Module 4 and we are delighted to have been designated as Core Participants. However, where vaccination relates to the CV and CEV we have included a couple of important experiences from our members.

(Q59) Quote from CVF Member

"I had a massive battle to try and get my CV (clinically vulnerable) son his vaccine as he was 14, and the government prioritised healthy 18-year-olds over a vulnerable child. I wrote to everyone in authority I could think of and got nowhere. It was horrendous. That affected my mental health more than anything. The medical professionals couldn't quantify his risk but equally didn't want to stick their heads above the parapet and say he could get a vaccine. I then had to fight for his brother who is a young carer to get one as well – his anxiety was through the roof at 15 at being forced back to an unsafe school environment and he was terrified of catching Covid and bringing it home to kill his mum and brother. The fight for paediatric vaccines was just an horrendous time. To know the government aren't interested in your vulnerable child was awful – but it was a portent of the future as now all CV/CEV are in that position." (May 2023)

Mary, aged 50

(Q60) Quote from CVF Member

“As my vulnerable child was under 5 years old and due to start school at 4 years old in September 2022, I felt very worried that there was no vaccination available for this age group. This is not to say there was not a vaccination available, in fact Pfizer by then had a vaccination for under 5’s which was used in the US and other countries such as Germany. We decided to take our daughter to Germany for vaccination through an organisation set up by the German people to help people like us to access vaccination for our child. The vaccination itself was free. I had to contact a coordinator group who informed us of everything. All we had to do was book our travel and accommodation. We have returned to Germany on three occasions to vaccinate our child. Our child suffered no side effects and started school. Despite being vaccinated, our child caught Covid within 6 weeks of starting school and was quite poorly with it. However, he was not admitted to hospital and for that I am surely grateful to the vaccination. I know of many other parents of children under 5 years who have travelled to Germany for their compassionate vaccination programme. However, it’s such a crying shame this could not be done in the UK.’ May 2023

Maria, aged 39

R. Covid-19 Antiviral Treatments

176. CVF understands that antiviral medication will be fully covered in Module 4. We will therefore only address that relating to the CEV/CV and Severely Immunosuppressed. We have much more information to share on this subject and are delighted to have been designated as Core Participants for Module 4.
177. CVF know that many, many of our members people who are eligible for antivirals struggle to get access to it within the required 5-day period. Again, this information comes from the informal peer support CVF offers its members, including advocating on anti-virals specifically, and from the discussions which have been reported to CVF through its social media channels. Often no one knows who to contact to get the medication. Often the GP refers to 119, 119 refers to 111 and 111 refers to 119 or back to the GP. Some patients do not know how to register a positive test online or do not have access to the internet, or

the digital 'know-how'. This creates health inequalities in access to antivirals as there is not an equivalent phone number to call to notify someone you have a positive test.

178. When the antiviral pathway first began it was based on a PCR test. This added an additional layer of complexity as it was often difficult to get the test done, posted and a result all within the five days. Quite quickly it was changed to a positive Lateral Flow Test (LFT). People eligible for Covid-19 treatments can order LFTs online but only for their own use. This is so they can access treatment.
179. However, this means they cannot use LFTs to follow the Government Guidance 'Covid-19: Guidance for people whose immune system means that they are at higher risk' updated 21 September 2023 [**Exhibit CF/74 - INQ000408866**], and ask their visitors to test before visiting them. They even cannot use them for their carers to test. This means vulnerable people often must purchase additional LFTs for their guests or carers.
180. CVF have supported many people who have reported their LFT but then hear nothing. They are already feeling unwell, and the onus is then on them to 'chase' it up. Currently, people are referred to the Covid-19 Medical Decisions Unit (CMDU) where a decision is made if the eligible person is still eligible for treatment. This is quite often not the case and perplexed and confused people are left without treatment.
181. The eligibility for antivirals has constantly changed. Many previously CEV are still excluded from accessing them and many Clinically Vulnerable have never been eligible but would benefit from being offered them.
182. CVF are of the view that the list of eligibility is particularly limited, especially given the underlying conditions and age profile of people admitted to hospital and sadly dying of Covid-19. We would welcome an increase in those eligible for antivirals.
183. Often the CMDUs are not open at weekends or on bank holidays which was a huge concern during long bank holiday periods over Easter or Christmas. This can eat into the five-day pathway quite a lot resulting in many patients falling outside of the timeframe by the time they were referred. It is also known that the earlier you can access the antivirals the better.
184. Some providers, presumably due to the high numbers of patients, especially during 'waves' of Covid have changed the 'window of treatment' to seven rather than five days. CVF are concerned this is not the best clinical protocol for patients.

185. Eligible patients have no ability to have them 'in advance' e.g., for holiday etc. This means they are often worried to go abroad as they would not be able to have them in advance. This is in an inequality as it means Clinically Extremely Vulnerable people and especially the Severely Immunosuppressed often do not feel able to holiday as the rest of the population, save for access to antivirals. CVF would like this to be addressed, for antivirals to be available to patients to take with them on trips abroad (including visiting relatives or for business etc). CVF would also support the move to allowing antivirals to be available for private purchase from pharmacies, along with Covid-19 vaccination (as with Influenza vaccination).

186. The communication to patients throughout for antivirals has been poor; it has been complicated, confusing and conflicting. Added to the constant changing of eligibility groups means people are very confused.

187. A sample of CVF members' antiviral experiences as case studies discloses:

CVF Member B – Example of influencing access to antivirals

It became apparent through the group that people were struggling to get their antivirals within the critical 5 day window. Through internal analysis of cases we were able to establish that there were several barriers along the pathway.

1. Having to wait for a postal PCR to be processed, rather than using a positive lateral flow test (LFT).
2. Contacting the GP
3. Referral to the Covid Medicines Delivery Unit (CMDU) to assess
4. Waiting for a call back from CMDU

We were able to influence points 1 and 2. In terms of 1 we recommended that LFTs were accepted in place of PCRs. This was accepted shortly thereafter. For 2. We were able to influence the NHS to design a form that sits within the e-consult system which enables high risk patients to inform their GP of a positive LFT electronically therefore reducing the phone barrier whilst people felt unwell. It also reduces the time for this step within the critical 5 day window. There was an alert put on the e-consult system to enable the GP to see that an urgent request for antivirals had been logged and to enable them to prioritise that referral.

CVF Member M – Case Study

“M” was 58 years old when he was first diagnosed with a blood cancer, chronic lymphocytic leukaemia (CLL). He was reassured however that, although his condition required chemotherapy, it was very treatable. A plan was made for a six-month regime of IV and oral chemotherapy, after which it was expected that he would be able to return to his work as a social worker for kids in a residential setting, and life as normal.

His family understood that both his condition, and the chemotherapy to treat it, put “M” at increased risk from covid. Having found information that blood cancer patients were less likely to produce antibodies to the covid vaccines, his daughter purchased an at-home antibody test kit which found he had indeed not developed an immune response. However, “M” was an otherwise very healthy and fit man; he chose to be careful in light of this information - wearing masks in public places such as shops, and for the most part avoiding busy restaurants for example - but he didn’t wish to isolate himself.

At the end of January 2022, “M” finished his course of chemotherapy. He posed for a picture with the cancer nurses “ringing the bell” to mark the end of his treatment. Nineteen days later, he tested positive for covid.

His family were concerned given their knowledge of his vulnerability. They understood that clinically extremely vulnerable patients like him were eligible for antiviral treatments given within the first five days of testing positive, as a prophylactic measure to reduce the severity of their symptoms. Immediately they began researching means of contacting somebody to ensure he received the recommended treatments. The 111 service was “too busy” and the automated message told callers to find answers to their queries online. One call to the out of hours line for “M”’s local haematology department, led to them being informed that he did not require antiviral treatments unless he became “very unwell”. The 119 line informed them that should his PCR test be positive, his status as CEV would automatically be flagged up and “M” would be called to assess his eligibility for prophylactic treatment.

The following day the PCR test did indeed return as positive, and as promised “M” received a call from the local CMDU shortly after. By this time his partner had also tested positive, and the both of them were feeling quite unwell with flu-like symptoms of coughs, aches and tiredness. “M” was asked by the CMDU how he was feeling; being a typical stoic man, and believing that his symptoms - rubbish as he felt - were no worse than an especially bad cold

or flu, his answer was that he didn't feel too bad. For this reason, he was informed that it was not necessary that he receive treatment at that time. He did receive follow-up calls in the subsequent days - his symptoms appeared to be easing and so, as he was ascertained to be "improving", again he was advised antiviral treatment was unnecessary.

Over the following weeks "M"'s condition waxed and waned. For the most part, his symptoms were still mild to moderate, but by early March he was experiencing more and more significant bouts of breathlessness. He was admitted to the hospital for the first time in early March, where he spent five days being treated for pneumonia. After discharge, he failed to improve at home, and was re-admitted a little over a week later for a further five days.

Another couple of weeks later again "M" returned to hospital, and this time spent two weeks hospitalised. He improved significantly during this stay, and on discharge felt very well, but within a couple of days found it incredibly difficult to even use the stairs, and the pulse oximeter he was provided gave oxygen saturation readings in the low 80s, which are remarkably lower than a usual, healthy, reading. "M" returned to A&E to be admitted for the fourth and, it would turn out, final time, on 11th May.

It was during this time that it quite quickly became apparent that "M"'s condition was quite serious. By this time, a multi-disciplinary team of medics was discussing his case frequently. A week after his admission he was sent to ICU where he was put on CPAP and, initially, his condition improved. After returning to the main ward however he deteriorated again and returned to ICU. Different treatments with very limited evidence of their use in such instances were implemented, including sotrovimab (a monoclonal antibody usually used prophylactically shortly after a positive covid test result), antivirals, and immunoglobulins.

Unfortunately, despite the best efforts of the medical teams, on the 1st June "M" and his family were told by medics that there was nothing more that could be done. Mechanical ventilation was deemed not to be in "M"'s interests as his lungs were damaged beyond repair and even if he survived, would be dependant on invasive oxygenation permanently. After withdrawing medications and oxygen on the 4th June 2022, "M" passed away with his family present in ICU.

S. Covid-19 Preventative Treatments (Evusheld)

188. Evusheld is a prophylactic treatment for Covid-19 composed of monoclonal antibodies that can protect people at higher risk of Covid-19 and especially those who have had a poor response to vaccination. We have noticed that Evusheld or the 'prophylactic' class of drug has not been mentioned yet in the inquiry possible list of future modules. We believe prophylactic therapeutics such as Evusheld to be a very important part of the Inquiry's lines of inquiry.
189. Evusheld was initially found to be effective against variants and was approved by the MHRA on 17th March 2022. However, unlike vaccination, it was decided in the UK not to expedite the decision to allow Evusheld to be used as detailed within The Long Shot: The Inside Story of the Race to Vaccinate, by Kate Bingham & Tim Hames, published 20th October 2020, page 178 to 179 [Exhibit CF/75 - INQ000408867]. This is despite it being used in the US, Germany, Poland and France.
190. People who are Severely Immunosuppressed who have not had a satisfactory response to Covid-19 vaccination are eligible for Evusheld. However, in the UK it was never been provided on the NHS.
191. Instead, people have had to travel to access it, sometimes to foreign places as experienced by some of CVF's members.
192. Many Severely Immunosuppressed feel completely let down unable to access this treatment, affecting every area of their lives. They still feel 'stuck' in 2020, when the whole country has otherwise 'moved on'.

(Q61) Quote from CVF Member

"Partner and I both immunocompromised and don't respond to vaccines. Feel totally abandoned and also playing Russian Roulette with hospital appointments trying to second guess whether or not getting treatment and tests is more dangerous than potentially getting Covid. Pick your poison. Daughter turns 18 tomorrow. We've spent 3 years shielding from her in our home so she can lead a relatively normal life. Heart-breaking for u all. Worse thing is apparently seeing kind, rational friends and colleagues skipping along to the government tune that Covid is over."

Sally, aged 55

(Q62) Quote from CVF Member

“Initially I felt safe and protected when restrictions lifted, I felt abandoned and unsupported especially as I am part of the cohort that cannot respond to vaccination. When Evusheld was approved by MHRA, I was elated but devastated afterwards when I realised that NICE hadn’t yet approved it. I still feel let down, ignored and dismissed. There are insufficient guidelines for employers and also for our hospital consultants. I had an infusion today and chatting to the ward sister about Evusheld etc she said about half of her former shielded patients are still shielding and she can see their mental decline.” (May 2023)

Melanie, age 53

T. Current Situation

(Q63) Quote from CVF Member

“Who knows what the future holds for CEV. Catching Covid for CEV is gambling with CEV lives. Will we be OK or not?”

Victoria, aged 50

193. Currently people at higher risk from Covid-19 infection are frequently feeling ‘let-down’ by society as they are left alone to assess their risks and exercise their personal responsibility.
194. There is an increase in mask aggression/abuse with a recent poll by CVF showing that, including all mask wearers, 48% have experienced this and that specifically CVF members had experienced mask aggression in 55% of occasions (77 out of 139 people).
195. Despite there still being clear government guidance [Exhibit CF/74 - INQ000408866] because there have been no public communications, it is now very much the responsibility of each higher risk individual to explain the situation. This is both exhausting and draining. People feel excluded from society.
196. People are responding with their own ‘personal responsibility’ solutions. These are not perfect but are helping some people to manage their risks and give some control over their lives.

(Q64) Quote from CVF Member

“Waiting rooms feel like particularly risky areas, and I try to avoid them as much as possible. When I have had to attend a UTC for my child, they have allowed me to wait in the car and phoned me when it was our turn, which was very helpful”.

Millie, aged 41

(Q65) Quote from CVF Member

“I mostly feel misunderstood’. Because ‘Covid’s over’ is everyone’s battle cry, it’s humiliating and exhausting trying to explain that it’s not over for everyone. As well as the sensible stuff like mandatory masks in medical settings, I honestly think we desperately need some sort of public awareness campaign, to educate the majority about the situation that we are in. Just to inform people that we are not lunatics, to some the threat is as real as it ever was.”

Lisa, early 50s

U. Additional Costs for People at Higher Risk From Covid-19 infection

197. Vulnerable people with a higher risk from Covid -19 infection are not provided with protective masks (FFP3). They can be quite expensive to buy and so this can create a health inequality for people who cannot afford them.
198. People at high risk are purchasing other items to try to create a safe environment. These include various nose sprays both from the UK (Nasalese **[Exhibit CF/76 - INQ000408868]**, Viraleze **[Exhibit CF/77 - INQ000408869]**) and those from abroad (Enovid, VirX **[Exhibit CF/78 - INQ000408870]**). People also have invested in portable HEPA filters **[Exhibit CF/79 - INQ000408871]**. All these things are additional costs that must be afforded.
199. People are often purchasing HEPA units for their homes; a unit can be anywhere from £80 - £700 depending on the model and space needed to be covered by HEPA filtration. HEPA units also have filters that need to be changed regularly, another significant ongoing cost (approximately £20 - £70 per filter depending on the model).

200. Many people no longer use or buy Lateral Flow Tests (LFTs). The burden of members of our group is often to buy LFTs for their visitors, adding to their costs [**Exhibit CF/80 - INQ000408873**]. Opening windows in colder weather, even a small amount can mean you need to increase your heating, again another increasing expense for our members. In addition, not everyone who is at higher risk qualifies for free LFTs; it is only those who are on the eligibility list for antivirals who qualify.
201. CVF understands that with the changes in the anti-viral pathway for high-risk patients, where currently all medication is provided by the Covid-19 Medical Decision Unit (CMDU) will now be provided by local systems and possibly by Community Pharmacy. We understand that there will now be a prescription cost for people to pay who need to access these therapies because they are higher risk. This is an additional cost on people at higher risk of Covid, another health inequality.
202. CVF hope it is seen that there is a substantial increased cost emanating from being CV/CEV or severely immune suppressed. At a time, when many of our members have also had to leave their jobs due to the lack of Covid 19 Health and Safety practices at work or the lack of agreed reasonable adjustments to make the workplace safer for these individuals, they also have increased costs to find from a lower income.
203. Some CVF members have felt they have had to access private healthcare due to having no choice as the NHS was unsafe. Some members are insured and facing higher premiums for using their insurance but many are not and are spending large amounts on private healthcare.
204. A small proportion of severely immune suppressed privately purchased Evusheld at the end of 2022 because it was not made available through the NHS and it was the only option available. This cost approximately £1500-2000 and included the medication cost and the physician cost. Often people had to travel some distance to get to a healthcare unit that was providing Evusheld. A CVF member provides evidence of their invoice for their Evusheld injection which confirms the total prescription cost as £680 [**Exhibit CF/81 - INQ000408874**].
205. A small proportion of families (mostly who have a clinical vulnerability themselves or in their households), travelled to Europe and the USA up to three times to complete a course of vaccination for their children. Although the vaccination was free under compassionate vaccination programmes, the accommodation and travel costs have to be found This resulted in another inequality for those who either not aware of this route or

could not finance such trips and had to wait for UK vaccination as families were frequently still shielding and with their children trapped out of schools or forced to take risks in often completely unmitigated school environments.

206. There is a substantial additional financial burden on the CV/CEV/severely immune suppressed.

V. Patient Engagement

207. At no point during the pandemic have the CEV/CV or severely immune suppressed been asked their views formally by the government. Although CVF have at various times engaged with parts of Government, Parliament and other bodies to advance the views of the CEV/CV or severely immune suppressed, our work as an independent, voluntary support and advocacy group necessarily has not been able to engage and lobby the Government comprehensively on every issue of importance to this wide group. Nor have opportunities been given to facilitate this or engage directly with decision-makers.

X. Lessons Learned for Future Pandemics for Individuals in 'High Risk Groups'

208. Shielding was neither good nor bad. It had positive points within it that could be used to design a future response to protect the most vulnerable in society. Shielding was helpful in that it meant people with high risk of poor outcomes to Covid-19 could work from home or not work, if in a public facing job. Shielding also benefitted people to access food and medicine. However, shielding did create an inequality with some vulnerable groups (such as the Clinically Vulnerable) who were not shielding and who received none of the protections. *For example, diabetics and people with COPD were not included in the shielded list and therefore had no protections.*
209. Protections need to be offered to family members of those shielded. For example, non-shielded family members still had to attend work and school as usual even if in high-risk public jobs and therefore had a higher risk of infection, which in turn they would bring back home and put the vulnerable person shielding at risk.
210. There needs to be better identification of vulnerable people based on early scientific evidence. There needs to be good communication to people at high risk with information on how to reduce their risks. This includes education on issues such as masks and ventilation/HEPA.

211. Clean air needs to be a priority now, to protect those at higher risk against Covid-19 now but also in the future (everyone ages) and to guard against future pandemics. Government needs to bring out standards for clean air in public buildings, workplaces and education establishments. Both mechanical ventilation and HEPA can be used.
212. Financial support needs to be offered, to offset the costs faced by people at higher risk of Covid-19.
213. Social care and mental health support needs to be available from the start of the pandemic or risk period, all the way through. Rehabilitation should be offered to people who were shielded, including from Covid-19.
214. The pandemic highlighted the need for better coordination and data sharing among government agencies, healthcare provider and other relevant stakeholders, such as supermarkets.
215. Healthcare needs to be a safe place for people at higher risk of Covid-19 with protections such as clean air (e.g., HEPA filters); high filtration masks (FFP2/FFP3); and use of Lateral Flow Tests on admission (just as we currently test for MRSA). This is relevant now, in 2023 and will stand us in good stead for any future pandemics.
216. Accessibility of healthcare: Many clinically vulnerable individuals faced barriers in accessing healthcare, with some experiencing a lack of support or dismissiveness from health professionals. Future pandemic responses should ensure safe, stigma-free access to healthcare for high-risk groups.
217. No one should be 'left behind'. People who do not mount a response to vaccination for whom there is a treatment, (e.g., prophylactic antibody treatments such as Evusheld or the updated AZ5156), should not be put at disadvantage in terms of accessing this, through government policy.
218. Blanket policies for DNACPR or Covid-19 Decision Support Tools should never again be used. The damage done through DNACPRs needs to be addressed.
219. All vulnerable people but especially people who were CV frontline workers or shielded/CEV should be offered psychological support. The abrupt withdrawal of support and protective measures post-shielding left many feeling exposed. A gradual transition with support would likely be more effective and less traumatic.

220. Recognise and protect the rights of vulnerable groups in work and education: CV individuals and their families faced significant challenges in safely accessing education and work. Policies need to allow for remote working and learning, and workplaces and schools should implement adequate health protections like air filtration systems and support mask use.
221. Promote public health measures that benefit everyone: Implementation of public health measures like mask mandates, improved ventilation, and air cleaning in indoor spaces can help protect the vulnerable while benefiting the general population.
222. Avoid one-size-fits-all approaches: People's choices, circumstances and risk levels vary greatly. Future pandemic responses should be flexible and adaptable to individual needs, with a focus on informed choice and personalised risk assessment.
223. Improve Public Health messaging: Clear, consistent, and honest public health messaging is vital. Mixed messages and policy changes led to confusion and mistrust.
224. Address inequalities and discrimination: The pandemic response often overlooked the needs of vulnerable populations, or drew unwanted attention and blame from the public for measures such as lockdowns – even though vulnerable people often experienced stricter measures for much longer than others. This led to feelings of abandonment and discrimination. Future strategies should aim for inclusive, equitable approaches that acknowledge and address the needs of all groups, especially the vulnerable.
225. Address inadequate support for CV people, including elderly people without specific health conditions, who often did not receive the same level of protection or guidance as CEV individuals. This lack of support could have left them more vulnerable to infection.
226. Inconsistencies in policy implementation: Variations in how guidance was implemented across different countries, regions and settings led to confusion and a sense of inequality. These inconsistencies affected both adherence to and effectiveness of measures.
227. Lack of flexibility in response to changing situations: As our understanding of COVID-19 evolved, the guidance sometimes struggled to adapt quickly. This lack of flexibility might have led to periods where the guidance did not align with the current level of risk.
228. Impact on non-Covid healthcare: The focus on COVID-19 risk sometimes came at the expense of other healthcare needs. Many individuals, particularly the vulnerable, faced delays or obstacles in receiving care for non-COVID-related health issues.

229. Occupational risks: The guidance did not always account for the workplace risks faced by clinically vulnerable people who needed to reduce their exposure. Early in the pandemic many CV people lost jobs or pay, particularly those who didn't qualify for furlough or were keyworkers. Subsequently, following the removal of protections and dependent on reasonable adjustments (which may or may not have been maintained by employers) CEV have also lost jobs. This oversight has led to difficult choices between health and financial stability.

230. Governments should actively learn from the experiences of other countries and adapt successful strategies to their own context. The government needs to invest in long-term planning and preparedness for future health crises. The government should invest in strengthening healthcare systems, improving pandemic response infrastructure, and prioritising research in relevant areas.

Statement of Truth

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

Signed:

Personal Data

Dr Catherine Finnis for and on behalf of CVF

Dated: 31/01/2024