IN MODULE 3 OF THE UK COVID-19 PUBLIC INQUIRY

OPENING STATEMENT ON BEHALF OF CLINICALLY VULNERABLE FAMILIES ('CVF')

A. INTRODUCTION AND SUMMARY

1. This opening statement is made on behalf of Clinically Vulnerable Families (**'CVF'**). CVF is a grassroots organisation born of the pandemic. It represents a group of vulnerable individuals who have underlying health conditions, many of whom are immunosuppressed, who are at high risk of severe outcomes from Covid-19, including greater mortality and Long Covid. Prior to the pandemic, people had not been designated as 'clinically vulnerable' (**'CV'**), 'clinically extremely vulnerable' **('CEV')** or 'at highest risk';[1] nor had their safety and wellbeing been placed so centrally, and so precariously, into the hands of government. Decision-makers were unprepared for the scale of the challenge.

2. Whilst shielding in formal terms may be a thing of the past, many CV people continue to shield to this day, and CVF's mission – to support, inform and advocate for those in clinically vulnerable households – remains pressing. In a world in which continually evolving Covid-19 variants pose an ongoing and insufficiently mitigated threat, many CV people lack the confidence and means to exercise their freedoms. This is why this Inquiry is so important to CVF.

3. CVF hopes to assist the Inquiry by giving a voice to a group who have been largely forgotten since 'Freedom Day'. It seeks to highlight the uneven impact of the pandemic on people that continue to face greater risks to their lives than any other category of person, including when accessing healthcare. And it seeks to emphasise the urgent need to learn lessons, and put in place basic yet effective protections, to ensure that this group can once again participate and flourish in society on an equal footing to others.

B. SUBMISSIONS

Issue 12a[2]: The decision-making process used to identify CEV, CV and those at highest risk

4. The following experiences of CVF members were all too common:

> *"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"* (Catherine).[3]

---

[1] A brief note on terminology: whilst the term 'clinically extremely vulnerable' has been retired by the government (with reference to those 'whose immune system means they are at higher risk' continuing), the term 'clinically vulnerable' remains in active use today. It encompasses all those who remain at higher clinical risk to Covid-19 and who qualify for vaccines based on risk: see the UK Health Security's Agency's 'Covid-19: Green Book', ch. 14a, pp.25-26 [INQ000408795_0001].
[2] Preliminary List of Issues, Version 3
[3] CVF, §16 [INQ000409574_0011].

"We were very concerned that my father initially did not get the shielding letter even though he clearly should have. Trying to get that resolved was very problematic" (Dr Adrian Warnock).[4]

5. CVF has been dismayed but not surprised to learn that at the beginning of the pandemic, there was no pre-existing national mechanism or organisation responsible for identifying, or indeed supporting, a significant number of people advised to shield. The testing and plans for this central non-pharmaceutical intervention had not been part of any previous pandemic preparedness exercise, including, in 2016, Exercise Cygnus.[5] In CVF's submission, this reflects pre-existing and deeply entrenched attitudes regarding the (lack of) value accorded to the most vulnerable in society. The result was significant delay in many people being identified as needing to shield, with the cohort of 1.3 million CEV people initially identified as needing to shield growing to 2.2 million by 7th May 2020.[6]

Identifying the CEV for the purposes of issuing shielding advice

6. CVF accepts that an iterative process, by which clinical criteria for shielding were adapted as more evidence about the nature of the disease emerged, was to some extent unavoidable.[7] But this does not explain some key omissions. For example, learning disabled adults were not added to the shielding patients' list ('**SPL**') until 19th February 2021 despite evidence published in November 2020 that the death rate for people with learning disabilities from Covid-19 was 3.6 times the rate in the general population.[8] Many people who met the CEV criteria were not added to the SPL. Others had conditions which rendered them obviously extremely vulnerable but were deemed not to meet the criteria.

7. In the numerous corporate statements setting out in lengthy narrative detail the evolution of the shielding programme, CVF has noted little willingness to engage in the question of what went wrong. Why, as GPs in Scotland asked in May 2020, was there such a *"lack of robust evidence available to definitively identify who is at risk"*?[9] Why was it left to already overstretched GPs to undertake an *"immense amount of work ... identifying patients who should be on the shielding group without an agreed national system and without the full information they needed to make decisions*"?[10] Why were systems designed in such a way that relevant and accurate clinical data was so difficult to extract? CVF urges the Inquiry to investigate whether solutions have been put in place to overcome seemingly basic problems, such as the missing or inaccurate telephone numbers in NHS patient records that meant 375,000 CEV people could not be reached in the early phase of the pandemic.[11]

---

[4] §9 [INQ000490087_0004].
[5] NAO, 'Protecting and supporting the clinically extremely vulnerable during lockdown', 10th February 2021, §1.4 [INQ000059879_0017].
[6] Sir Stephen Powis, §§624-626 [INQ000412890_0164]; Sir Christopher Wormald, §369 [INQ000253807_0101].
[7] On which, see Sir Chris Whitty, §§9.19-9.20 [INQ000410237_0088].
[8] PHE, 'Research and analysis: COVID 19 deaths of people identified as having learning disabilities: summary' [INQ000408816_00002].
[9] Letter from Royal College of GPs Scotland and BMA Scotland GP Committee to Dr Smith, Interim CMO for Scotland, dated 15th May 2020, p.2 [INQ000280659_0002]; see further Royal College of GPs, §155 [INQ000339027_0027].
[10] Royal College of GPs, §§154-155 [INQ000339027_0027]. See also Sir Stephen Powis, §§642-643 [INQ000412890_0169].
[11] NAO, 'Protecting and supporting the clinically extremely vulnerable during lockdown', 10th February 2021, §3.24; see also §2.8 [INQ000059879_0042; _0029].

The effect of delays in being advised to shield

8. The practical impact of these failings was grave. The omissions, inconsistencies and delays meant that some very vulnerable people were unaware of the need to shield,[12] and were therefore left more exposed to the risk of serious illness and death, at a time when the virus was spreading widely. They meant that some people who were aware of the risk but who had not been added to the SPL could not benefit from vital protective measures, such as the ability to work from home or to access food or medicines. And they meant that confusion, uncertainty and anxiety took hold at a time when people ought to have been able to trust in decision-makers and to look to them for reassurance and support. From the very outset of the pandemic many CEV people felt that they were treated as an afterthought.

The failure properly to identify and warn the CV of their risks

9. Many of CVF's members are those who were identified as 'CV' for the purposes of vaccination i.e. those deemed to be part of a 'wider' vulnerable group at increased risk of contracting Covid-19 and at significantly increased risk of mortality compared to the healthy population. Those who were CV were never actively contacted or informed of their risk status until they were called for their first vaccines in 2021. That created the obvious problem that, unless individuals had educated themselves independently, CV people were left unaware of their increased risk from Covid-19 and the need to take extra precautions.

10. A significant proportion of UK Covid deaths were CV and yet much of the public messaging was focused on those designated as CEV. For some CV people, the potential risk from catching Covid-19 was severe and striking. Many UK Covid deaths involved CV individuals, even though they were not designated as Clinically Extremely Vulnerable. For example, people with diabetes were not identified and warned of their risks, resulting in a lack of adequate protections for this group. A study published in The Lancet in August 2020 found that out of 23,698 COVID-19 hospital deaths in England up to May 11th, 2020, a third occurred in people with diabetes. Further analysis[13] revealed that people with type 1 diabetes had 3·5 times the odds of in-hospital death and those with type 2 diabetes had twice the odds, compared to those without diabetes, despite diabetes being a condition which in itself would not have led to a person being designated as CEV.[14] The lack of transparency surrounding the decision-making process and the specific risk levels required for conditions to be classified as CV or CEV also led to widespread confusion. In CVF member Carla's words,

> *"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."*[15]

---

[12] British Medical Association, §441 [INQ000477304_0169].
[13] After adjustment for age, sex, deprivation, ethnicity and geographical region.
[14] The Lancet (Diabetes & Endocrinology), 'Associations of type 1 and type 2 diabetes with COVID-19-related mortality in England: a whole-population study' [INQ000408818_0015].

[15] CVF, §85 [INQ000409574_0035].

11. Many members of this cohort, in the absence of clear guidance or support, were left to manage those risks without the knowledge or means to protect themselves. CV people were not advised to shield; nor were they offered protections such as entitlement to statutory sick pay or priority access to essential medicines and food.[16] As a result, working age CV people who were aware of their risks, particularly those in front-line roles, faced difficult decisions between their health and their livelihoods. Nor, to CVF's knowledge, were CV people's risks and behaviours during the relevant period analysed by the Office of National Statistics in the same way that CEV people were so that the impact of Covid-19 on them could be properly monitored and considered.

12. As the pandemic progressed, some of the CV were brought into the shielded group. For example, in February 2021, a further 1.7 million people were added to the shielded patients' list as a result of the application of the 'QCovid' model to national patient records.[17] Whilst this data-driven approach to risk assessment was, on the whole, welcomed by CVF, many of CVF's members did not have confidence that QCovid encompassed all the relevant risk factors or underlying conditions (particularly rarer conditions). More fundamentally, they struggled to have confidence in a decision-making process that had left them unprotected for the best part of a year.[18] As set out above, other CV individuals only discovered they were classified as severely immunosuppressed or immunocompromised once vaccines became available – far too late to take protective steps.

Issue 12b:The decision-making process used to decide when to start, pause and stop the shielding programme

13. CVF understands that decisions around when to start, pause and stop the shielding programme involved a complex balancing exercise of a range of competing considerations. However, CVF has deep concerns about, and urges the Inquiry to investigate whether the decision-making process failed to give sufficient weight to the risks and needs of the most vulnerable.

The shielding programme began too late

14. CVF considers that the shielding programme began too late, such that too many vulnerable people were put at unjustified risk. Many CV people were left to take matters into their own hands: a poll of 370 CVF members found that 63% began informally shielding before 15th March 2020, with a further 28% starting to shield the following week.[19] In the words of CVF member Lesley Jean Moore:

> *"The way we had been treated before the pandemic by the Government gave me no hope that we would be high up on the list of priorities, since they had no understanding of the needs of those who had complex health needs and who would be most vulnerable to the bad effects of Covid-19. They also did not understand what support would be needed to help keep someone like [my son] safe."*[20]

---

[16] Royal College of Midwives, §51 [INQ000347411_0019].
[17] See, e.g., Dame Jenny Harries, §§78-80 [INQ000410865_0027].
[18] British Medical Association, §452 [INQ000477304_0171].
[19] CVF, §19 [INQ000409574_0012].
[20] §8 [INQ000485656_0004].

The 'stop-start' nature of shielding: a drive to return to normality at all costs

15. The 'stop-start' nature of shielding advice throughout 2020 and 2021 reflected the government's overwhelming drive to 'return to normality' and 're-open the economy', seemingly at any cost. When shielding advice was paused for most from 1st August 2020, this coincided with a wider relaxation of various social distancing measures, and indeed the introduction of the 'Eat Out to Help Out' scheme. This decision was made in the knowledge that exponential growth was likely to re-start if restrictions were largely lifted.[21] At this time, vaccinations and antivirals were not available; treatments were in their infancy. Other important mitigations, such as ventilation and robust guidance in relation to face masks, had not been put in place.

16. An important effect was that those who had been shielding lost vital protections overnight, including entitlement to claim statutory sick pay and the right to work from home (with a third of CEV people surveyed by the ONS reporting feeling uncomfortable returning to work outside the home).[22] They were thrust into a world in which the public were being given false confidence that the virus no longer posed a significant threat. This led to many CEV people feeling unsafe and frightened:

"Initially [I felt] 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" (CVF member, Hannah).[23]

***Stopping shielding "was like falling off a cliff"*[24]**

17. National shielding advice and associated support came to an end on 31st March 2021.[25] At this time, around 30% of the 3.8 million CEV people on the SPL had still not received a first dose of the vaccine, and some CEV people (in fact an unknown number at this point in time) were unable to mount an effective response to the vaccine at all.[26] The focus shifted to providing *"precautionary advice on managing the risk of exposure".*[27] The Inquiry is urged to note that this 'advice', and the focus on individuals making their own risk assessments, often proved impossible to implement in practice. Many people who had previously been advised to shield felt cast adrift. As one formerly CEV member of the public wrote in desperation to Prof. Whitty:

"[Since shielding ended] I have struggled to get any kind of fresh guidance from the government about the current risks that Omicron, or indeed any newer variants, now pose to me. I have repeatedly told myself to remain patient, ... and to hope that in the near future, I would be offered an informed view and/or information that would help me to make some kind of judgement about the risks to me, and allow me to make some cautious moves back towards a life, if not a 'normal' life. And still, nothing. No

---

[21] Sir Peter Horby, §129 [INQ000226562_0037]; British Medical Association, §§447-448 [INQ000477304_0170].
[22] ONS bulletin, 'Coronavirus and shielding of clinically extremely vulnerable people in England: 9 July to 16 July 2020', [INQ000339267_0002].
[23] CVF, §53 [INQ000409574_0025].
[24] CVF, §62 [INQ000409574_0028].
[25] With the shielding programme coming to an end on 15th September 2021: Sir Chris Whitty, §9.5 [INQ000410237_00].
[26] Paper from SSHC to COVID-O, 'Future of Shielding Policy', 11th March 2021, §29 [INQ000092395_0006].
[27] Cabinet Office, §7.91 [INQ000436880_0060].

information. No perspective. No parameters. ... How do I go about making a practical assessment of the risks to myself of 'ending restrictions'? I feel entirely disregarded.".[28]

18. It is telling that in seeking input from colleagues on how to respond, Prof. Whitty noted that he received *"a lot of variants of these"* emails.[29]

19. The support was ended despite officials' stated recognition that CEV individuals *"may face or perceive greater risks ... and therefore face a disproportionate impact from ending support, particularly on their mental health"*[30] (see further, in the Scottish context, recognition that *"substantial work was first needed to foster the conditions in communities which could support personal choice"*).[31] There was no bespoke mental health offer for this group;[32] no financial safety net for those with employers demanding they return to work despite ongoing risks; ;[33] and intransigence regarding the need for action and clear communications in relation to mitigations.[34] CVF concurs with the assessment of Prof. Banfield on behalf of the British Medical Association that *"[t]he dismantling of testing infrastructure and the end of free testing weakened our ability to safeguard the most clinically vulnerable in our society"*.[35] The Inquiry is invited to investigate whether transitional or rehabilitative support after the end of the shielding programme was fit for purpose.

Issue 12c: Communication and advice for people shielding and designated as CV/at highest risk

20. People shielding and those designated as CV and at highest risk had the right to expect timely, evidence-based and sensitive communications and advice. Yet CV people frequently felt as if they had been forgotten or as if their needs and concerns did not matter.[36]As CVF member Dr Adrian Warnock writes in his impact statement:

"The emerging groups of the Clinically Vulnerable Families ... helped us all deal with the pandemic since we did not feel supported by the official bodies. But trying to help others navigate the bewildering and toxic official communication we were receiving was very distressing and added to psychological pressure".[37]

21. On the most basic level, vital communications, such as those advising people to shield, did not always reach the right people or reach them in good time.[38] The initial decision to use letters as the default method of

---

[28] [INQ000074822_0001]. See also Forgotten Lives, §11: 35% of the group continue to shield as and when they consider it necessary to protect themselves [INQ000260635_0005].
[29] [INQ000074822_0001].
[30] Paper from SSHC to COVID-O, 'Future of Shielding Policy', 11th March 2021, §37 [INQ000092395_0007].
[31] Sir Gregor Smith, CMO for Scotland, §209 [INQ000484783_0049].
[32] Paper from Ministry of Housing, Communities and Local Government and Department for Health and Social Care to COVID-O, §47 [INQ000066820_0008].
[33] Paper from Ministry of Housing, Communities and Local Government and Department for Health and Social Care to COVID-O, §§47; 52-55; 66 [INQ000066820_0008-0009; _0011] and minutes of COVID-O meeting held on 11th March 2021, p.3(f) [INQ000091808_0006].
[34] Sir Peter Horby, §146 [INQ000226562_0044].
[35] §453 [INQ000477304_0172].
[36] Sir Michael McBride, CMO for Northern Ireland, §126, summarising the findings of a survey by the Patient and Clinical Council published in July 2020 [INQ000421784_0088].
[37] §10 [INQ000490087_0004].
[38] NAO, 'Protecting and supporting the clinically extremely vulnerable during lockdown', p.10, §17 [INQ000059879_0012].

contact failed to consider accessibility issues.[39] Texts and emails excluded those suffering from digital poverty.

22. The Inquiry may also consider that the advice itself was frequently problematic. The iterative and disjointed development of the SPL caused confusion as people struggled to understand why they had been advised to shield or told they no longer needed to shield.[40] This was compounded by a lack of transparency as to the decision-making process used to identify those who were CEV, CV and at highest risk. Some people did not understand the nature and degree of their own vulnerability.[41] National communications were not always consistent with local guidance, and there were inconsistencies between media reports, ministerial comments, official guidance and guidance issued by professional bodies.[42] These inconsistencies mattered, as the effect was to leave people anxious and uncertain as to whether they should shield or not, or what steps they should be taking to protect themselves and their loved ones.

23. Some communications lacked basic care, such as text messages sent to those on the SPL advising them to *"[b]e prepared in case you need to go into hospital"*.[43] Far from informing or empowering people, such messages left many in immediate concern for their life and confused as to their immediate risks.

24. The advice was also incomplete. It did not address practical realities, such as individuals' varying degrees of capacity to adhere to guidance or the steps people could take if, contrary to advice (or, if they were CV and so not formally shielding), they had to leave home. There was a lack of clarity for family members and carers of the CEV/CV who may or may not have been able to informally shield. The advice lacked appropriate guidance for CV people, including elderly people without specific health conditions. It did not address non-Covid-19 healthcare needs or the risk of delays in treatment (a particularly worrying omission given that the CEV by definition had underlying health conditions, as did many CV people). It did not provide appropriate information about steps that might have alleviated the long or short-term negative impact of shielding.[44] It should not have fallen to CVF and other groups to try and fill these and other gaps in the official guidance.[45]

25. CVF invites the Inquiry to scrutinise the underlying reasons for these problems, the effect of which has been to leave the CV exposed, unsafe and, as a result of widespread public misunderstanding, at risk of discrimination and abuse. Too many of CVF's members have shared the experiences of CVF member Amanda, who describes the difficulties *"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"*.[46]

---

[39] Sir Stephen Powis, §1872 [INQ000485652_0541].
[40] Prof. Edwards et al., §134 [INQ000474283_0042].
[41] See, for example, Forgotten Lives, §8 [INQ000260635_0003].
[42] NAO, 'Protecting and supporting the clinically extremely vulnerable during lockdown', 10th February 2021, §§2.12-2.13 [INQ000059879_0032]; see further Royal College of Obstetricians and Gynaecologists, §§32-34 [INQ000470853_0011].
[43] Sent on or around 25th March 2020: CVF, §26 [INQ000409574_0015].
[44] CVF, §57 [INQ000409574_0025] and notes of PHE's Behavioural Science Team and Imperial College London's focus group review [INQ000224000_0002 (referred to by Dame Jenny Harries, §100 [INQ000410865_0038]).
[45] CVF, §32 [INQ000409574_0017].
[46] CVF, §48 [INQ000409574_0022].

Issue 12e: The impacts of the shielding programme

26. The shielding programme was designed to reduce the incidence of infection and therefore also the risk of severe disease and death in the most vulnerable.[47] CVF has serious doubts that meaningful conclusions as to the lack of a protective effect of shielding can be drawn from the limited evidence base cited by Prof. Snooks (who does acknowledge challenges in the evaluation design of the studies referred to),[48] and urges the Inquiry to exercise caution in this regard.[49]

27. CVF is well placed to give an insight into the varied impacts of shielding on the CEV and those in their households. Plainly this is a complex and nuanced issue, not least because those who shielded are not a homogenous group (and indeed represent a hugely diverse cohort), and because the effects and impacts of shielding were multi-faceted and may have differed at different points in time.

28. Many CVF members felt that, despite the challenges, there was a clarity of purpose associated with shielding:

"Absolutely petrified, isolated, lonely and sad but at the same time, safe. It was the only safe option." (Becky)[50]

"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)[51]

"Protected and safe. When we were forced out of shielding, I and my children were terrified." (Nikki)[52]

29. At the same time, as these quotes also touch on, there were negative psycho-social effects, as well as practical limitations, associated with shielding:

a. **Mental health impacts**: In a survey carried out in August to September 2020, 90% of responders reported worrying about Covid-19, with a further 43% reporting a negative impact on their mental health as a result of shielding.[53] Many shielding people experienced daily anxiety as a result of difficulties accessing food and medicine.[54] Mental health support was lacking both during the official shielding programme and after it. In order to facilitate their safe reintegration back into society, CVF's members required proper efforts to address the ongoing risks of Covid-19 for CV and CEV people

---

[47] Sir Chris Whitty, §9.1 [INQ000410237_0079].
[48] §125 [INQ000474285_0046].
[49] See, e.g., Sir Chris Whitty at §9.26 [INQ000410237_0090].
[50] CVF, §44 [INQ000409574_0021].
[51] CVF, §52 [INQ000409574_0024].
[52] CVF, §55 [INQ000409574_0025].
[53] Lasseter et al. BMC Public Health (2022) 22:2145, 'Exploring the impact of shielding advice on the wellbeing of individuals identified as clinically vulnerable amid the COVID-19 pandemic: a mixed-methods evaluation', p.7 [INQ000408813_0007]. See also the findings of the Patient and Client Council, cited by Sir Michael McBride, CMO for Northern Ireland, §126 [INQ000421784_0087]. Numerous other studies have found adverse mental health impacts associated with shielding: see, e.g., those referred to by Prof. Snooks et al., §§133; 136-139 [INQ000474285_0048 - 0049] (though Prof. Snooks considers it difficult to disentangle the effects of shielding from lockdown more generally, which she notes may have affected the vulnerable disproportionately: see §135 [INQ000474285_0049]).
[54] CVF, §§94-106 [INQ000409574_0040].

(such as clean air programmes, see below) but also support addressing the psychological effects of living so restrictedly for a prolonged period.

b. **The impact on family/household members of those shielding:** Many of CVF's members are working age adults with families living with them. Partners, family members and sometimes children shielded alongside CEV people (creating difficulties for some when shielding was paused and 'lockdowns' lifted and children were required to return to school and family members to work). Other CEV people were forced to live apart from family members. CVF submits that the generic nature of official guidance failed to recognise the many and varied practical complexities that arose in direct consequence of shielding advice. This in turn is likely to have impacted on the effectiveness of the shielding programme.[55]

c. **The impact on those needing care**: Many of those who prior to the pandemic had received care at home were forced to make the difficult decision to stop carers visiting their homes: see, for example, Lesley Jean Moore's impact statement, which describes her experience of carers seemingly not understanding the risks to her vulnerable son posed by the virus or the importance of complying with protective measures to mitigate these risks.[56] CVF considers that the government's failure properly to communicate vital public health measures, and to provide sufficient appropriate PPE such as FFP3 masks, played a significant part in such problems. Access to healthcare is discussed further below.

d. **Social isolation, stigma and 'othering'**: For many CEV people, formal identification as a person "shielding" was socially advantageous as it legitimised their urgent need to reduce their risks and provided them with benefits and support to enable them to stay safe. At the same time, many CEV people equally felt 'othered, devalued' and 'isolated' by their status, compounded by government briefings which attempted to provide reassurance to the general public by emphasising that Covid-19 was most life-threatening to those with "*underlying health conditions*".[57] Many CVF members' feelings of social isolation became more acute as the formal shielding programme ended, particularly if they continued to shield. People in this cohort report feeling left behind, struggling to assess their risk 'in the dark', and misunderstood by a misinformed public. CVF member Imogen describes her experience in the following terms:

"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".[58]

e. **Financial implications**: These were many and varied. Some of those who shielded lost businesses and jobs. Targeted financial support was limited to the duration of the formal shielding programme

---

[55] Prof. Snooks et al., citing the EVITE study, §156 [INQ000474285_0054].
[56] §§9-13 [INQ000485656_0004-0005].
[57] Lasseter et al. BMC Public Health (2022) 22:2145, 'Exploring the impact of shielding advice on the wellbeing of individuals identified as clinically vulnerable amid the COVID-19 pandemic: a mixed-methods evaluation", p.7 [INQ000408813_0007].
[58] CVF, §66 [INQ000409574_0029].

and was still limited. It directly excluded CV people who were not formally shielded and received no statutory support or benefits at all. It also did not help CEV people who, in the absence of safe conditions such as proper ventilation, remained at high risk and continued to shield after the formal end of the shielding programme.

30. CVF submits that many of these impacts could have been mitigated by support that was targeted, meaningful and long-term. This would have been intrinsically worthwhile (by improving the wellbeing of those who shielded) and would also have been likely to improve the protective effects of the shielding programme (by facilitating greater compliance). Overall, it has been deeply distressing and disempowering for CEV and CV people to feel that government policy was something that simply happened *to* them, leaving them without any sense of confidence that their needs and concerns had been understood or prioritised.

Issue 12d: Access to healthcare for people shielding and those designated as CV and at highest risk

31. As a result of failure to implement basic protective measures across healthcare many CEV and CV people have felt, and continue to feel, that they cannot access healthcare safely: see, for example, CVF member Amanda's description of how *"[s]seeking medical attention has become a truly terrifying ordeal"*, like *"a game of Russian roulette"*;[59] or Lesley Jean Moore's lack of *"confidence that her son would be kept safe in a healthcare setting because there was a lack of understanding of how Covid-19 was spread, what protections were needed to stop you from getting it and how at risk someone like [her son] was"*.[60]

32. In a November 2023 CVF poll of 827 CV members, 90% reported that they had in the past or would in future delay or cancel medical appointments due to unmitigated Covid-19 risks in healthcare settings.[61] It is striking that it is essentially impossible for those at highest risk to comply with the government's own guidance (for example in relation to testing, mask wearing and reducing the amount of time spent in crowded, unventilated spaces) when seeking to access healthcare.[62] The Inquiry should consider this to be a matter of serious concern, given that many CV people have serious underlying health conditions.

33. Two issues are of particular relevance: (a) the lack of clean air and adequate ventilation and (b) the lack of evidence-based guidance in relation to face masks. CVF submits that both of these shortcomings have contributed to avoidably high levels of nosocomial (hospital-acquired) infection which have put vulnerable people at particularly high risk.[63] In relation to both issues, infection prevention and control guidelines have repeatedly lagged behind scientific knowledge. This caused a loss of trust in IPC guidance amongst medical professionals, leading to a lack of compliance and improvisation.[64] Other medical professionals without IPC expertise have accepted poor Government guidance and failed to appreciate the need for high quality

---

[59] CVF, §48 [INQ000409574_0022].
[60] §15 [INQ000485656_0006].
[61] CVF, §131 [INQ000409574_0055].
[62] 'Covid-19: guidance for people whose immune system means they are at higher risk', updated 21st May 2024: CVF, §45 [INQ000409574_0021]; [INQ000408811].
[63] Prof. Snooks et al., §121 [INQ000474285_0044]. Snooks et al. conclude that this in turn undermined the effectiveness of the shielding programme: see §157 [INQ000474285_0054].
[64] Dr Shin, Prof. Gould and Dr Warne, §13.13 [INQ000474282_0136].

masks.[65] It has been frustrating and distressing to CVF's members who have frequently felt as if they have been shouting into a void.

Lack of clean air and adequate ventilation (Issue 9a(vi))

34. Covid-19 is an airborne virus. As Prof. Beggs' expert report outlines in detail, the importance of clean air and adequate ventilation has long been established by robust evidence.[66] Despite this, it has taken years for guidance reflecting the obvious utility of HEPA (high efficiency particulate air) filters to emerge;[67] many guidelines, especially those relating to hospital ventilation, still reflect out-of-date misconceptions regarding the transmission of infection.[68] CVF submits this is unacceptable. Whilst improving building design may be a longer-term (and essential[69]) project, the effectiveness of air cleaning devices such as HEPA filters in removing or inactivating viruses is well-established. As Prof. Beggs notes, it is now incontrovertible that air cleaning devices such as HEPA filters are *"relatively low cost and can be rapidly deployed as required to boost effective air change rates"*.[70]

35. CVF invites the Inquiry to conclude that meaningful and urgent changes are needed to ensure the air in healthcare settings is clean and safe to breathe. In the meantime, interim measures should be implemented to provide immediate protection for CV people.[71] As Professor Noakes has identified, in order to deal with airborne transmission, mitigation measures must be addressed at an organisational level (e.g. by building owners). Ultimately, ventilation and air cleaning are not within individuals' power to control.[72]

Lack of evidence-based guidance in relation to face masks (Issues 9a and 9b)

36. Despite strong evidence that FFP2 and FFP3 respirator masks are much more effective than surgical masks in providing protection against infectious aerosols,[73] their use in the NHS for both healthcare workers and patients has been, and continues to be, limited.[74] Guidance has consistently recommended high risk patients wear "face coverings" rather than medically appropriate FFP2/3 masks.[75] There is no good rationale for the limited use of respirator masks, given the indisputable relevance of (a) asymptomatic and pre-symptomatic Covid-19 transmission as an ongoing *"major driver"* of nosocomial (hospital-acquired) infections and (b)

---

[65] CVF, Q46 [INQ000409574_0055].
[66] Prof. Beggs, §211 [INQ000474276_0079].
[67] See, e.g., 'NHS Estates Technical Bulletin (NETB 2023/01A): application of HEPA filter devices for air cleaning in healthcare spaces: guidance and standards', published 9th May 2023, updated 2nd October 2023 [INQ000408856].
[68] Prof. Beggs, §§134; 285 [INQ000474276_0052,101]; Dr Shin, Prof. Gould and Dr Warne, §13.11(i) and (iii) [INQ000474282_0136].
[69] Dr Shin, Prof. Gould and Dr Warne, §13.10 [INQ000474282_0136].
[70] Prof. Beggs, §283 [INQ000474276_0101].
[71] These are summarised in CVF, §145 [INQ000409574_0058].
[72] Witness Statement of Professor Catherine Noakes, chair of the SAGE sub-group Environment and Modelling Group (20 July 2023), §10.11(4) [INQ000236261_0051]
[73] Prof. Beggs, §§203-204 [INQ000474276_0077]. See also Dame Ruth May, §§270-273 [INQ000479043_0058] and Covid-19 Airborne Transmission Alliance, §139 [INQ000273913_0041];
[74] To healthcare workers (a) managing confirmed or suspected patients with Covid-19 and (b) performing AGPs: see Prof. Beggs, §207 [INQ000474276_0078].
[75] See, e.g. Department of Health and Social Care, 'Covid-19: guidance for people whose immune system means they are at higher risk' (21/09/2023. [INQ000408811]).

inadequate ventilation throughout many healthcare settings.[76] Yet calls for better provision of RPE, including by professional bodies representing frontline healthcare workers, remains unheeded.[77]

37. CVF is deeply concerned that a lack of evidence-based guidance and political meddling in relation to masks has allowed misconceptions to become embedded. Nonsensical and risky policies have been the result: several CVF members have reported being required by hospitals to remove their own higher quality respirator masks and replace it with a surgical mask.[78] Mask-wearing also became a needlessly politicised and divisive issue during the pandemic,[79] unfortunately encouraged by some politicians. The effect has been to create a culture in which many CV people have become targets of abuse simply for wearing a face mask (with a poll of 139 CVF members finding that close to half had experienced mask aggression/abuse).[80]

38. There is a pressing need for guidance in relation to face masks to be amended to ensure wider use of FFP2s and FFP3s for both healthcare workers and patients. As urgent interim measures, CVF would welcome: (a) clarification that people should not be required to remove their own respirator masks; and (b) policies that support CV/CEV people to request that staff in direct contact with them wear FFP2/3 masks.

Other issues relating to access to healthcare (Issue 12d)

39. Other issues concerning access to healthcare which CVF submits it is important for the Inquiry to consider include:

    a. **The difficulties many CV/CEV people experienced in accessing their usual care for their underlying conditions,** especially during the early part of the pandemic.[81] As Prof. Edwards et al. note, the result of unprecedented and unplanned for pressures on healthcare systems was that *"little attention appeared to have been given to long-term conditions"*, particularly those that would tend to present more frequently in primary care.[82] For some patients, remote care was neither safe nor appropriate.[83] The effects of reduced access to healthcare amongst this already vulnerable cohort were grave. As the Academy of Medical Royal Colleges notes, *"[t]he "collateral damage" of delayed presentations is a recognised feature of pandemics and there is little doubt we are suffering the consequences of this now in many areas. Failure to treat conditions at the right time leads to mortality or increased morbidity"*.[84] Awareness of these risks was a further cause for anxiety and distress for

[76] Prof. Beggs, §§208-209 [INQ000474276_0078,79].
[77] See, e.g., by the Royal College of Nursing, §§13; 82-91; 120-123 [INQ000475580_0006; _0031; _0045].
[78] CVF, §128 [INQ000409574_0052].
[79] Simon Ridley, §137 [INQ000252914_0034].
[80] CVF, §194 [INQ000409574_0076]; see further the quote from CVF member Maria CVF, §49 [INQ000409574_0023].
[81] CVF, §147 [INQ000409574_0060]. See Prof. Edwards et al., §171 [INQ000474283_0049].
[82] §171 [INQ000474283_0049].
[83] Royal College of GPs, §95 [INQ000339027_0018]. See also Sir Stephen Powis, §188 [INQ000485652_0047]; Prof. Edwards et al., §185 [INQ000474283_0052]; Prof. Snooks et al., §§133-134 [INQ000474285_0049].
[84] §35 [INQ000396735_0011]. The backlog of undiagnosed patients with multiple long-term conditions is further highlighted in the expert report of Prof. Edwards et al. at §§170-175 [INQ000474283_0049-0050].

the CV, as highlighted by Dr Adrian Warnock: *"I was scared of getting Covid, but I was also scared of dying from getting other infections. ... I felt incredibly vulnerable and frightened"*.[85]

b. **The experience of some CV/CEV people being discharged** from both medical and dental clinics and removed from waiting lists if they did not attend as a result of shielding, concerns around Covid-19, or because alternative (for example digital) appointments were not facilitated.[86]

c. **Challenges in accessing antiviral treatment within the required five-day period**. Rapid provision of antivirals was, supposedly, *"specifically designed to provide additional protection to many of those who had been shielding"*.[87] Yet many CVF members report confusion around the frequently changing eligibility criteria (which CVF considers are too narrow). Even if eligible, the burden is on the patient – who may be experiencing Covid-19 symptoms or risking imminent illness – to secure the medication, all within a system which was and is not currently fit for purpose. CVF members describe GPs referring to 119, 119 referring to 111 and 111 referring back to 119 or the GP. Even if eventually referred to the Covid-19 Medical Decisions Unit, people have been dismayed to find that the Unit is closed over weekends or bank holidays. All of these delays eat into the 'five-day pathway' to access crucial antivirals.[88] CVF consider antivirals must properly be commissioned and made accessible those who need them the most.

d. **The non-availability of prophylactic monoclonal antibody treatment (Evusheld and more recent treatments) on the NHS**. For those who are immunosuppressed and unable to mount an effective response to vaccination, this was their vaccine. Yet unless they were in the position to travel and pay for the treatment themselves, those at highest risk remained unprotected; many continue to shield as a result. In CVF member Melanie's words, *"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"*.[89] Access to proper treatment is an urgent need, as many immunosuppressed individuals have been living in isolation or limited lives for over four years, with no end in sight.

Issue 7: Decision making about healthcare provided for Covid-19 patients

DNACPRs (Issue 7d)

40. Some of CVF's members, including middle-aged people, were shocked to be asked, seemingly out of the blue and often via the medium of an impersonal letter or rushed phone call, whether they would wish to be resuscitated if in cardiopulmonary arrest:

---

[85] §17 [INQ000490087_0006]. In relation to fears around accessing healthcare, see further: Royal College of GPs, §45 [INQ000339027_0010]; Age UK, §65 [INQ000319639_0021]; Prof. Edwards et al., §179 [INQ000474283_0051]; and Royal College of Emergency Medicine, §60 [INQ000412904_0029].
[86] CVF, §151 [INQ000409574_0061].
[87] Sir Sajid Javid, §128 [INQ000485736_0060].
[88] See the experience of Dr Adrian Warnock at §67 [INQ000490087_0018]; the case studies set out at CVF, §187 [INQ000409574_0072]; and Forgotten Lives, §§65-68 [INQ000260635_0040].
[89] CVF, §192 [INQ000409574_0076]. See also Forgotten Lives, §§69-82 [INQ000260635_0043].

"I received a phone call and this letter asking about DNACPR amongst other things from my GP. It really scared and upset me at the time. I honestly thought that is it, I'm going to die" (CVF member, Helen).[90]

41. Other CVF members were dismayed to learn that DNACPR notices had been issued without involving them or their families and/or carers in the decision:

"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" (CVF member, Jennifer).[91]

42. These and many other reports from CVF members are consistent with accounts reflected in the interim and final reports of the CQC, including that 'blanket' decisions were being made on the basis of underlying health conditions.[92] This has been deeply traumatising and distressing for those affected, compounding concerns (partially arising from the Government's own messaging) that they had been or would be discarded by society:

"It felt like the state were imposing a DNACPR on [my son] because he was a burden and it would be easier to let him die than to save his life. ... [I] at no point consented for there to be a DNACPR in place. I felt that if [my son] turned up at hospital as one of four people needing a bed on an Intensive Care Unit, and there were only three beds, he wouldn't be the one chosen to get one" (CVF member, Lesley Jean Moore).[93]

43. CVF is concerned that there remain people who to this day who may not have been made aware that a DNACPR notice has been issued. CVF considers that there should be an urgent systematic review of DNACPRs put in place during the height of the pandemic. This should be accompanied by a bespoke offer of psychological support for those affected by decisions forced upon them or made without their knowledge.

Issue 12f: Decision support tools

44. A similar theme emerges in relation to the discussion and development of 'Covid-19 Decision Support Tools'. This was a highly sensitive and emotionally charged area of work. The NICE decision-making algorithm issued early in the pandemic, widely circulated in the media, caused considerable concern amongst CVF members:

"I saw it on the web and was shocked and particularly worried that an innocent mention of being slower or of walking ... might gain an extra 3 or 4 points. I felt I would have to be very careful in what I said. It reduced trust" (CVF member, Derek).[94]

45. As Prof. Summers and Dr Suntharalingam note in their expert report, the algorithm required amendment to *"clarify wording on frailty scoring to ensure that people with stable disabilities were not disadvantaged"*.[95] Yet again, those who were vulnerable by reason of underlying conditions were not given sufficient

---

[90] CVF, §112 [INQ000409574_0047].
[91] CVF, §116 [INQ000409574_0048].
[92] Helpfully summarised by Prof. Summers and Dr Suntharalingam, §§45-48 [INQ000474255_0026-0027].
[93] §19 [INQ000485656_0007].
[94] CVF, §110 [INQ000409574_0046].
[95] §107 [INQ000474255_0045].

consideration from the outset; yet again, they were left at risk of being excluded from healthcare to benefit the wider population.

46. CVF remains concerned about the longer-term impact of pandemic conversations around clinical prioritisation, given the potential for the *"scoring systems"* initially under consideration to be resurrected during other times of pressure in the NHS,[96] or subconsciously to affect decision-makers going forward. CVF welcomes the Inquiry's scrutiny of this issue, and hopes this will bring clarity as to the design of the putative prioritisation framework by the working group in late March 2020, as well as DHSC's decision not to continue with this work.[97]

C. CONCLUSION

47. CVF's concerns are linked by a common theme: the inescapable reality that the disproportionately severe impact of Covid-19 on the CV, and associated decision-making, were insufficiently considered and mitigated since the emergence of Covid-19. It was all too easy to make official pronouncements in March 2020 that the vulnerable would be protected;[98] and too easy to leave the vulnerable behind. The CV continue to feel the effects and to live in the shadow of the virus today.

48. It is for these reasons that CVF also considers it essential that the CV be identified as a specific group/protected characteristic, both under the Equality Act 2010 and in the Inquiry's Equalities and Human Rights Statement, to enshrine in law the ongoing threat to the CV of Covid-19, and ensure that support for the CV can no longer be switched on and off at the whim of public officials.

49. CVF is grateful for the Chair's care and attention throughout this important module.

KIM HARRISON
SHANE SMITH
Solicitors for CVF
Slater & Gordon

ADAM WAGNER
DANIELLA WADDOUP
ROSA POLASCHEK

Counsel for CVF
Doughty Street Chambers
22rd August 2024

---

[96] CVF notes that the academic output from the work was published *"so that the learning from the discussions would not be lost"*: Prof. Summers and Dr Suntharalingam, §114 [INQ000474255_0048].
[97] Prof. Summers and Dr Suntharalingam, §114 [INQ000474255_0048]; Matt Hancock, §101 [INQ000421858_0026].
[98] See, e.g., Matthew Style on behalf of the Department of Health and Social Care, §104 [INQ000472172_0031]. Indeed it is all too easy to claim today, as Matt Hancock does in his statement at §169, that *"[c]onsidering the effect of policy decisions on the vulnerable was at the heart of the Government's strategy"* [INQ000421858_0041]).