IN THE UK COVID-19 PUBLIC INQUIRY
MODULE 3

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

A. INTRODUCTION

1. This is the closing statement of Clinically Vulnerable Families (**"CVF"**). CVF is a grassroots organisation born of the pandemic. It provides advice and support to vulnerable individuals who have underlying health conditions rendering them clinically vulnerable (**"CV"**) to Covid-19, those formerly classified as clinically extremely vulnerable (**"CEV"**), those who are severely immunosuppressed, and those living in the same household.[1]

2. CVF was founded in August 2020, by which point it was clear that the government was ill-prepared for the challenge of protecting those most vulnerable to adverse outcomes from Covid-19. Public assurances that the government was putting the protection of the CV *"at the centre"*[2] of its pandemic response had begun to ring increasingly hollow for many affected individuals and their families. The fears expressed by Lesley Moore that her son *"would not be valued during the pandemic"*[3] had become a reality, both for Ms Moore and for countless others. CV people felt unsafe, forgotten and left behind.

3. This feeling has continued beyond the emergency phase of the pandemic to 'Freedom Day' and beyond. The final protections were withdrawn following 'Learning to Live with Covid'; problems persist because the necessary 'learning' did not happen. For those who remain at high and unmitigated risk, continue to lead very restricted lives, or receive abuse for the simple act of daring to wear a mask, freedom remains an elusive prospect today. The CV find themselves living in a society *"that is running as if Covid-19 doesn't exist anymore"*.[4] They are left to shoulder the burden of taking 'personal responsibility' for protecting themselves, without society-wide mitigations and in the absence of public understanding that they continue to face very real risks.

4. This is why the Inquiry is so important to many CV people. CVF is grateful that the Chair has received written and oral evidence from CVF that has sought to highlight the uneven impact of the pandemic on a large group of people (up to 3.2 million formerly CEV and 17 million CV) who have faced, and continue to face disproportionate impacts. Such impacts are particularly acute when the CV seek to access healthcare. The evidence heard by the Inquiry has brought

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[1] A brief but important note on terminology: whilst the term "clinically extremely vulnerable" has been retired by the government following the end of the shielding programme (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.

[2] Statement of Matt Hancock, §18, INQ000421858_0006.

[3] 30 Oct 2024, 6/19-20.

[4] Prof. Banfield (BMA): 28 Oct 2024, 159/22-25.

into sharp focus how unsafe the NHS estate was, and is, particularly for those with clinical vulnerability. This is an issue of real concern given that the CV are, by definition, frequently reliant on healthcare. Safe healthcare is necessary and is necessary now. The evidence before the Inquiry has also highlighted how arbitrary distinctions between the CEV and CV left millions of people on the 'wrong' side of the dividing line and without basic protections and support. Moving forwards, there is an urgent need to restore trust and confidence that the lives and wellbeing of all CV people matter, and that their distinct concerns and needs will be addressed, both now and in a future pandemic. While the scale of the challenge faced by the Chair is considerable, given competing demands and entrenched attitudes, the recommendations called for by CVF are simple, cost effective, and disadvantage no one.

5. This closing statement aims to bring this call to action to life through incorporating as many of the experiences and perspectives of CV people as space will permit. It is hoped that in doing so the Inquiry will understand why one of CVF's central asks is for equality legislation to be strengthened, including through recommending that clinical vulnerability be included as a distinct protected characteristic. Throughout this statement CVF also proposes (in underlined text) a number of targeted recommendations on issues specifically impacting all CV people and which are designed to assist the Inquiry in its *"important forward-looking perspective"*.[5]

6. This statement accordingly addresses: (i) the shielding programme; (ii) how to better protect all CV people, both now in and in a different future pandemic; (iii) the urgent and at present unmet need to make healthcare safe for CV people; and (iv) the concerns raised by the use of DNACPRs and decision support tools, and the need to restore trust amongst the CV that they will be treated as equally worthy of protection, no matter the pressures on the health service.

B. THE SHIELDING PROGRAMME

Recognising diversity of experience and the importance of shielding as a 'passport' to accessing vital support

7. It is hopefully clear from the evidence of CVF, as well as the impact and Every Story Matters (**"ESM"**) evidence, that behind the labels "CEV" and "CV" lies a diverse group of people. Individual circumstances varied, with some more able than others to adhere to shielding advice. Some were in a position to shield immediately; others had caring responsibilities of their own, requiring them to leave their homes; others still were in precarious work. Individual perspectives on risk also varied, both during and after strict shielding advice. This was highlighted, for example, by Prof. Sir Gregor Smith, discussing the attempt in Scotland, later in the pandemic, to develop a more person-centred approach which was designed to recognise that individuals might have a *"different attitude to risk or tolerance about what ... was important to them"*.[6]

8. Yet despite this diversity of experience, many formerly CEV people will identify with Dr Finnis's evidence to the Inquiry that:

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[5] As CTI put it in her opening statement: 9 Sept 2024, 10/20-21.

[6] 25 Sept 2024, 123/10-12. See further Vaughan Gething, noting his understanding that some CEV people *"are worried. Some of them are just keen to get out and about. ...People still have to make their own choices"*: 20 Nov 2024, 94/5-13.

> *"given how worried people were with the information coming from, first, China and then Italy and understanding that people with underlying conditions were at much higher risk of severe disease and sadly death, I think that shielding was something for us to at least hold on to. It felt that perhaps we were being offered something by society".*[7]

9. There is also broad agreement amongst those of CVF's members who shielded that shielding played an important 'passporting' function, ensuring access to essential support.[8] This included the right to work from home (with the shielding letter functioning as a 'fit' note); entitlement to statutory sick pay if working from home was not possible; entitlement to food and essential medicine deliveries;[9] priority access to supermarket slots; and, later, priority access to vaccines for those on the shielding patients' list (**"SPL"**).

10. The sections which follow seek to illustrate how the potential benefits of shielding were undermined because of flaws in the conceptual design of the programme and in its execution, as well as a failure to recognise that the shielding programme alone was not enough to protect CEV people.

Flaws in the conceptual design of the shielding programme

Tone matters: fear and disempowerment

11. Even making allowances for the emergency nature of the pandemic, the tenor and tone of the advice conveyed as part of the shielding programme was problematic. Dr Finnis described repeated text messages, such as those advising CEV people to keep a hospital bag by their front door, as *"very frightening messages to a group of people who hadn't really been given any information on how to reduce their risk. ... Many CEV people didn't see themselves as vulnerable, as indeed I didn't. I was a part, or am a part of the society, community, I have a job, I have a child. ... [A] lot of us were in those situations and then suddenly we were disempowered hugely by really being told to just 'Stay at Home'" ... We really didn't know what to do. We felt really stuck.*[10] A contributor to ESM recounted how they were *"told not to even go outside to my own bin because it was deemed too dangerous. This was incredibly scary, being told that I was likely to become seriously ill or die if I were to be exposed to Covid-19".*[11]

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[7] 8 Oct 2024 90/18-24.

[8] As described by Dr Catherine Finnis: 8 Oct 2024 74/14-17. See further Prof. Sir Chris Whitty: when asked whether shielding was effective, he pointed to beneficial, harmful and uncertain impacts. In the first category he put the *"practical level of support from the government, which otherwise would not have been present"*: 26 Sept 2024, 126/2-3. There was official recognition from the outset that a package of support would be *"crucial to ensure that people who are clinically vulnerable are able to physically and psychologically cope with a lengthy period of isolation in their homes"*: Briefing from Cabinet Secretariat, 'Secretary of State for Health and Social Care, Healthcare Ministerial Implementation Group 20(1), dated 18 March 2020, INQ000055939_0005.

[9] As Vaughan Gething recognised, an ancillary but important function of deliveries was the opportunity they provided for even the smallest dose of human contact: 20 Nov 2024.

[10] 8 Oct 2024, 81/1-13 to 82/1.

[11] INQ000474233_0191.

12. Prof. Sir Michael McBride candidly reflected that *"[t]he approach that was taken in good faith initially did not fully think through the loss of agency and the loss of control that people would experience"*.[12] Similarly, one of the key findings of the Northern Ireland Patient and Client Council's (**"PCC"**) survey was that the shielding advice engendered a *"significant degree of ... fear and isolation"* in those who were shielding.[13]

13. The problem was not simply being bombarded with texts, emails and letters saying, *"you're at high risk of dying should you step outside your house"*.[14] As the PCC findings made clear, and as Sir Michael recognised, it was the lack of accompanying information to help CEV people understand the *"rationale for why the guidance was being provided [and] what was the scientific basis for this"*,[15] as well as information about practical mitigations available to CEV people if they were not in a position to simply follow to the letter the advice to cut off contact with the outside world.

Individual rather than household approach

14. For many, the shielding advice was unrealistic and unworkable, for example for those with small children. Or, if it was followed, it gave rise to distressing consequences, as in the case of individual family members forced to live in a caravan in the garden, or in the shed or loft, or who *"lived their lives completely upside down, [s]o their family were up in the day and then they did their cooking and eating in the night"*.[16] ONS data for England suggested that 75% of CEV people lived with others and 15% lived with children under the age of 16.[17] It should therefore come as no surprise that the REACT-SCOT study found that rates of Covid-19 infection in the shielded population were associated with the number of adults in the household.[18] One of the conclusions of the study was that in future programmes, <u>policymakers should consider support for household members to isolate with vulnerable individuals</u>. CVF agrees.

15. The absence of such support meant it was *"psychologically extremely difficult for people to still go out and do their jobs knowing that they may well return home with a virus that could kill their loved ones"*, as Dr Finnis described.[19]

Shielding was a blunt tool: millions of CV were on the wrong side of an arbitrary dividing line and left without support

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[12] 24 Sept 2024, 103/23-25.

[13] 24 Sept 2024, 102/5-17; INQ000344088_0012. Prof. Sir Michael McBride concluded that, *"looking back, I think some of the initial messaging around that could've been more nuanced"*: 24 Sept 2024 27/20-21.

[14] Dr Finnis: 8 Oct 2024 83/21-25 to 84/1-2.

[15] 24 Sept 2024, 102/23-25 to 103/1-3; INQ000344088_0031-0032.

[16] Dr Catherine Finnis, 8 Oct 2024, 94/14-22.

[17] 'Coronavirus and shielding of clinically extremely vulnerable people in England': 9 July to 16 July 2020, INQ000339267 _0005.

[18] Expert report of Prof. Snooks, §122, INQ000474285_0045. One of the conclusions of the study was that policymakers should consider support for household members to isolate with vulnerable individuals.

[19] 8 Oct 2024 95/4-19.

16. The wider non-CEV but CV cohort (which included people aged over 70 and those with conditions including diabetes, COPD and chronic respiratory, heart, kidney or liver disease)[20] suffered disproportionately high numbers of deaths and adverse effects from Covid-19. By way of example, a study in The Lancet in August 2020 found that out of 23,698 Covid-19 hospital deaths in England up to 11 May 2020, a third occurred in people with diabetes.[21] Diabetes was not a condition which in and of itself would have led to a person being designated as CEV.

17. The non-CEV but CV cohort were not shielded. As a result, they did not have the various 'passporting' benefits associated with shielding, including: priority access to food, despite the risks associated with mixing in overcrowded supermarkets;[22] priority delivery of medications, despite many needing essential treatments to live, and despite busy pharmacies posing a clear risk of transmission;[23] the right to work from home, despite many frontline roles carrying high risks to CV people; or entitlement to statutory sick pay if they could not work from home, with long waits for universal credit leaving many at financial risk.[24] Some CV people faced an impossible choice between their health and their livelihoods.[25] Employers were not required to carry out risk assessments of CV people, and reasonable adjustments to mitigate risk in the workplace were not made.

18. The CV were not even actively contacted or informed about their higher level of risk.[26] This created the obvious problem that, unless CV people had educated themselves independently, or had otherwise been alerted to their higher risk status, they would have been unaware of their increased risk from Covid-19, and so unaware of the need to take additional precautions. And of course without government support, many CV people would have lacked the ability to take such precautions.

19. After ten weeks of hearings, CVF is not any clearer as to the decision-making process by which the line between CEV, CV and non-CV people was drawn: if this issue was addressed by witnesses, it was only by way of oblique reference to a clinical process. In these circumstances,

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[20] For the full list as at 1 April 2020, see NHSE's document, INQ000408797_0003-0004.

[21] The Lancet (Diabetes & Endocrinology), 'Associations of type 1 and type 2 diabetes with COVID-19-related mortality in England: a whole-population study', INQ000408818_0009. Further analysis, after adjustment for age, sex, deprivation, ethnicity and geographical region, 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. See further the evidence in relation to other CV groups, including those with dementia and Alzheimer's disease and COPD, and older people, set out at §78 of CVF's statement, INQ000409574_0033.

[22] See statement of CVF, §86, INQ000409574_0036 and INQ000308822 (newspaper article entitled 'Sainsbury's dedicated shopping hours for vulnerable people 'chaotic and crowded'').

[23] See statement of CVF, §§90-91, INQ000409574_0037.

[24] Statement of CVF, §85, INQ000409574_0035.

[25] As vividly highlighted, for example, by the evidence of Alex Marshall on behalf of the Frontline Migrant Healthcare Workers: he described how a significant number of frontline migrant healthcare workers were CV but did not have a choice about whether to work or not: 10 Oct 2024, 37/14-17. See also the report of Prof. Snooks, §114, INQ000474285_0042.

[26] See, for example, the statement of Caroline Lamb, which confirms that in Scotland the "non-shielding at risk" (i.e. CV) were not individually identified, but were instead encouraged to self-refer to local authority services should they require support: INQ000485979_0032, §824. In her oral evidence Ms Lamb agreed that *"the more targeted we can get, the more helpful that is"*: 14 Nov 2024, 1-2.

and as Prof. Snooks notes, the line appears to be an *"almost arbitrary"* one.[27] On the available evidence, the possibility that the economic impact of shielding a wider group was a relevant factor in the delineation of the CEV and CV cannot be ruled out.[28] As can be seen from the evidence referred to above,[29] it quickly became clear from UK and global mortality figures that large groups of individuals, including those who were older, and those with diabetes, were at significant and high risk. Yet still the shielding offer was not extended to members of these groups. CVF is of the firm view that more lives could and should have been saved.

20. The Inquiry should be alive to the emotional effect on people of not *"hit[ting] the criteria that got them into the clinically extremely vulnerable group"*.[30] Dr Mulholland gave a vivid insight into this:

> *"So for someone to feel that they were vulnerable enough that they were prepared to isolate for 12 weeks and not talk to someone else or be in their space -- my parents had to do it and they reluctantly said goodbye to the grandchildren and all that sort of thing -- for them to feel that concerned, if someone had turned to them and said, "Actually, you're not that vulnerable after all, you're not as sick as you think you are", was very difficult. And it wasn't saying it that you're not as sick as you think you are, because we often knew that these people were very ill, they just did not hit the list of criteria that we've been given"*.[31]

21. Dr Finnis also spoke about the development of a dangerous narrative that said, *"you are only CV, you are not CEV ... and people started to not want to put themselves in harm's way to help these people"*.[32] This is echoed by the experience of CVF member Carla:

> *"Being a clinically vulnerable teacher who was not officially shielded during the pandemic was an incredibly stressful experience. It has 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. ... 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"*.[33]

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[27] 30 Oct 2024, 169/10-13. As also recognised in the draft miunutes of the UK Clinical Panel for Shielded Patients meeting, 8 July 2020, INQ000421830_0002.

[28] See, in this context, the explanation that in *"In this way we are not taking everybody out of the workforce except the particularly vulnerable 1-2 m so easier for OGDs"*: email between James Harrison and DHSC colleagues, regarding definition at risk groups, dated 8 March 2023, INQ000381246_0005; 0007.

[29] At para. 16.

[30] Dr Mulholland: 23 Sept 2023, 194/11-23.

[31] 23 Sept 2023, 194/11-23.

[32] 8 Oct 2024, 82/10-25; 82/1, emphasis added.

[33] Statement of CVF, §85, INQ000409574_0035, emphasis added.

22. Some CV people remained unaware of their heightened risk, and of the need to take additional precautions, until they were called for their first vaccines in 2021. Of particular note, some 1.7 million people were added to the SPL in February 2021, as a result of the application of the QCovid algorithm to patient records.[34] But by this time, shielding advice (and associated protections) was no longer in place and priority vaccination of the CEV had already been completed. Whilst a data-driven approach to risk stratification was and is on the whole welcomed by CVF,[35] many of CVF's members did not have confidence that QCovid encompassed all the relevant risk factors or underlying conditions (especially rarer conditions). Perhaps more fundamentally, they struggled to have confidence in a decision-making process that had left them unprotected for the best part of a year. As Prof. Banfield of the BMA set out:

> *"Disability charities, such as the MS Society, highlighted how the sudden announcement 11 months into the pandemic would "come as a huge shock" to some, and that the government must prioritise clear communication and comprehensive support.[36] This chimes with the findings from a Guardian article dated 19 February 2021,[37] which explores the experiences of those who were added to England's shielding list. For example, an individual with a rare blood disorder expressed feeling panic and immediately contacting his GP for further clarification. Similarly, a woman who had a high BMI described feeling "quite angry" and "kind of wobbly", particularly as her high BMI "would have been a risk factor a year ago""*.[38]

23. <u>In a future pandemic (and in advance of a future pandemic), more careful thought ought to be given to how **all** those at heightened risk to a particular virus can be protected effectively from the outset</u>. Shielding was an exclusionary and blunt tool. There should instead be a spectrum of support and the flexibility to account for varying degrees of vulnerability and need. This is consistent with <u>CVF's calls for a broader, more nuanced and person-centred approach to protecting those at risk</u> (as set out in further detail below at para. 71).

<u>Flaws in the execution of the shielding programme</u>

Identifying the CEV for the purposes of issuing shielding advice

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

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[34] As explained, for example, by Dame Jenny Harries, §§78-80, INQ000410865_0027.

[35] CVF was somewhat perplexed to hear Sir Christopher Wormald describe QCovid as *"replacing shielding"*: 12 Nov 2024, 123/4-16. QCovid was in fact used to add 1.7 million people to the SP (see, for example, the statement of Dame Jenny Harries, §§78-80, INQ000410865_0027): as Prof. Sir Chris Whitty put it, its *"immediate aim"* was to make the SPL a much more *"accurate tool, and based on individual risk"*: 26 Sept 2024, 116/18-19. Once the shielding programme formally ended, QCovid was not deployed so as to further identify CV people and nor did identification through QCovid prior to that lead to any *"specific assessment of vulnerable people and what they needed to do"* (contrary to the suggestion of Sir Christopher: 12 Nov 2024, 14-16), for example by GPs or secondary care clinicians.

[36] INQ000397316.

[37] INQ000397338.

[38] INQ000477304_0171-0172, §452.

> *"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).[39]
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> *"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).[40]

25. CVF has been dismayed to learn that there was no pre-existing national mechanism or organisation responsible for identifying (never mind supporting) a significant population advised to shield. Testing and planning for this had not been part of any previous pandemic preparedness exercise, including, in 2016, Exercise Cygnus.[41] As Prof. Edwards put it, when describing the lack of preparedness in the context of general practice, *"we were flying by the seat of our pants"*.[42]

26. In CVF's view, this likely 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 advised to shield, with the cohort of 1.3 million CEV people initially identified as needing to shield growing to 2.2 million by 7 May 2020.[43] Judith Paget described how, in Wales, when shielding was paused, some individuals had not realised that they were on the shielding list until they received a letter advising them that they no longer needed to shield. When increased restrictions were again advised on 22 December 2020, some individuals who had previously been advised to shield did not receive this letter.[44] It is not clear whether this is because they had been removed from the shielding list or because there was a failure to contact all those who were on the shielding list with updated advice.

27. It is important for the Inquiry to publicly acknowledge that the results of these delays, which left many people unaware of their risk and the need to take protective measures, would sometimes have been fatal. Dr Arshan, giving evidence on behalf of Covid Bereaved Families for Justice UK, described the fact that communication on shielding came *"too late for many, especially during the second wave"* as *"unforgiveable"*.[45] CVF agrees.

28. Others who did know that they were at heightened risk but had not, or not yet, received a shielding letter to show employers, supermarkets or pharmacies were left entirely unsupported.[46] As Jackie O'Sullivan of Mencap noted, this placed *"intense pressures on families"* who decided

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[39] Statement of CVF, §16, INQ000409574_0011.
[40] INQ000490087_0004, §9.
[41] NAO, 'Protecting and supporting the clinically extremely vulnerable during lockdown', 10 Feb 2021, §1.4, INQ000059879_0017.
[42] 23 Sept 2024, 35/24-25 to 36/1.
[43] Statement of Sir Stephen Powis, §§624-626, INQ000412890_0164; statement of Sir Christopher Wormald, §369, INQ000253807_0101.
[44] INQ000486014_0147, §§417(b)-(c). Ms Paget noted in particular that *"many letters advising people to shield directly issued by their GP surgery or hospital clinician did not always result in the patients being added to the SPL"*.
[45] 26 Nov 2024, 72/19-25 to 73/1-2.
[46] An issue that CTI pressed Dame Jenny about, unfortunately to little effect: 6 Nov 2024, 79-80.

to shield informally, or who split their households to protect a vulnerable family member.[47] Informal shielding was in fact a common phenomenon, highlighting the lack of trust that CEV and many CV people had in the official government response from the outset.[48] A CVF poll of 370 members (including both CEV and CV members) found that 63% began informally shielding before 15 March 2020, with a further 28% starting to shield the following week.[49] In the words of Lesley 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".*[50]

29. Those who shielded informally (whether as CEV, CV or as household members of either) endured the same hardships associated with formal shielding but without any of the attendant benefits. There were also inequalities associated with informal shielding (which in fact primarily affected CV people): many people of working age in frontline (non-office based) roles could not shield without a shielding letter.[51]

30. A further consequence of delays in shielding letters being issued was that the CEV and CV were left *"confused at the end of it all"*, as Dr Mulholland noted.[52] Uncertainty, anxiety and distress took hold at a time when vulnerable people should have been able to look to decision-makers for reassurance and support.

31. In its opening statement, CVF noted that in the numerous corporate statements setting out in lengthy narrative detail the evolution of the shielding programme, there was little evidence of willingness to engage with the question of what went wrong.[53] CVF is grateful for the Inquiry's endeavours in seeking to explore this question, and invites the Chair to make clear findings in relation to at least the following two key themes: (a) data challenges and (b) too much pressure, and a lack of support for, already overstretched GPs.

Data extraction was and remains a "colossal issue"

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[47] 28 Oct 2024, 97/14-19. Ms O'Sullivan spoke of *"tales of two parents having to live in different bits of the house not speaking to each other while one looked after a child with a disability and the other the other child"*.

[48] Statement of CVF, §§109-111, INQ000409574_0045.

[49] Statement of CVF, §19, INQ000409574_0012. See further a survey of the Patients' Association, set out at §138.1 of the John's Campaign statement, INQ000283957_0059, which found that two-thirds of respondents who had shielded had not been advised to do so by the NHS, and that most shielded on their own judgment. Ms Julia Jones reflected that these results showed *"people's caution and people's fear ... and also people's wish to protect others who they love"*: 29 Oct 2024, 30/25 to 31/1-2. See also ESM, INQ000474233_0190.

[50] INQ000485656_0004, §8.

[51] Dr Finnis, 8 Oct 2024, 77/7-20.

[52] 23 Sept 2024, 167/8-9; see also Dr Finnis: 8 Oct 2024, 75/6-19.

[53] INQ000502156_0002, §7.

32. There were significant difficulties in extracting information about potentially vulnerable patients from disconnected data systems.[54] Dame Jenny Harries spoke of the need in England to connect seven different databases in order to achieve *"digital cohorting"*. This was not always straightforward where records were not good or coding was not consistent, and the process took too much time. Further problems were caused by databases being updated at different times.[55] Similar issues were encountered in the devolved nations. Sir Robin Swann referred to 370 different databases in Northern Ireland that sometimes had to be *"manually trawled through"*.[56] Sir Frank Atherton described Welsh digital records systems as being *"behind the curve"*.[57] Prof. Sir Gregor Smith noted that where the correct clinical coding was not in place, *"it was very difficult"*.[58] As Sir Christopher Wormald accepted, data sharing in the NHS was, and is, a *"colossal issue"*.[59] Matt Hancock's frustration around the need to resort to the issuing of copy notices to allow data sharing between the DWP and NHS was palpable.[60]

33. The consequences were dire. As Prof. Sir Gregor Smith conceded, in *"not all instances [did the] coding lead to the identification of people who should be shielding (or sometimes it led to the identification of people who actually didn't require to shield)"*.[61] Even once the CEV had been identified, problems persisted. Letters were sent to the wrong addresses (in Wales, 13,000 of the initial 91,000 shielding letters were not delivered to the correct recipients).[62] In England, missing or inaccurate telephone numbers in NHS patient records meant that 375,000 CEV people could not be reached in the early part of the pandemic.[63]

34. It was deeply concerning to hear Sir Christopher say it was not possible to give a timescale for when the availability of data will be *"good enough"*.[64] Dame Jenny Harries considered that *"[t]here was a lot of learning through the pandemic, so the data foundry in the NHS has improved significantly ... but nevertheless we would hit many of the problems that we had before"*.[65] Matt Hancock's view was that data sharing had taken a backwards step again since the pandemic.[66] CVF notes with particular concern Dame Jenny's view that it would take *"months"* to roll out a QCovid-type algorithm in a future pandemic.[67]

35. CVF recognises that the challenges are significant, raising complex legal and practical issues. Dame Jenny suggested that part of the solution lies in ensuring that patients *"understand why*

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[54] NAO, 'Protecting and supporting the clinically extremely vulnerable during lockdown', 10 Feb 2021, §§2.4-2.7, INQ000059879_0026.

[55] 6 Nov 2024, 73/22-25 to 75/1-17.

[56] 18 Nov 2024, 132/22-25 to 133/§-2. See also Prof. Sir Michael McBride, confirming the absence of a central database in Northern Ireland: 24 Sept 2024, 106/8-23.

[57] 30 Sept 2024, 77/11-12.

[58] 25 Sept 2024, 178/25 to 179/1-2.

[59] 12 Nov 2024, 58/15.

[60] 21 Nov 2024, 162-164; INQ000421858_0022, §86.

[61] 25 Sept 2024, 179/3-7.

[62] Dr Andrew Goodall, 13 Nov 2024, 57/10-14; 60/4-8; and the statement of Prof. Banfield, INQ000477304_0169, §443.

[63] NAO, 'Protecting and supporting the clinically extremely vulnerable during lockdown', 10th February 2021, §3.24; see also §2.8, INQ000059879_0042; 0029.

[64] 12 Nov 2024, 60/2-6.

[65] 6 Nov 2024, 78/3-13.

[66] 21 Nov 2024, 164/15-20.

[67] 6 Nov 2024, 98/19-22.

it's beneficial to share data" and to reassure them that their data would be *"carefully used"*.[68] Plainly this is a long-term undertaking. Concerningly, however, there is little evidence that DHSC, NHSE and other government departments have even begun to grasp the nettle: it would appear that little progress has been made on the NAO's 2021 recommendations.[69] CVF urges the Inquiry to make robust recommendations regarding the urgent need to dedicate time, motivation and resource to tackling the challenges that caused delay in the identification of CEV people, and to improving easy and secure access to healthcare data.

Too much pressure on, and a lack of support for, already overstretched GPs

36. The Inquiry has heard how already overstretched GPs were left to undertake an *"immense amount of work ... [manually] identifying patients who should be in the shielding group without an agreed system and without the full information they needed to make decisions"*.[70] As Prof. Banfield described, the lack of clear instructions and rapidly changing criteria added significantly to the workload of GPs, and caused confusion for both clinicians and patients. Prof. Banfield considered this issue to be one of the key reasons for delays in identifying CEV people.[71] In the absence of clear information from government, it was left to the BMA's General Practice Committee to publish guidance for GPs.[72] In May 2020, the Royal College of GPs and BMA felt compelled to write to the Interim CMO for Scotland, setting out concerns that the burden of GPs doing shielding work was becoming *"unmanageable"*, particularly in the light of the complexity of the work and the challenges arising from often needing to have very difficult conversations with vulnerable patients.[73] The letter further highlighted that the effect of the guidance frequently changing, being contradicted and redelivered was to damage trust between patients and clinicians, as well as in the whole system, and risked impacting on patients' wellbeing and ongoing care.[74] The Inquiry should recognise the important work undertaken by GPs in relation to the shielding programme, and make recommendations to ensure that any future reliance on GPs to assist in identifying vulnerable individuals is underpinned by appropriate resourcing and provision of information.

Flawed decision-making around when to start, pause and stop the shielding programme

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[68] 6 Nov 2024, 16-20.

[69] As set out in Sir Christopher Wormald's statement (§363, INQ000389241_0107), these included that the DHSC should: (a) ensure healthcare data systems allow easy but secure access to healthcare data; (b) set out the core data requirements it is likely to need in a future pandemic or civil emergency and how it can access those data in a timely manner; and (c) establish a robust plan on how to communicate clearly, quicky and consistently with CEV people to ensure that people are clear if they need to shield, why they need to shield, how to shield, and the support available to them.

[70] Statement of the Royal College of GPs, §§154-155, INQ000339027_0027. See also the report of Prof. Edwards et al., which described this task, and the task of responding to calls from concerned patients who felt they should or should not be shielding, as an *"urgent"* additional pandemic-related burden on GPs: INQ000474283_0031, §98. See also INQ000397298, a briefing dated 28 April 2020 indicating that GP practices were spending 26 hours a week verifying SPLs.

[71] INQ000477304, §§434-445; INQ000477304_0167-0170, §§434-445.

[72] INQ000397241.

[73] INQ000280659_0001. As one GP described to ESM, *"[i]f there had been a bit more communication as to who was thought to be high risk it would have made it a bit simpler"*, INQ000474233_0192.

[74] INQ000280659_0002; see also the statement of CVF, §§109-111, INQ000409574_0045.

37. 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 invites the Inquiry to find that the decision-making process failed to give sufficient weight to the distinct risks faced by the most vulnerable and their particular need for support.

The shielding programme began too late

38. Throughout January and February 2020 there was rising knowledge about the potential for catastrophic impacts on the CV from Covid-19. The need to identify and support those at highest risk ought to have been identified before 5 March 2020.[75]

Pausing and re-starting shielding: a drive to return to normality at all costs

39. 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 in August 2020, this coincided with a wider relaxation of various social distancing measures, mandatory mask wearing and testing requirements, and the introduction of the 'Eat Out to Help Out' scheme. The message sent by this policy shift was that it was safe for CV and CEV people to dine in restaurants and to increase their social contacts, when nothing could have been further from the truth. The decision to pause shielding advice was made in the knowledge that exponential growth was likely to re-start if restrictions were largely lifted.[76] That is precisely what happened, with the second wave leading to what Prof. Sir Chris Whitty described as *"extraordinary mortality"*.[77]

40. In August 2020, vaccinations and antivirals were not available and treatments were in their infancy. Vital mitigations, such as widespread and effective ventilation, and proper emphasis on high grade face masks, were absent: the official line continued to be that Covid-19 was largely transmitted through droplets. Crucially, the risk to the CEV, and to the CV for that matter, had not changed. This explains concerns expressed by disability rights groups and other advocates for the CEV in Wales, leading to the Welsh health minister rejecting the CMO's advice to follow the other nations in pausing shielding in August 2020. It was recognised, but seemingly in Wales only, that a significant number of CEV would have *"felt abandoned and not liberated by being taken out of shielding"*.[78]

41. The official rationale for the pause in shielding was that the harms outweighed the benefits. The impacts of shielding are addressed in further detail below, but for present purposes CVF notes that many of the harms of shielding were not inevitable, or could at least have been mitigated

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[75] Covering email and briefing titled 'Shielding', 15 March 2020: INQ000346717 and INQ000346718.

[76] Statement of Prof. Sir Peter Horby, §129, INQ000226562_0037; statement of the BMA, §§447-448, INQ000477304_0170.

[77] 26 Sept 2024, 58/16-18.

[78] Email chain between Clare Jenkins, Welsh Government, and colleagues, regarding 'Next steps for Shielding in Wales' (MA/VG/2163/220), dated between 2 July 2020 and 06 July 2020, INQ000252524; see the underlying advice at INQ000136796. See also the email chain between COVID 19 Shielding and Bereavement Response and Private Secretary to Deputy Minister and Chief Whip, copying in various Welsh Government colleagues, regarding MA/VG/2163/20 dated between 2 July 2020 and 3 July 2020, INQ000252522.

by, the provision of targeted and meaningful support. Instead, however, there was a dramatic shift to the CEV *"assessing their own circumstances, situation and risks to provide a greater sense of agency and control in minimising risk"*.[79] The most important condition which could have supported any such personal choice was mitigating the risk of contracting Covid-19. As set out above, such mitigations were absent, and so the shift to personal responsibility was doomed to fail given the community position, over which the CEV had no control. As Prof. Banfield described, a lack of clear guidance at that time (such as in relation to whether CEV should visit GP surgeries in person for their medical treatment)[80] created *"doubt in [the] minds [of the CEV] where safety existed and didn't exist and to a certain extent that continues today"*.[81]

42. The pause in shielding advice meant that the CEV lost vital protections overnight, including entitlement to claim statutory sick pay and the right to work from home. A third of CEV people surveyed by the ONS at this time reported feeling uncomfortable about returning to work outside the home.[82] Many CEV experienced the withdrawal of support as *"like falling off a cliff"*.[83] They were thrust into a world in which the public were being given false confidence that the virus no longer posed a significant threat. Many CEV people felt 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).[84]

The 'end' of shielding: a fallacy for many

43. When national shielding advice came to an end on 31 March 2021,[85] around 30% of the by that time 3.8 million CEV on the SPL had still not received a first dose of the vaccine.[86] Some CEV people (in fact an unknown number at that point in time) were unable to mount an effective response to the vaccine at all.[87] Indeed, the same was true for some severely immunosuppressed people who were classed as CV and were never identified as CEV. In any case, given the difficulty of keeping up to date with new variants, vaccines provide only incomplete protection against transmission or severe outcomes, particularly for CV people.

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[79] As Prof. Sir Michael McBride put it: INQ000421784_0095, §134.

[80] On 31 May 2020, then chair of the BMA's GPC England, Dr Vautrey, publicly expressed concerns that it remained unclear from the Government's announcement of 1 June 2020 that CEV could go outside again whether they should visit GP surgeries for medical treatment. He also indicated that the BMA had not been directly informed about the new guidance: INQ000477304_1070, §448.

[81] 28 Oct 2024, 158/24-25 to 159/1.

[82] ONS bulletin, 'Coronavirus and shielding of clinically extremely vulnerable people in England: 9 July to 16 July 2020', INQ000339267_0002.

[83] Statement of CVF, §62, INQ000409574_0028.

[84] Statement of CVF, §53, INQ000409574_0028.

[85] With the shielding programme being formally closed on 15 September 2021: see the statement of Prof. Sir Chris Whitty, §9.5, INQ000410237_0083.

[86] Paper from SSHC to COVID-O, 'Future of Shielding Policy', 11th March 2021, §29, INQ000092395_0006.

[87] Paper from SSHC to COVID-O, 'Future of Shielding Policy', 11th March 2021, §29, INQ000092395_0006. See further a letter sent to Baroness Eluned Morgan in December 2021 highlighting that vaccination provided effective protection against severe

44. Reliance on the availability of antiviral treatment as a further justification for ending shielding was similarly flawed.[88] CVF was surprised to hear Baroness Morgan describe the system for ensuring access to antivirals in Wales as *"quite a sophisticated operation"* that ensured a *"very speedy response"*.[89] This does not reflect the experiences of CVF members, as set out in further detail below at para. 98.[90]

45. Again, the focus shifted to providing *"precautionary advice on managing the risk of exposure"*.[91] <u>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 – not least in the healthcare context</u>. Many people who had previously been advised to shield felt cast adrift, unsupported and unsafe. As one formerly CEV member of the public wrote in desperation to Prof. Sir Chris 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 perspective. No parameters. ... How do I go about making a practical assessment of the risks to myself of 'ending restrictions'? I feel entirely disregarded"*.[92]

46. It is telling that in seeking input from colleagues on how to respond, Sir Chris noted that he received *"a lot of variants of these"* emails.[93]

47. The support associated with shielding advice came to an end despite officials' stated recognition that CEV people *"may face or perceive greater risks ... and therefore face a disproportionate impact from ending support, particularly on their mental health"*.[94] In the Scottish context, there was recognition that *"substantial work was first needed to foster the conditions in communities which could support personal choice"*.[95] Caroline Lamb was prepared to accept that these aims were only *"partially achieved"*,[96] whilst Prof. Sir Michael McBride conceded that it *"proved very hard to allow people the ability to make nuanced decisions"* about the level of risk they were prepared to take on.[97]

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illness and death in only 40% of the CEV: 20 Nov 2024, 153/8-17. This chimes with the evidence of Kathryn Rowan on behalf of ICNARC that after vaccination Covid-19 remained *"serious enough"* to bring some complex patients with comorbidities into ICU: 2 Oct 2024/11/20-25 to 12/1-4.

[88] See, for example, statement of Sir Sajid Javid, §125, INQ000485736_0059.

[89] 20 Nov 2024, 196/16-25 to 197/1-4.

[90] Sir Sajid was prepared to accept that *"it is possible ... that for some people [the] process didn't work as well as it should have"*: 25 Nov 2024, 143/6-7.

[91] Statement of the Cabinet Office, §7.91, INQ000436880_0060.

[92] INQ000074822_0001.

[93] INQ000074822_0001.

[94] Paper from SSHC to COVID-O, 'Future of Shielding Policy', 11 March 2021, §37, INQ000092395_0007.

[95] Statement of Prof. Sir Gregor Smith, §209, INQ000484783_0049.

[96] 14 Nov 2024/18-19.

[97] 24 Sept 2024, 143/22-25 to 144/1-3.

48. Further, despite the stated recognition of Dame Jenny, Sir Sajid and others that the ending of shielding had to be handled sensitively, with careful communications and tailored support,[98] when it came to it, such communications and support failed to materialise.[99] There was no consultation with those who had been advised to shield prior to the end of shielding,[100] and no equality impact assessment was completed. There was a marked lack of transitional support to bridge the gap between the passporting protections associated with shielding and the Enhanced Protection Programme ("EPP"), and then from the EPP to nothing. There was no bespoke mental health offer for this group;[101] no financial safety net for those with employers demanding they return to work despite ongoing risks;[102] no information about the spread of the virus that would have assisted people in assessing the risk to them; and overall intransigence regarding the need for a national action plan and clear communications in relation to mitigations (which might have included, for example, a targeted offer of PPE to the formerly CEV and their carers).[103] 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"*.[104] In the circumstances, and as recognised by Prof. Sir Michael McBride, it was *"very difficult"* to *"provide assurance"* to those who had been shielding.[105] The Inquiry is urged to make a finding that there was a marked failure to put in place transitional or rehabilitative support after the end of shielding.

49. In the light of this backdrop, it should come as no surprise that whilst shielding in formal terms may be a thing of the past, many formerly CEV and CV people continue to shield, or lead very restricted lives, to this day.[106] Many of CVF's members have felt that, despite the challenges, shielding was and is a necessity:

> *"Absolutely petrified, isolated, lonely and sad but at the same time safe. It was the only safe option"* (Becky).[107]

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[98] See INQ000333929_1 re: the need to *"reassure"* this group given the frequency of concerns raised to DHSC about this group feeling forgotten. Sir Sajid accepted that *"there were people in this important group that clearly felt that they weren't getting enough communication"*, and described how the issue was frequently raised in Parliament: 25 Nov 2024, 97/3-10.

[99] Humza Yousaf accepted that *"communications is one area where we possibly could have been better in terms of a transitional approach"*: 19 Nov 2024, 168/6-8.

[100] Dr Finnis: 8 Oct 2024 113/6-17.

[101] Paper from Ministry of Housing, Communities and Local Government and Department for Health and Social Care to COVID-O, §47, INQ000066820_0008.

[102] 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 11 March 2021, p.3(f) (INQ000091808_0006).

[103] Statement of Prof. Sir Peter Horby, §146, INQ000226562_0044.

[104] INQ000477304_0172, §453.

[105] 24 Sept 2024, 27/6-25 to 28/1.

[106] As confirmed by Prof. Snooks: 30 Oct 2024, 167/16-24. See also the findings of Part 2 of the PHS Impact and Experience Survey that, as at the date of the survey in late 2021, 81% of those in the highest risk group still made decisions influenced by concerns around contracting C-19. Caution was highest in those who were severely immunosuppressed or immunocompromised. 76% of respondents reported an ongoing negative impact on their quality of life.

[107] Statement of CVF, §44, INQ000409574_0021.

> *"I panicked at first as [I was] 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).[108]

> *"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"* (Imogen).[109]

Communication, advice and support for those shielding fell short

50. People shielding had the right to expect timely, evidence-based and sensitive communications and advice. As Prof. Sir Chris Whitty recognised, *"you cannot overcommunicate ... where someone has been essentially taken out of society, and information is very important"*.[110] The importance of good communication has been further emphasised in the CMOs' Technical Report:

> *"[C]ommunication around clinical vulnerability is complex and can have long-term impacts. ... Communication about the intervention itself therefore needed to be clear as to who was vulnerable and why this was changing, as well as what was being asked and why"*.[111]

51. Yet communication fell short in a number of ways, leaving CEV people to feel as if they had been forgotten.[112] Sir Frank Atherton felt *"sure there are plenty [of people who shielded] who felt communications let them down, and we need to learn from that"*.[113] 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"*.[114]

52. On the most basic level, vital communications, such as letters advising people to shield, did not always reach the right people or reach them in good time.[115] As the CMOs' Technical Report recognised, it took too long for letters to be translated into different languages or made available

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[108] Statement of CVF, §52, INQ000409574_0024.
[109] Statement of CVF, §66, INQ000409574_0029.
[110] 26 Sept 2024, 124/2-5. See also Matt Hancock, 22 Nov 2024, 17/21-22: *"Being able to communicate [with those at risk] is incredibly important"*.
[111] 'Technical report on the COVID-19 pandemic in the UK', 1 Dec 2022, INQ000203933_0258.
[112] Statement of Prof. Sir Michael McBride, §126, INQ000421784_0088. Sir Robin Swann accepted that ongoing engagement through the PCC would have gone towards addressing the issue of CV feeling forgotten: 18 Nov 2024, 167/9-20.
[113] 30 Sept 2024, 137/7-9.
[114] INQ000490087_0004, §10.
[115] NAO, 'Protecting and supporting the clinically extremely vulnerable during lockdown', §17, INQ000059879_0012. See also para. 33 above re: the 13,000 missing letters in Wales.

as easy read and audio described versions.[116] Texts and emails excluded those suffering from digital poverty. ESM summarises the problem in the following terms:

> *"[S]ome contributors with additional needs said they found it difficult to access information from GPs in the right format for them. This meant they did not understand what having to shield meant in practice, making them feel less safe and more isolated"*.[117]

53. The mechanisms for effective communication were not always there. Prof. Sir Chris Whitty described how *"Sir Patrick Vallance and I only appeared on TV if we were asked to by the government. ... I tried to get and then signpost to people some information myself, but that's clearly inadequate and a hopeless way of trying to achieve this aim"*.[118]

54. Communications providing actual guidance and information (as opposed to those simply reiterating the high level of risk posed to the CEV by the virus) were not frequent enough. When communications did come, they were often 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.[119] This was compounded by a lack of transparency as to the decision-making process used to identify those who were CEV and CV, and the dividing line between them (described by Prof. Snooks as an *"almost arbitrary"* one).[120] Some people did not understand the nature and degree of their own vulnerability. National communications were not always consistent with local guidance, and there were discrepancies between official guidance, ministerial comments, guidance issued by professional bodies and media reports.[121] These inconsistencies mattered, because the effect was to leave CEV 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. This is clear from the findings of Sharp et al., summarised by Prof. Snooks as follows:

> *"[S]ome shielding people reported that messages around shielding were confusing or felt inconsistent, especially when they sought advice from medical professionals: "It just wasn't clear as to what I should or shouldn't do"* (ID11)*; "one consultant was saying one thing and one was saying the other*" (ID9)".[122]

55. The advice was also incomplete. Importantly, it did not address the scientific rationale for the advice.[123] It did not provide up-to-date information about the virus (including routes of

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[116] 'Technical report on the COVID-19 pandemic in the UK', 1 Dec 2022, INQ000203933_0258.
[117] INQ000474233_0192.
[118] 26 Sept 2024, 123/24-25 to 124/6-8.
[119] Report of Prof. Edwards et al., §134, INQ000474283_0042.
[120] 30 Oct 2024, 169/10-13.
[121] NAO, 'Protecting and supporting the clinically extremely vulnerable during lockdown', 10th February 2021, §§2.12-2.13, INQ000059879_0032; see further the statement of the Royal College of Obstetricians and Gynaecologists, §§32-34, INQ000470853_0011.
[122] INQ000474285_0053-0054, §155.
[123] As reflected in the findings of the NI PCC survey (INQ000344088_31-32), as summarised by Prof. Sir Michael McBride: *"[T]he shielding population] asked for clearer guidance on a more regular basis and actually a clear rationale for why the*

transmission and prevalence rates by local area). It did not outline the practical steps that all vulnerable people, including the CV, could take to protect themselves, for example when they needed to leave their homes to work in frontline or face-to-face roles (in the case of the CV), or to access healthcare, or to visit other high-risk settings, or when strict shielding advice was paused. This would have included advice as to the benefits offered by high-quality face masks or in relation to the importance of ventilation. It did not recognise practical realities, such as individuals' varying degrees of capacity to adhere to guidance. There was a lack of clarity for family members and carers of the CEV to whom shielding support did not extend: many of CVF's members are working age adults living with families, creating particular difficulties for some when lockdowns were lifted and children were required to return to school and family members to work.[124] There was no specific advice for CV people, who were never contacted directly with targeted advice. The advice also failed to make clear the importance of continuing to access healthcare for non-Covid-19 healthcare needs or the risks of delaying treatment (a particularly worrying omission given that the CEV and CV by definition had underlying health conditions). It should not have fallen to CVF and other groups to try and fill these and other gaps in the official guidance.[125]

Failure to mitigate the negative impacts associated with shielding

56. It ought to have been predicted, and indeed it quickly became clear, that the benefits of shielding[126] were accompanied by a host of negative psycho-social effects, as well as practical problems. CVF considers that many of these impacts could have been mitigated by support that was targeted, meaningful and long-term. This would have been of value in and of itself (by improving the wellbeing of an already vulnerable group) and would also have been likely to improve the protective effects of the shielding programme (by facilitating greater compliance). Measures should have included:

    a. Support to address the negative mental health impacts associated with following shielding advice. A survey carried out by Lasseter et al. in August to September 2020 found that 90% of respondents reported worrying about Covid-19, with a further 43% reporting a negative impact on their mental health as a result of shielding.[127] Such impacts were felt particularly acutely once lockdowns eased and there was a disconnect between the

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guidance was being provided. You know, what was the scientific basis for this. So there were some very clear and strong messages": 24 Sept 2024, 102/23-25 to 103/1-3.

[124] See the report of Prof. Snooks, citing the EVITE study, §156, INQ000474285_0054.

[125] Statement of CVF, §32, INQ000409574_0017.

[126] As set out above, at para. 7 re: passporting and para. 49 re: the reassurance derived from feeling safe. CVF notes that the benefits of shielding are sometimes overlooked, and urges the Inquiry not to do the same (see, for example, the report of Prof. Snooks which, despite including a sub-heading entitled 'Research on the positive and negative impacts of the shielding programme' (§119, INQ000474285_0043) did not go on to focus in any meaningful way on the positive impacts experienced by some CEV who shielded).

[127] 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', 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).

restrictive lives that many CEV continued to lead and the greater freedoms accorded to their friends and family. As one contributor to ESM noted, *"My sisters were able to go places together and do things, and my daughter and her children ..., they were all able to ... and I just had to watch them, so we became more isolated as the time went on and you had less people to talk to. And it got to the stage then where ... you ended up getting into bed and you didn't want to come out, even on the most beautiful day of the year, because I had nothing to get up for"*.[128] ESM goes on to summarise how *"[a]s well as being afraid, [shielding] meant contributors often experienced overwhelming boredom and isolation. Many of the stories shared how people's ... mental health deteriorated quickly throughout the pandemic"*.[129] There were inequalities associated with socio-economic status and age. Those without outside space or with jobs that could not be done remotely faced greater challenges.[130]

Dr Finnis spoke powerfully about how some simple signposting to available resources might have made all the difference.[131] For some, more bespoke and intensive mental health support would have been necessary. Yet across the board, there was a failure to consider and deliver such measures, both during the official shielding programme and after it. This was recognised by Prof. Sir Gregor Smith who wondered whether, given that the shielding population were *"essentially cutting themselves off from society and [are] surrounded by fear ... an in-built mechanism for greater mental health support during that period would have been an additional benefit for them"*.[132]

b. Support to alleviate social isolation. CVF agrees with the evidence of Julia Jones on behalf of John's Campaign, Care Rights UK and the Patients' Association that there *"could and should have been a more sophisticated understanding of the impact of isolation on people ... and the impact of disconnection. I think perhaps we've all learned quite a lot through the pandemic about how people need each other for their identity and how people need to feel valued. If you're in the situation where people are either voluntarily or on advice withdrawing from society, I think it's extremely important to try and alleviate that. ... And people have mentioned some of the excellent voluntary mutual aid initiatives that sprang up but I'll bet you they only sprang up in certain areas"*.[133]

c. Public education to address misconceptions and reduce social 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 felt othered, devalued and isolated by their status, compounded by government briefings which either

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[128] INQ000474233_0193-0194.
[129] INQ000474233_0193.
[130] ESM, INQ000474233_0194-0195. See Welsh Government report, 'Shielded patients' access to private outdoor space during the coronavirus (Covid-19) pandemic', June 2020, INQ000227225.
[131] 8 Oct 2024, 13-20.
[132] 25 Sept 2024, 118/10-17.
[133] 29 Oct 2024, 33/20-25 to 1-5.

attempted to provide reassurance to the general public by emphasising that the risks of Covid-19 were most significant to those with underlying health conditions,[134] or which sought to minimise the ongoing threat posed by the virus completely. Once shielding was paused and after the shielding programme came to an end, there ought to have been simple and straightforward public messaging that the virus continued to circulate, that some people remained at heightened risk, and that they continued to need the benefit of mitigations.

d. Support to address the negative effects of shielding on physical health. One ESM contributor described how, *"[b]y shielding the real risk to me was not being able to manage my health condition, which I do mainly through exercise"*.[135] CVF addresses in further detail below the problems the CEV and CV experienced in accessing their usual care for their underlying conditions.[136]

e. Financial support. The financial implications were many and varied. Some of those who shielded lost businesses and jobs. Many people faced disproportionate costs associated with needing to access healthcare on a private basis. Targeted financial support was limited to the duration of the formal shielding programme 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 those who, in the absence of safe conditions, such as proper ventilation, widespread mask wearing and testing, remained at high risk and continued to shield after the formal end of the shielding programme.

Shielding was not enough

57. The existence of a shielding programme appears to have been viewed by many of the official witnesses as evidence that the government had done all it could and needed to do to protect those at heightened risk from the virus. This cannot be correct.

58. First, as set out above, at paras. 16-23, and throughout section B, the shielding programme did nothing to protect the wider, and much larger CV cohort. Members of this cohort suffered disproportionately high numbers of deaths and adverse effects from Covid-19. Yet despite this knowledge, they were not shielded, and so did not have the various 'passporting' benefits that for so many would have been necessary in order to take precautions to stay safe. Nor were they offered any alternative forms of support. They were not even contacted directly and informed that they were at heightened risk. It is beyond doubt that these failures led to avoidable deaths and suffering. These failures cannot be justified, and must not be repeated in a future pandemic.

59. Secondly, the sacrifice and suffering associated with shielding (whether formal or informal), lockdowns and restrictions were in too many instances undermined when CV people contracted Covid-19 in healthcare settings. CVF understands this to be a broad conclusion of Prof. Snooks'

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[134] 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", INQ000408813_0007.
[135] INQ000474233_0194.
[136] At paras. 75 to 80.

report, which is also echoed in other reviews and surveys. For example, the report of the PHS Impact and Experience Survey concluded that *"[t]he shielding programme could only influence some aspects of exposure to the virus: it could not stop people from needing to access health care. It is recommended that future programmes consider more fully the risk of hospital-onset infections"*.[137] CVF emphatically agrees, and addresses this issue, and suggested recommendations, in further detail below, at paras. 81-98.

C. PROPOSED RECOMMENDATIONS TO ENSURE BETTER PROTECTION FOR ALL CV PEOPLE, NOW AND IN A FUTURE PANDEMIC

60. CVF submits that the Inquiry should find that Prof. Snooks goes too far to rule out any form of shielding ever again. The nature of a future pandemic cannot be predicted, and nor can the broader circumstances in which any such pandemic might occur, including, for instance, the state of preparedness and capacity within the healthcare system at the time. CVF notes that Prof. Snooks' conclusion in this regard is an outlier (compare, for example, the evidence of Prof. Sir Chris Whitty,[138] Sir Frank Atherton,[139] Dame Jenny Harries[140] and Matt Hancock,[141] as well as the findings set out in the CMOs' Technical Report).[142]

61. It is hoped, however, that all can agree that it is eminently possible to devise, and for the Inquiry to make recommendations regarding, *"suggestions for better planning and [for] things [to be] arranged in a better way and more empowering way for people who are at greater risk, rather than just leaving this only option of locking them away"* (as Dr Finnis put it).[143]

62. CVF sets out a number of overarching proposed recommendations below. These are designed to be read alongside the more specific recommendations already set out above (in underlined text) and are directed towards ensuring better protection for all CV people now,[144] given the ongoing risk posed to them by Covid-19, and in the event of a future pandemic.

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[137] INQ000401271_0068.

[138] Sir Chris's view was that there was an *"absence of evidence one way or the other rather than evidence that [shielding] didn't work]"*. He would not *"go as far as Snooks [did]"* : 26 Sept 2024, 130/21-22.

[139] Sir Frank considered the findings in the report to be *"rather definitive"*: 30 Sept 2024, 85/10.

[140] 6 Nov 2024, 110-119 (see, in particular, 115/8-14). Asked directly whether she would recommend a shielding programme in a future pandemic, Dame Jenny said she would (6 Nov 2024, 118/15-25 to 119/1-9): *"I would find it very difficult as a clinician to say I know there are people who, for plausible clinical reasons, are likely to be at heightened risk from an infection which has no vaccine, no countermeasures, no therapeutics, and just say, sorry I'm not going to give any particular advice or support. That feels wrong. Would I do it differently? We've discussed lots of different communication elements, yes. Would I try to set things up sooner? Yes. Would we have ... a tool ... to support risk assessments ... the sooner that's set up, then obviously again we have more information"*.

[141] Who put it in perhaps the most emphatic terms: *"There is no reasonable assessment of the shielding programme that can find that if you give people support and ask them to protect themselves from interactions with others then they are anything but less likely to die of Covid. And, of course, there were higher – a higher proportion of deaths amongst the shielded population than there were amongst the population at large and that's because they were vulnerable"*: 21 Nov 2024, 167/25 – 168/1-10. See also Mr Hancock's statement, INQ000421858_0023, §90, in which he expressed the view that the shielding programme saved many hundreds of thousands of lives.

[142] INQ000203933_0257: *"It is currently difficult to quantify the impact of shielding on either SARS-CoV-2 transmission, COVID-19 outcomes or wider impacts, because its early and universal application for relevant groups left no control groups"*.

[143] 8 Oct 2023 93/3-8.

[144] I.e. encompassing **all** those who today remain at higher clinical risk to Covid-19, including those formerly classified as CEV and those who were identified as not being CEV but CV, as well as those whose immune system means they are at higher risk.

Falling through the cracks of equalities law

63. Many CV people cannot currently avail themselves of the protections of equalities legislation. This needs to change. If it does, it would be a vital first step towards ensuring that the safety, wellbeing and distinct needs of the CV do not continue to be overlooked. It is beyond doubt that the CV face enhanced risks during pandemics, epidemics and generally in high-risk environments: as the Covid-19 pandemic has shown, the CV experience heightened mortality and other adverse outcomes, and require additional health protections that may not always be necessary for other groups, or not to the same extent.

64. At present, equalities law does not provide the necessary protection. A substantial number of CV people will not come within the protection of the Equality Act 2010, because they do not fall within the existing protected characteristics, particularly disability and age. This will be the case where conditions are well-managed or short-term (or treatments, such as immunosuppressant treatments or steroids, are short-term), such that the conditions do not have a *"substantial"* or *"long-term"* negative effect on the ability of CV people to carry out normal daily activities within the meaning of s. 6(1) of the Equality Act 2010.[145] However, this is just part of the problem, because even if they do fall within the protected characteristics, the practical reality is that they often remain unprotected. This is because employers and institutions do not recognise, let alone fulfil, the requirements not to discriminate against CV people, whether directly or indirectly (for example on the basis of wearing a mask: see further para. 73 below re: mask abuse), or to make reasonable adjustments (with this duty in any case only arising in relation to those who are disabled within the meaning of the Act and not also on the basis of age). Reasonable adjustments should include, for example, clean air, changes to physical space to avoid too many people in poorly ventilated spaces, the right to wear a mask, and the right to work from home where risk cannot be sufficiently mitigated. Such adjustments are unfortunately rare, because employers do not appreciate their legal duty to put them in place in the context of CV people.

65. The CV also rarely benefit from the requirement that those exercising public functions must comply with the public sector equality duty. Organisations do not, as far as CVF is aware, at present impact assess policies and practices before implementing them (and on an ongoing basis) with a specific focus on CV people, and to identify potential mitigating steps to reduce or remove adverse impacts.[146] It is recognised that some impact assessments did consider the impacts of certain policies on the CV. However, this was patchy and did not go far enough. In Wales, for example, an integrated impact assessment was undertaken only at the end of the shielding programme and only in respect of the support provided, rather than focusing on the broader

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[145] See further the guidance, 'Disability: Equality Act 2010 – Guidance on matters to be taken into account in determining questions relating to the definition of disability'.

[146] A practical example may assist. Prof. Edwards et al. recommend that Integrated Care Boards, Primary Care Networks, Health Boards, and the HSC work with GPs to specifically plan for the unequal impacts of a future pandemic on particular patient groups, and to consider how these can be mitigated: INQ000374283_0093, §327. It is vital that the specific needs of CV patients are considered as part of any such assessments.

potential impacts of a shielding programme.[147] As is the case in the workplace, because clinical vulnerability is not referred to explicitly in equalities legislation, the CV fall through the cracks of the legislative framework.

66. These failures are costing livelihoods (because CV should not be required to work in unsafe environments) and, ultimately, lives (because CV people are being put at unjustified and unlawful risk). The simplest and most effective way to combat these failures is to make clinical vulnerability a specific protected characteristic under the Equality Act 2010. As well as filling the at present unjustified gap in the existing legislative framework, this would signal in the clearest possible terms to employers and institutions the duties they have towards CV people. The Inquiry is urged to give careful consideration to the clear benefits of recommending a discrete amendment to the Equality Act 2010 to ensure that this happens.

67. CVF recognises that it will take some time to bring about the legislative change required to ensure that CV people are recognised as a formally protected group. In the meantime, CVF proposes that the Inquiry recommend that the Equality and Human Rights Commission urgently amends its statutory guidance on workplace equalities in order to make clear (a) that it is necessary to consider whether the CV fall within existing protected characteristics and (b) what reasonable adjustments should be made immediately in order to ensure that CV people are able to work and be part of social institutions on a safe and equitable basis.

68. There is little or no legal accountability for the many and significant ways in which CV have been overlooked, forgotten and failed during the Covid-19 pandemic. The CV continue to be overlooked, forgotten and failed today. CVF will continue to campaign for legal reform in the hope of bringing about systemic change, and urges the Inquiry to exercise its powers so as to bring about the necessary change on an urgent basis.

Public engagement and education

69. Government must meaningfully engage with the CV to better understand their distinct needs, and their requirements in terms of communication, advice and support.[148] This needs to happen now, on an ongoing basis, and certainly in the event of a future pandemic. We know that some of the surveys of CEV people conducted during the emergency phase of the pandemic directly informed clinical advice and government policy: in the Northern Irish context, for example, and as explained by Prof. Sir Michael McBride, *"the findings of the PCC survey clearly demonstrated the significant adverse social and psychological impacts of shielding and specifically was a significant factor contributing to my advice to the Minister and the Executive to pause shielding in July 2020 and informed my discussions with UK CMO colleagues on the*

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[147] As accepted by Dr Andrew Goodall, 13 Nov 2024, 85/15-25 to 86/1-12. By way of further example, see Covid-O Paper on Disproportionately Impacted Groups and the Covid-19 Taskforce, INQ000053842. The paper did not consider disproportionate impacts on the CV, or ways to mitigate such impacts.

[148] As recognised by Caroline Lamb in her supplementary statement, §11, INQ000474694_0004.

balance of benefit and harm".[149] Whilst there were some positive examples of engagement with the CEV, these tended to exclude the CV, so there are real and significant gaps in information. A further illustration of this problem is provided by the candid recognition of Caroline Lamb that the Scottish government has no information about the CV who are to this day still shielding in some way. As a result, the government has no grasp of the scale of the issue or of what help this group might need.[150]

70. <u>Advice, communication and support must be tailored to what the CV say they need</u>. Better engagement will lead to more meaningful advice, communication and support for the CV. In addition to the specific measures set out above (including in relation to communication and support for mental and physical health, and finances),[151] and those which will be addressed in further detail below (concerning safe access to healthcare and antiviral treatments),[152] CVF invites the Inquiry to make an overarching recommendation to the effect that protective measures and support must be devised with the need to respect, include and empower CV people in mind. As Dr Finnis put it:

> *"[A]lthough we were scared and frightened, ... there's many capable people who have underlying conditions [who] would be really ready to understand ... information, to empower themselves to be able to reduce their own risk and indeed that's what CVF has tried to do."*[153]

71. <u>CVF supports in principle a person-centred approach which recognises that individual circumstances vary, and in particular that different people in different circumstances have different attitudes towards risk</u>. For such an approach to work, in practice, however – for people *"to be able to assess ... risk for themselves and take the approach which [is] most suited to their risk tolerance"*[154] – CV people need to be provided with the right information at the right time. This includes up-to-date evidence about Covid-19 or any future virus (including in relation to routes of transmission, prevalence by local area, variants of concern, and effective mitigations).

72. <u>Public education</u>. CV people have been left to explain themselves, and to fight for support, recognition and respect. Their attempts to do so are frequently met with resistance or hostility. CVF is entitled to look to the government to properly educate the public that Covid-19 continues to circulate,[155] that some people remain at heightened risk, and that some CV people continue to

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[149] INQ000421784_0088, §126. It should also be noted that other surveys did not appear to have any direct impact on policy: for example, in England, the ONS data compiled in four reports, consistently highlighted the negative mental health impacts of shielding, but no specific action was taken in order to seek to mitigate these problems.

[150] INQ000485979_269, §910.
[151] At para. 56.
[152] At paras. 86 to 98.
[153] 8 Oct 2024, 19-25.
[154] As Prof. Sir Gregor Smith put it: 25 Sept 2024, 123/21-23.
[155] It is also important to dispel common misperceptions, e.g. that C-19 is a typical 'winter' respiratory virus: as the CDC has indicated, C-19 can surge throughout the year, in part due to the emergence of new variants and in part due to waning immunity from previous infections and vaccinations. The CDC's advice is to *"layer" "additional"* prevention strategies in particularly high-risk scenarios, including during a surge.

need the benefit of mitigations and IPC protections.[156] The approach of the CMO for Northern Ireland that encouraged the wider public to *"put yourself in the shoes of those who have shielded"* is a positive example of public messaging which does not appear to have been replicated in the other nations.[157] Such messaging is not difficult to devise and implement, and the potential benefits to the CV are vast.

73. It is in direct consequence of a failure to educate the public that 'mask abuse' has become an increasingly concerning and worrying reality for many CV people. In her oral evidence, Dr Finnis described how she wears a mask *"everywhere"* and *"never know[s] what kind of reaction [she is] going to get"*:

> *"Certainly I've been coughed on, spat on, that kind of thing, just out and about in shops or on public transport. Certainly other CVF members report people forcibly taking their mask or pinging their mask, and we've had people call us, you know, sheep, kind of a whole load of different things. I think that probably almost all of us have experienced now some kind of unpleasantness simply surrounding wearing a mask".*[158]

74. Dr Finnis also spoke of her concern that the continued vulnerability of CV people has been *"minimised in all quarters of life, even in healthcare"*, the practical effect of which is to expose the CV to risk.[159] This needs to change, and change begins with understanding. Public education is also vital given that some CV are not engaged with groups like CVF, and so will continue to need information from the government as to their ongoing risks and the ways in which these can be mitigated.

D. MAKING HEALTHCARE SAFE FOR THE CV

Difficulties faced by the CV and CEV people in accessing their usual care

75. Before turning to address in detail one of CVF's central concerns in this module, namely the urgent need to make healthcare safe for the CV, it is important to highlight one of the deleterious consequences of the government's pandemic response in terms of access to healthcare. This was that pursuit of the aim of preventing the NHS from becoming *"overwhelmed"* at all costs led to

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[156] The Inquiry will recall that Prof. Gould spoke of the importance of winning *"hearts and minds"* when it comes to IPC guidance: she picked as her headline recommendation that guidelines be formulated in such a way that *"everyone can access [them], that people believe in [them] and want to put [them] in place and can put [them] in place and understand why they're doing it"* (19 Sept 2024, 6/10-15; see further the report of the IPC experts, INQ000474282_0047). It is noted that this was a discussion specifically around the formulation of IPC guidelines; CVF agrees, and suggests that the general point made – that people need to understand in order to buy into mitigations – has wide application in the context of making healthcare safe for the CV.

[157] INQ000421784. Sir Robin Swann agreed that it is a *"job for government collectively"* to communicate these issues rather than putting the burden on CV individuals *"in regards to them having to explain their condition continually"*: 18 Nov 2024, 169/20-24.

[158] 8 Oct 2024, 109/7-17. See also quote 13 in CVF's statement, INQ000309574_0023.

[159] 8 Oct 2024, 111/1-8.

many CV and CEV people not being able to access their usual care.[160] Given that many CV and CEV people are, by definition, reliant on regular and specialist healthcare, this was deeply problematic.

76. This was an issue especially during the early part of the pandemic,[161] but persisted throughout the relevant period (indeed, the effects of unresolved backlogs are that the issue persists for some today). This is illustrated, for example, by research from the Health Foundation, which found a marked decrease in emergency admissions and A&E attendances for the CEV;[162] see also a July 2020 Scottish Government survey of individuals on the SPL found which found that almost one in five respondents had experienced a healthcare appointment being postponed or cancelled.[163] As ESM records:

> *"The changes to hospital services had a damaging and lasting impact on many patients. They shared examples of not being able to access the care they needed, across all types of Covid and planned care: "Everything was shut down, they were overrun with patients ... [T]hey stopped everything, people died because of not getting their appointments, and not getting their treatment" (hospital patient)."*[164]

77. Contributors to ESM specifically described problems and delays with care and treatment for long-term conditions.[165] Some believed that by neglecting to prioritise certain health issues, *"individuals were left to become sicker or, in some cases, die"*.[166] This is echoed in the report of Prof. Edwards et al., which notes that as a result of unprecedented and unplanned for pressures on healthcare systems, *"little attention appeared to have been given to long-term health conditions"*, particularly those that would tend to present more frequently in primary care.[167] See also the evidence of Dr Mulholland, who described the concern of the RCGP and the BMA that the *"enormous amount of chronic care for long-term conditions in general practice ... was not happening in the same way as it had pre-pandemic"*.[168]

78. Whilst for some CV and CEV patients remote care mitigated some of these difficulties, for others it was neither safe nor appropriate. Prof. Edwards identified *"particular risk groups"* (including the elderly, people with certain disabilities, ethnic minority groups, the digitally excluded and people with lower educational attainment).[169]

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[160] CVF considers that it is an inescapable conclusion of the totality of the evidence that the NHS was in fact overwhelmed, applying any reasonable definition of the word.

[161] Statement of CVF, §147, INQ000409574_0060; report of Prof. Edwards et al., §171, INQ000474283_0049.

[162] INQ000408810_0001.

[163] As summarised in the statement of Nick Phin, §9.3.11, INQ000401271_0125.

[164] INQ000474233_0081.

[165] INQ000474233_0082.

[166] INQ000474233_0084.

[167] INQ000474283_0049; 23 Sept 39/7-39 to 41/1-6.

[168] Leading to the development of guidance for GPs on workload prioritisation: INQ000280653, INQ000280654, as explained by Dr Mulholland (23 Sept 2024 146/24-25 to 1151/1-13). Dr Mulholland went on to say that *"the work of many of the chronic clinics that we do, many of that follow-up side, the long-term conditions, probably did take a back seat as we provided acute care for those that needed it on the day ..."*: 23 Sept 2024 153/24-25 to 154/1-3.

[169] 23 Sept 2024 38/11-24. Prof. Banfield considered that insufficient consideration was given to inequalities, highlighting communication barriers as an issue for remote consultations: 28 Oct 2024, 111/9-11. See further the statements of the Royal College of GPs, §95, INQ000339027_0018; Prof. Sir Stephen Powis, §188, INQ000485652_0047; Prof. Edwards et al., §185,

79. The effects of reduced access to healthcare amongst this already at-risk 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"*.[170] Research by the Health Foundation confirms that the CEV experienced a higher rate of deaths compared to the general population in the emergency phase of the pandemic. At the peak of the first wave (2 April 2020), the rate of deaths amongst the CEV population was over two and a half times that of the general population. By the end of August 2020, the CEV population accounted for 19% of all deaths while only making up 4% of the total population in England. The Health Foundation concludes that there remains a *"particularly high level of health need and potential long term impacts concentrated within the [formerly] CEV population"*, and has called for action to ensure that the needs of the formerly CEV are better understood and prioritised.[171] Awareness of the issues with accessing care caused anxiety and distress for many affected CV and CEV people, 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"*.[172]

80. CVF invites the Inquiry to reflect the specific experiences of CV people in relation to this important issue in its report, and to make recommendations to ensure that future pandemic responses appropriately prioritise the importance of CV people being able to access appropriate and safe care for their underlying conditions.

Unmitigated risks of nosocomial infection : healthcare was and is not safe for the CV

81. *"You're more likely to catch Covid in a hospital than in almost any other setting.*[173] *... It is a cultural problem within the NHS that it simply does not do enough to tackle nosocomial infection."*[174] This was the frank evidence of Matt Hancock, who went on to recognise that the CV are particularly affected.[175] During the emergency phase of the pandemic, rates of

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INQ000474283_0052; Prof. Snooks et al., §§133-134, INQ000474285_0049; and Matt Stringer (DCC), 10 Oct 2024, 74-77. There were also frustrations re: the difficulties of accessing remote appointments: ESM, INQ000474233_0197.

[170] §35, INQ000396735_0011. The Inquiry will recall in this context the vivid and distressing examples given by Prof. Edwards, one of which involved the death of an 11-year-old boy with diabetes who had not presented to general practice at all: 23 Sept 2024, 55/4-22. The report of Prof. Edwards et al. describes in further stark detail the effect of the pandemic on rates of new diagnosis for long term conditions, such as COPD, depression, type 2 diabetes, hypertension, anxiety disorders, asthma and cancer: §§173-183, INQ000474283_0049-0052. The issue of a backlog of undiagnosed patients with multiple long-term conditions is further highlighted in the report of Prof. Edwards et al., §§170-175, INQ000474283_0049-0050. See also the evidence of Prof. Banfield (BMA), who described how CV patients *"stay[ing] away from engaging with services and [continuing] to do so ... [means] they are not optimising their treatment, and many of them are suffering in silence at home"*: 28 Oct 2024, 159/4-13.

[171] INQ000408810_0001-0002.

[172] INQ000490087_0006, §17.

[173] 21 Nov 2024, 28/3-10.

[174] 21 Nov 2024, 135/19-24, discussing the specific problem of some hospitals being reluctant to introduce testing for staff *"because they might find too many staff with Covid"* (135/11-12).

[175] *"[I]t was not safe clinically to go for some cancer treatment during the pandemic because cancer treatment sometimes involves reducing the immune system"*: 21 Nov 2024, 28/3-10. He later went on to say: *"[H]ospitals are dangerous places in pandemics.*

nosocomial infection were disproportionately high in the CEV group.[176] This is of course deeply concerning in and of itself, but has also created a knock-on problem: reluctance amongst many in the CV cohort to access the healthcare that they require. In a November 2023 CVF poll of 827 CVF members, 90% reported that they had in the past or would in future delay or cancel medical appointments due to the unmitigated risk of contracting Covid-19 in healthcare settings.[177] This problem has persisted throughout the various stages of the pandemic, but CVF's research shows that more CV people delayed or cancelled appointments once it was no longer a requirement to wear face masks in hospital:[178]

> *"I feel healthcare is no longer safe, now that masking has been removed, I find every visit stressful. ... I can't cancel appointments, I need my treatments. ... But I have delayed having a minor surgery. ... It seemed safer in 2020 because everyone [was] masked, there were more virtual appointments available, and the hospitals were much quieter"* (CVF member, Juliet).[179]

82. See also the experience of CVF member Amanda that *"[s]eeking medical attention has become a terrifying ordeal"*, like a *"game of Russian roulette"*,[180] as well as Lesley Moore's evidence that she did not believe 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"*.[181]

83. CVF submits that this is not about CV people feeling 'anxious' or 'fearful', or 'lacking confidence'.[182] It is about them *not being safe*, and making rational decisions in consequence.

84. It is particularly striking that it is essentially impossible for those at highest risk to comply with the government's own guidance (including in relation to testing, mask wearing and limiting the amount of time spent in crowded, poorly ventilated spaces) when accessing healthcare.[183] It is not enough to focus, as some witnesses have done,[184] on particular areas of the hospital which by definition will see higher footfall from CV patients (for example, haematology or oncology

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... the estimate is that more people caught Covid in hospitals than in almost any other setting, and that's often forgotten in the debate around this": 21 Nov 2024, 69/1-5.

[176] Report of Prof. Snooks, INQ000474285_0044, §121.

[177] Statement of CVF, §131, INQ000409574_0006. See also: the findings of a Sept 2021 SAGE paper, which noted that a significant proportion (17%) of those who had in the previous 12 months avoided making a GP appointment had cited concern about the risk of contracting Covid-19 as a key reason for doing so (INQ000469724_0047, §209); statement of the Royal College of GPs, §45, INQ000339027_0010; statement of Age UK, §65, INQ000319639_0021; report of Prof. Edwards et al., §179, INQ000474283_0051; and statement of the Royal College of Emergency Medicine, §60, INQ000412904_0029.

[178] Statement of CVF, §131, INQ000409574_0055, as further described by Dr Finnis: 8 Oct 2024, 9-25 to 101/1-2.

[179] Statement of CVF, §131, INQ000409574_0055.

[180] Statement of CVF, §48, INQ000409574_0022.

[181] INQ000485656_0006, §15.

[182] As accepted, for example, by Dr Andrew Goodall in response to questions from CVF's counsel: 13 Nov 2024, 83/6-23. See also the evidence of Humza Yousaf, who described his government as being alive to the *"absolute dread"* CV have of potentially contracting C-19 in healthcare: 19 Nov 2024, 163/23-25.

[183] 8 Oct 2024, 103/16-21. See 'Covid-19: guidance for people whose immune system means they are at higher risk', updated 21 May 2024, INQ000408811; statement of CVF, §45, INQ000409574_0021.

[184] For example, Susan Hopkins: 18 Sept 2024, 162/15-20.

departments). CV patients will also need to access accident and emergency, radiology, clinical appointments and more: as Dr Finnis put it, *"I walk the whole hospital"*.[185]

85. The Inquiry is urged to take particular note of the views expressed by its own expert, Dr Warne, that safe access to healthcare for the CV is a *"poorly studied area"*, with the pandemic having highlighted the need for us to do more.[186] It appears that any specific measures that were put in place to mitigate the specific risks faced by CV in accessing healthcare were implemented on a hospital or trust/board level only[187] – leading to uneven provision of measures (to the extent that they did exist) and a lack of strategic, national oversight. It is vital to recognise that this remains a problem today. As Prof. Banfield of the BMA noted, *"[w]e still have inadequate ventilation … . We are still unable to separate out patients."*[188]

Looking forwards not back: recommendations to ensure safe access to healthcare for the CV

86. For too long, and even in the course of the Module 3 hearings, officials have attempted to prop up the *"house of cards"*[189] built on incorrect assumptions around modes of transmission. The Inquiry has heard various allegations and explanations (including 'groupthink';[190] 'confirmation bias'; 'entrenchment';[191] total deference to the IPC cell; overly complicated organisational structures;[192] and supply issues due to ill preparedness dictating guidance).[193] The Inquiry may consider that several or all of these factors in combination led to a failure to adopt a sufficiently precautionary approach, such that rates of nosocomial infection were allowed to spiral out of control. CVF does not propose to dwell on these reasons, which have been explored in detail by Counsel to the Inquiry and other core participants. Instead, now that the house of cards has come tumbling down, and the significant role played by airborne transmission is beyond doubt, CVF urges a focus on next steps.

The importance of improving ventilation across the NHS estate is not in dispute

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[185] 8 Oct 2024, 103/16-21.

[186] 19 Sept 2024, 197/14-21. As illustrated, for example, by Matt Hancock's evidence that despite discussing the problem of nosocomial infection *"regularly"* (INQ000421858_0029, §114) he could not recall being involved in any discussions about specific measures that might have addressed the heightened risk CV people faced when attending healthcare appointments: 21 Nov 2024, 169/24-25 to 170/1-3.

[187] See, for example, the measures discussed by Dr Warne: 19 Sept 2024, 197/14-25 to 198/1-12. More often than not, witnesses struggled to describe examples of measures taken to specifically assist the CV: see, for example, the evidence of Dr Andrew Goodall re: the arrangements put in place through the nosocomial transmission group in Wales on a local basis. He accepted that these measures were mostly likely general measures rather than measures designed to put a *"ring of protection around the CV in particular"* (as CVF's counsel put it in questions to Dr Goodall): 13 Nov 2024, 82/15-25 to 83/1-5. See further the supplementary statement of Caroline Lamb, §5, INQ000474694_0003.

[188] 28 Oct 2024, 130/3-8.

[189] As Prof. Beggs described it: 11 Sept 2024, 56/21-24.

[190] As discussed in Module 1 report: see, for example, the Chair's questions of Susan Hopkins, on 18 Sept 2024, 98/19-25 to 99/1-8.

[191] As described by Prof. Gould: 19 Sept 2024, 43/15-25: *"So there are some entrenched things that we do [in the context of IPC] and we do them because we've always done them because we just don't dare to change"*.

[192] As again discussed in the Module 1 report, and leading to a lack of clarity as to who was responsible for making critically important decisions: Prof. Sir Chris Whitty, 26 Sept 2024, 79/12-25.

[193] See, for example, Matt Hancock's impressions (albeit from officials not directly involved in developing IPC guidance): 22 Nov 2024, 37/10-25 – 38/1-7.

87. Adequate ventilation has often been *"something of an after-thought to many IPC professionals"*, Prof. Beggs noted.[194] Shortcomings in relation to ventilation touching on all aspects of the NHS estate – from hospitals to GP surgeries to ambulances – were raised by witness after witness.[195] There was clear recognition that such shortcomings had a specific impact on the CV: Dr Mulholland, for example, spoke of CV patients *"not want[ing] to sit in a waiting room with other people who are coughing or sneezing or whatever else in it. And so if we had better spaces and bigger spaces ... that's ventilated ... they may feel safer in that"*.[196]

88. It is important to note the obvious failure not to prioritise improvements sooner.[197] Turning to the here and now, however, it would appear that it is not in dispute that, at least as a matter of principle, improvements are vital and pressing.[198] This was the evidence of numerous witnesses, including those who disagreed starkly on other topics of importance – from Prof. Beggs[199] to Susan Hopkins[200] and Lisa Ritchie,[201] and many in between,[202] including the Inquiry's own expert, Dr Shin, who picked this as his *"headline recommendation"*:

> *"It would be really important to review and improve the NHS estate, particularly in ventilation and isolation capacity. The reason why this is important is because, in facing any epidemic or future pandemic, if the legacy inadequacies of our NHS estate across the country, which in some places is very old, if that is not improved we will face the next emergency with the same difficulties that we encountered this Covid pandemic"*.[203]

89. <u>Modernising the NHS estate, and in the course of doing so improving mechanical ventilation,[204] will dramatically reduce the risks of nosocomial infection,</u>[205] both in relation to Covid-19 as well as in relation to other respiratory viruses. There are other associated positive impacts, including

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[194] Report of Prof. Beggs, INQ000474276_0089, §235. As illustrated, for example, by the fact that public health agencies did not appear to have a role in advising on mechanical ventilation or portable air filtration devices, despite having a role in devising IPC guidance: see, for example, the statement of Fu-Meng Khaw, §59, INQ000469675_0020, and evidence of Laura Imrie, 5 Nov 2024, 170/3-25 to 176/1-7.

[195] Re: hospitals, see the evidence from the various spotlight hospitals; re: GPs, see Dr Mulholland, 23 Sept 2024 191/1-25, who spoke of GP practices having been set up in buildings that *"aren't suitable for modern healthcare"*; and re: ambulances, see Tracy Nicholls, who described advice to simply open a window (which most ambulances don't have), and indeed the only other option of opening the back door, as *"simply not acceptable"*: 23 Sept 2024 100/1-25.

[196] 23 Sept 2024 193/2-19.

[197] It is surprising, for example, that Sir Sajid could not recall ventilation, and specifically use of portable air filtration devices across the hospital estate, being raised with him during his time in office: 25 Nov 2024, 60/10-19.

[198] Jokes about underwhelming Christmas presents aside: see Baroness Eluned Morgan, 20 Nov 2024, 195/5-8.

[199] As summarised in his report, §332(vi)-(vii), INQ000474276_0113.

[200] *"[I]n healthcare, one of the biggest things that we can do to reduce respiratory infections that happen every single day and transmission of respiratory infections is to improve the ventilation in healthcare ..."*: 18 Sept 2024, 94/14-18.

[201] 16 Sept 2024, 6-10.

[202] See, for example, NHSE's Lessons Learned report: *"Ventilation was, and still is, vital in the management of Covid-19"*: INQ000226890_0052, §121.

[203] 19 Sept 2024, 5/24-25 to 6/1-7.

[204] i.e. ventilation that is integral to the building's structure.

[205] This is neatly illustrated by the contrasting experiences of the spotlight hospitals: for positive examples, see Dr Catherine McDonnell (Altnagelvin Hospital): 30 Sept 2024, 183-184, and Prof. Simon Ball (Queen Elizabeth Hospital): 7 Nov 2024, 30/1-11. Contrast this with Prof. Philip Kloer (Glangwili General Hospital): 12 Nov 2024, 135/22-25, and Prof. McKay (Glasgow Royal Infirmary), 14 Nov 2024 29/4-13: *"it's very clear that managing a respiratory pandemic in open wards without mechanical ventilation is extraordinarily difficult"*). See also Amanda Pritchard, 11 Nov 2024 154/14-15: *"the age of the estate does make it very hard"* and INQ000409250_0070, §256.

in relation to the reduction of indoor pollution.[206] It is clear that there are significant resource challenges associated with upgrading mechanical ventilation: Amanda Pritchard described a maintenance backlog of £14 billion, with work to improve ventilation having to line up with other competing demands on the capital budget.[207] CVF accepts that these challenges raise political questions regarding the allocation of finite resources that are outwith the Inquiry's terms of reference. It is, however, entirely appropriate, and indeed of pressing importance, for the Inquiry to record how critical improvements to mechanical ventilation are in order to make healthcare safe.

90. In the meantime, portable air filtration devices (such as 'HEPA' filters)[208] are *"low-hanging fruit"*:[209] *"[t]hey're cheap, easy, we know they clean the air, we know they do a similar job to ventilation. If ventilation is good then portable air cleaners are good"*.[210] They more than pay for themselves in bringing down rates of infection and staff absence, and there are no downsides to their use. They are ready to be deployed widely now and should be deployed as a matter of urgency.

91. As Prof. Sir Stephen Powis's supplementary statement makes clear, *"mobile and semi fixed HEPA devices [are] for use in existing healthcare and patient-related settings where there is poorly performing and inadequate ventilation"*.[211] We know that this is the case in very many parts of the NHS estate across the four nations. The statement goes on that, in accordance with the Further Ventilation Advice,[212] provision of these would be down to local Trust assessment of the current performance of the ventilation system. The Inquiry should recommend that all trusts carry out urgent reviews of their existing ventilation systems and to increase reliance on portable air filtration devices where shortcomings are identified. The *"further work"* NHSE says will be undertaken *"[g]oing forward ... to ensure effective ventilation of new and existing healthcare premises over the longer-term"* must be prioritised. As Prof. Noakes has identified, mitigation measures must be addressed at an organisational level: they are not within individuals' power to control.[213]

92. Finally, CVF urges the Inquiry to consider in detail Prof. Beggs' robust evidence that the current HTM ventilation guidelines are *"not fit for purpose"*, and to recommend that they be comprehensively reviewed and brought up to date as a matter of urgency.[214] See further the

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[206] See, for example, Prof. Sir Chris Whitty: 26 Sept 2024, 210/13-16.

[207] 11 Nov 2024, 143/3-9. See also Prof. Sir Stephen Powis, who noted that the Darzi report had pointed to an *"underinvestment, comparatively, in capital, ie in bricks and mortar, in the NHS. So there is no doubt that a sustained capital investment programme to bring the NHS estate up to date to make sure it's fit for purpose across all range of health settings would give us more resilience"*: 7 Nov 2024, 193/21-25 to 194/1-4.

[208] Although 'HEPA' is a standard of filtration, the term 'HEPA filter' has become a catch-all term for portable air filtration devices (sometimes also referred to as 'portable air cleaning devices' or 'portable air cleaners').

[209] As per Prof. Beggs: 11 Sept 2024, 176/1-4.

[210] As per Prof. Beggs: 11 Sept 2024, 176/1-4.

[211] INQ000474664_0012, §45, emphasis added.

[212] Related to HMT 03-01 [NETB 2023/01A and NETN 2023/01B].

[213] INQ000236261_0051, §10.11(4).

[214] Report of Prof. Beggs, §§245-266, INQ000474276_0091-0096; 11 Sept 2024, 154/16-25. It is noted that Ms Pritchard suggested that updates to the HTM in June 2021 plus specific advice on air filtration devices and UV devices meant that the HTM had been *"thoroughly reviewed"*: 11 Nov 2024, 152/12-16; see also Prof. Sir Stephen Powis's supplementary statement, §§34-45,

urgent interim recommendations which have been proposed by a number of Core Participants via letter.

Face masks and a package (rather than hierarchy) of controls

93. The FRSM vs. FFP2/3 issue has become polarised, and potentially an unhelpful distraction.[215] CVF invites the Inquiry to accept the common-sense evidence of its own independent experts on this issue.[216] As Prof. Beggs put it: *"wearing masks is better than not wearing masks; respirators are better than surgical masks"*.[217] The Shin, Warne and Gould report describes how FFP3 respirators are designed to protect the user against 99% of respiratory particles when properly fit tested and FFP2 respirators protect the user against 95% of respiratory particles.[218] In relation to fit testing, CVF cautions against making perfect the enemy of the good: even if not formally fit tested, FFP3 masks still provide a substantially greater degree of protection than FRSMs do (which do not qualify as RPE). As Dr Finnis described, many CV people have, often with the assistance of CVF, become adept at figuring out for themselves which masks fit them best and so offer the most optimal level of protection.[219]

94. CVF agrees with the BMA,[220] CATA[221] and others that the emphasis placed by public health officials on concerns that respirators are uncomfortable is a red herring and/or an after-the-fact justification for not ensuring their wider use. As Prof. Banfield put it:

> *"[N]one of us enjoy wearing protective equipment ... but we do it because it protects us and therefore protects our patients because we know that you could catch Covid from healthcare workers and, you know, there was nosocomial spread within hospitals so it is not just about yourself, it is about everyone else as well. ... [T]here are different versions of FFP masks available ... it is up to you and your employer to find the PPE that allows you to do your job ..."*.[222]

INQ000474664_0009-0012). For the detailed reasons set out in Prof. Beggs' report, despite these updates the guidelines continue to reflect out of date assumptions regarding the rigid 'airborne – non-airborne' dichotomy. They are also incomplete in a number of key respects, for example: they pay insufficient attention to the validation of ventilation rates in perceived low risk areas (Beggs, §262); they do not consider the use of sensors to monitor CO2 concentration in clinical and non-clinical spaces (Beggs, §263); they do not mention supplementary air cleaning, with the May 2023 NHS guidance functioning as an 'add on' rather than being incorporated in the HTM guidelines in a *"coordinated and comprehensive manner"* (Beggs, §264); and there is no mention in the current HTM guidelines about strategies for future pandemics and emergencies (Beggs, §265).

[215] See, for example, Fiona McQueen, the CNO for Scotland: *"The problem I think we had was it was very linear and it was either FRSM or FFP3; people were, in a way, defending their concerns, rather than trying to find the best possible solution, and because of that, I think we've been blinkered"* (17 Sept 2024, 190/1-10).

[216] To this CVF would add that waiting for randomised controlled trials (as per, for example, Susan Hopkins: 18 Sept 2024, 141/11-19) to bolster the laboratory and observational evidence that does exist re: the superior protection offered by FFP3 and FFP2 masks (as discussed in detail in Prof. Beggs' report (INQ000474276_79-86) is unrealistic (see, for example, Prof. Sir Chris Whitty: 26 Sept 2024, 150/16: *"trials in this area will be very difficult"*) and unnecessary (on which see Prof. Beggs' report, INQ000474276_0079, §211: *"Historically medical professionals have placed much emphasis on RCTs and effectively have tended to downplay evidence from observational lab and modelling studies"*). It is also internally inconsistent, given that FFP3s are recommended in the context of HCIDs and AGPs.

[217] 11 Sept 2024, 134/2-9.

[218] INQ000474282_0027, §§1.52 and 1.53.

[219] 8 Oct 2024, 114/12-14.

[220] See the BMA's oral closing statement: 27 Nov 2024, 29/15-25 to 30/1-12.

[221] See Dr Barry Jones: 12 Sept 2024, 39/15-20.

[222] 28 Oct 2024, 115/25 to 116/1-12.

95. CVF submits that there has been a distinct lack of consideration given to the potential utility of patients, especially CV patients, wearing higher grade masks in hospital and other high-risk healthcare settings, wherever possible.[223] Specifically in relation to face masks, CVF would welcome recommendations that:

a. clear evidence-based public guidance and information around higher-grade masks be made readily available to the public. This would allow CV patients (as well as other members of the public and of course healthcare workers) to make informed decisions about the relative benefits of FFP2/3 masks as compared to FRSMs and face coverings.

b. it is clarified across the NHS that CV people should never be required to remove their own respirator mask where they have made the decision to wear one.[224] Dr Finnis described a *"sea change"* once masks were removed from hospitals in summer 2022, and such demands became increasingly common: *"[P]eople are now really worried. There are no mitigations in hospitals and, moreover, people who go in wearing a mask, and we've had many, many reports now of people being sort of gaslit why they need to wear one, belittled, made fun of, harassed, dismissed".*[225]

c. policies be issued across the NHS to support CV people to request that staff in direct contact with them wear FFP2/3 masks;

d. there be further research and thought given to reducing the barriers to effective use of RPE in practice,[226] including adequate availability of a range of different masks that fit, and are comfortable for, a diverse range of faces,[227] and adaptations to reduce any impacts on communication (such as masks with a clear screen so as to permit lip reading (and facial expressions etc to be seen)). As a potentially very significant starting point, the Inquiry already has the evidence of Prof. Beggs that FFP2 masks represent a *"useful third option"* (i.e. alongside FRSMs and FFP3 masks). Prof. Beggs referred to research that *"even loose fitting FFP2 masks with ear loops resulted in a 2.5-fold reduction in mean infection risk compared with surgical masks, while well-fitting FFP3 masks with nosepiece adjustment produced a 30-fold reduction in risk".*[228]

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[223] As recognised, e.g., by CMO (S) Sir Gregor Smith: *"It is something that could have been explored but unfortunately it wasn't"*: 25 Sept 2024, 177/24-25 to 178/1. This is all the more surprising given the knowledge that patients were a key driver of nosocomial infection: see, e.g., statement of Matt Hancock, describing advice from the CMO, DCMO and others, INQ000421858_0030, §117; statement of Prof. Sir Stephen Powis, §432, INQ000412890_0119; and, in Wales, a Ministerial Briefing Paper dated 15 Nov 2020 indicating that the Welsh Government was aware that properly used PPE was, at that time, protecting staff from being infected by patients, but that patient to patient transmission was a significant problem: INQ000396261_0001.

[224] On which, see statement of CVF, §128, INQ000409574_0052.

[225] 8 Oct 2024, 99/19-24.

[226] As referred to, for example, by Susan Hopkins: *"[W]e have to talk about how it's worn for a 12-hour shift, how it's worn repeatedly day after day ..."*: 18 Sept 204/5-7. See further Prof. Sir Chris Whitty: *"if [the RPE] doesn't hold out [day to day in operational circumstances] it's not doing a heck of a lot of good"*: 26 Sept 2024, 149/15-17.

[227] Concerningly, several witnesses were not confident that an adequately diverse range of FFP3 masks is now available: see, for example, Matt Hancock, 21 Nov 2024, 142/1-23.

[228] Per Baghieri et al., 2021. Prof. Beggs concludes that this suggests that *"FFP2 masks with ear loops might be a useful third option, which although not as protective as FFP3 respirators, could nonetheless be effective because they are more comfortable,*

96. It is not CVF's position that FFP3/2 masks are a *"silver bullet"*.[229] But it is also too simplistic to say, as for example Lisa Ritchie did, that they are at *"the bottom"* of the hierarchy of controls and that other elements are *"more important"*.[230] Ventilation and masks, as well as other mitigations, are interdependent. As Prof. Beggs notes, *"[a]lthough the evidence in support of facemasks is relatively robust, it appears that performance is influenced by the viral load to which HCWs are exposed, with the infection risk increasing as the viral load increases"*.[231] In other words, in poorly ventilated virus-reach environments (i.e. in most parts of the NHS estate), the importance of respirators increases. Where some controls are missing or insufficient (such as ventilation), others (such as RPE) assume greater importance. Or, to put it even more straightforwardly, the more controls you have the better.[232] The Inquiry is invited to find that it makes more sense, therefore, and is likely to avoid some of the pitfalls that have hitherto arisen, to talk of a *"package"* of controls, rather than a *"hierarchy"* of controls.[233] There are different ways to bring this to life.[234] The Chair will recall that in CVF's oral closing statement, CVF's counsel referred to the "Swiss cheese model" of pandemic defence. The idea behind the metaphor is that multiple imperfect layers of protection, imagined as cheese slices, more effectively reduce the spread of the virus that causes Covid-19:[235]

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better tolerated and provide superior protection compared with FRSMs": §227, INQ000474276_0085-86. As Laura Imrie noted (5 Nov 2024, 179/17-20), the barrier to more widespread use of FFP2 use is that they are not recommended by health and safety legislation because they do not filter quite as effectively as FFP3 masks – the practical effect of which is that we are left with FRSMs which are significantly less protective than either.

[229] Lisa Ritchie: 16 Sept 2024, 111/22-23; 125/8. CVF agrees with Lisa Ritchie that *"there are many other precautionary measures that do need to be put in place"* (16 Sept 2024, 111/24-25), and with Susan Hopkins that *"it's really important to recognise that a golden bullet or silver bullet won't work if we just think about it in binary terms, and I'm really keen, coming out of the pandemic, that we understand ... the multiple different interventions that we need to use at once as complex interventions to reduce infection transmission"* (18 Sept 2024, 75/6-13).

[230] Susan Ritchie: 18 Sept 2024, 83/6-11. Compare the statement of Prof. Sir Stephen Powis, INQ000412890_0099, §338, and the expert report of Dr. Shin et al, §1.45, INQ000474282_0024.

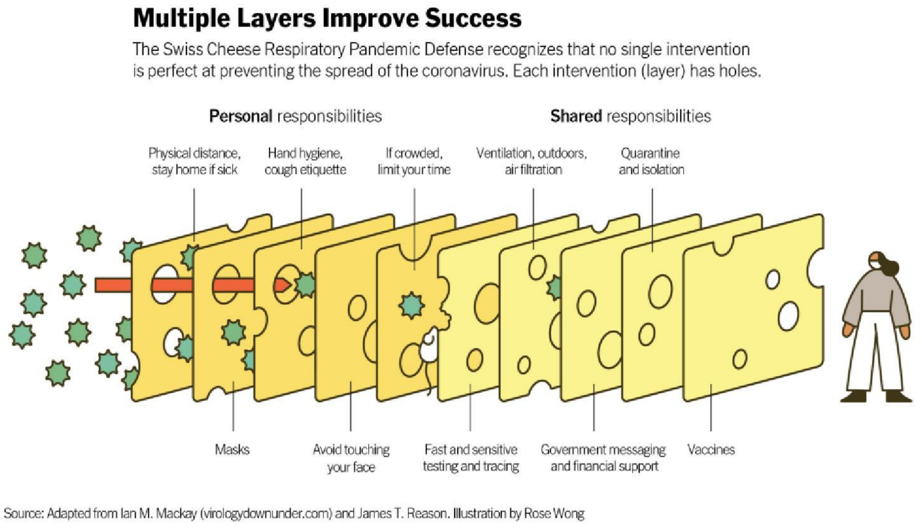
[231] INQ000474276_0084, §221.

[232] As the Chair appeared to note in her questioning of Laura Imrie: 5 Nov 2024, 158/14-25 to 161/1-3.

[233] As, for example, Jean White, the CNO for Wales did: *"Face mask wearing on its own would not stop the spread of disease, if people were not hand washing, were not keeping distance and doing all the other things that we were advising. So I would say it's part of a package. It's not a panacea of stopping all infections but it certainly has a part to play"*: 17 Sept 2024, 115/15-22.

[234] See, for example, the analogy of Rosemary Gallagher (RCN) re: *"how you protect people inside a castle from an invading arms. ... [Y]ou have a number of controls in place to prevent that army reaching you on the inside. So you might have a moat, you have a drawbridge, you have a number of other controls. You don't wait until the army has swum the moat, got through the drawbridge, climbed the wall, and got into the inner courtyard before you issue them with a bow and arrow. You give them a bow and arrow that's available first while you try and use the other controls that you have in place. ... And that's why the hierarchy of controls were viewed as being too restrictive"*: 4 Nov 2024, 98/2-18.

[235] As explained in a Dec 2020 article in The New York Times, 'The Swiss Cheese Model of Pandemic Defense': the image below is taken from the article, which is adapted from Ian M. Mackay (Virologydownunder.com) and James T. Reason (illustration by Rose Wong). The importance of putting in place a *"Swiss cheese model of having multiple interventions*" was also highlighted by Sir Jeremy Farrar (Chief Scientist at the WHO, though giving evidence in a personal capacity) in the course of the Inquiry's Module 1 hearings: 29 June 202 27/19-20.



Multiple Layers Improve Success

The Swiss Cheese Respiratory Pandemic Defense recognizes that no single intervention is perfect at preventing the spread of the coronavirus. Each intervention (layer) has holes.

Source: Adapted from Ian M. Mackay (virologydownunder.com) and James T. Reason. Illustration by Rose Wong

Other measures required <u>now</u> to ensure that the CV can safely access healthcare

97. In addition to the matters set out above, CVF invites the Inquiry to recommend implementation of the following measures. These are largely inexpensive and straightforward, but would vastly improve the position of the CV when seeking to access healthcare:

    a. <u>Reasonable adjustments to mitigate the risks to the CV when accessing healthcare</u>. The suggestions of Dr Warne are a good starting point. They include: staggered appointment times, greater social distancing in waiting rooms, and guiding patients directly into clinic rooms.[236] Further measures should include: the ability to request that healthcare workers in direct contact with CV people wear a FFP2/3 mask and do a lateral flow test, as well as options for remote appointments or home visits if necessary and appropriate. Availability of such measures needs to be accompanied by a <u>workable mechanism</u>, such as that suggested in the Welsh 'Locked Out' report,[237] for the CV to self-register and notify healthcare providers of their need for reasonable adjustments, ideally in advance of healthcare appointments.

    b. <u>Widespread use of CO2 monitors</u>, to allow healthcare providers, staff and patients to measure the ventilation (and so risk of Covid-19 transmission) in confined spaces.[238]

    c. <u>More routine asymptomatic testing</u> across the NHS, given that rates of Covid-19 remain high year-round, even in the highly vaccinated UK population, and given what we know

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[236] 19 Sept 2024, 198/1-12.

[237] 'Locked Out: Liberating disabled people's lives and rights in Wales beyond Covid-19 Report', by Prof. Debbie Forster and co-produced by a steering group of disabled people from Wales, INQ000227530_0010; 0066 (§5.20).

[238] CVF remains unclear why the Welsh Government rejected the recommendation of the RCN that CO2 monitors be widely deployed: Baroness Eluned Morgan was not able to assist with *why* the specialist estate service did not support their wider use – 20 Nov 2024. Judith Paget was also asked about this by CVF's counsel, but she too could not assist: 13 Nov 2024, 165/8-25 to 166/1-3.

about the impact of asymptomatic Covid-19 transmission. Identifying and controlling the spread of the virus helps protect everyone, including the CV.[239]

d. Financial support, for example through VAT-relief, for CV people, who currently bear the burden of buying for themselves: masks, nose sprays, CO2 monitors (and, in their home, and in some cases work and education environments), and portable air filtration devices.

98. Finally, although these important issues received disappointingly little attention in Module 3 (with CVF very much hoping that this will be redressed in Module 4):

a. Antiviral treatment must be properly commissioned and made accessible to all those who need it. Rapid provision of antivirals was supposedly *"specifically designed to provide additional protection to many of those who had been shielding"*.[240] Yet many CVF members report confusion around the frequently changing eligibility criteria (which CVF considers are too narrow). Even if in theory eligible, the burden is on the patient – who may be experiencing or about to experience Covid-19 symptoms – to secure the medication, all within a system which 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 again. 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 problems eat into the 'five-day pathway' to access the antivirals.[241]

b. When available, prophylactic medications should be made available on the NHS to those who are eligible. For those who are immunosuppressed or immunocompromised and unable to mount a response to the vaccine, such treatments are their 'vaccine'. Once available, there needs to be an expedited process for making such treatments available on the NHS, so that all those who are eligible can benefit, not just those who are in a position to pay for them privately.[242]

E. RESTORING TRUST AND CONFIDENCE THAT THE LIVES AND WELLBEING OF THE CV WILL BE TREATED AS WORTHY OF PROTECTION

99. The twin issues of DNACPRs and decision support tools have led to a loss of trust and confidence amongst many CV people that their lives and wellbeing were, and will be, treated as equally worthy of protection. This was vividly highlighted by the evidence of Lesley Moore: *"I felt if my son was to turn up at hospital requiring a ventilation machine that if there were three other people and him that he probably would not be the person that got the ventilation machine"*.

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[239] See, for example, the report of the IPC experts, §1.33, INQ000474282_0019. See also Dr Warne: *"[W]e know that more frequent testing is more likely to pick up asymptomatic or pre-symptomatic cases"*: 19 Sept 2024, 199/11-12. Dr Shin spoke of how in his hospital, *"even to this day, in our haematology-oncology population, the most vulnerable, we maintain once-weekly surveillance PCR testing in our inpatients":* 19 Sept 2024, 200/9-15.

[240] Statement of Sir Sajid Javid, §128, INQ000485736_0060.

[241] See the experience of Dr Adrian Warnock at §67, INQ000490087_0018; the case studies set out in the statement of CVF, §187, INQ000409574_0072; and the statement of Forgotten Lives, §§65-68, INQ000260635_0040. Sir Sajid was prepared to accept that *"it is possible that for some people the process didn't work as well as it should have":* 25 Nov 2024, 143/3-7.

[242] See further statement of CVF, §192, INQ000409574_0076.

Ms Moore described being *"absolutely horrified"* to receive a letter in relation to DNACPR, and also spoke of her concern that her son would not be treated early enough so as to avoid the need for CPR in the first place.[243]

An urgent systematic review of DNACPRs is needed

100. Some of CVF's members, including middle-aged people with well-controlled conditions,[244] were shocked to be asked, out of the blue and often via the medium of an impersonal letter or rushed telephone call, whether they would wish to be resuscitated if in cardiopulmonary arrest:

> *"I received a phone call and this letter asking about DNACPR amongst other things from my GP. It really scared and upset me. I honestly thought that is it, I'm going to die"* (CVF member, Helen).[245]

101. Other CV people 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, I don't remember being asked"* (CVF member, Jennifer).[246]

102. These and many other reports from CVF members, as well as those conveyed by core participants throughout the hearings, are consistent with accounts reflected in the interim and final reports of the CQC, including that 'blanket' decisions were made on the basis of underlying health conditions.[247]

103. The Inquiry has also heard evidence that DNACPRs were applied in a way that conflated decisions not to resuscitate in the event of cardiopulmonary arrest with decisions not to treat or to escalate care.[248] Prof. Summers and Dr Suntharalingam noted that although DNACPR is *"not meant as a proxy for broader treatment decisions ... in the absence of [a] clearly document discussion and decisions about other forms of treatment, there is potential for inappropriate over-interpretation of DNACPR[s] as a generalised treatment limitation option"*.[249] Dr Finnis's

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[243] 30 Oct 2024, 12/23-25 to 13/1-2; 13/17; 14/7-10.

[244] Dr Finnis described examples of *"relatively young people in their 30s, 40s and 50s who have been either asked [about a DNACPR] or have found it on their discharge letters when they come out of hospital, it having not been discussed with them at all and it being a real shock"*: 8 Oct 2024, 122/12-17.

[245] Statement of CVF, §112, INQ000409574_0047.

[246] Statement of CVF, §116, INQ000409574_0047.

[247] Helpfully summarised in the report of Prof. Summers and Dr Suntharalingam, §§45-48, INQ000474255_0026-0027.

[248] Most poignantly from the bereaved. See also Prof. Sir Michael McBride who accepted that given the pressures on staff and the practical barriers to communication it is *"possible"* that DNACPRs were treated in this way: 24 Sept 2024, 133/20-25 to 134/1-23. See further: CTI's questions to Paul Chrisp (NICE) about the risk of including a paragraph re: DNACPR decisions in the section of NG159 re: admission of critical care leading to these two issues being conflated: 30 Oct 2024, 84/7-10; Matt Hancock's comments re: not going to hospital may be the best decision (though he said he was *"absolutely"* clear in his mind that DNACPRs were only there to prevent cardiopulmonary resuscitation and not to be treated as a 'do not treat order': 21 Nov 2024, 108/1-13; and Jackie O'Sullivan (Mencap): 28 Oct 2024, 71/1-25 to 72/1-10.

[249] INQ000474255_0024; 0027, §§40; 49.

concerns about *"mission creep"* appear, therefore, to be well founded.[250] CVF is deeply concerned that decisions to withhold care may have been influenced by (a) severe constraints on resources and capacity,[251] and (b) discriminatory value judgments about the CV.

104. This issue has been deeply traumatising and distressing for many CV people, compounding concerns that the CV had been or would be discarded by society: *"It felt like the state was 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."*[252] Trust and confidence has been damaged, and there have likely been impacts on patient safety as a result: Jeane Freeman noted, for example, that as a result of public anxiety around GPs initiating discussion about DNACPRs, *"it is reasonable to assume that some people would have avoided making an appointment with their GP for fear of being deprioritised in relation to ICU care"*.[253] There is no evidence of any steps having been taken to allay such concerns.

105. CVF shares the fears of bereaved families that concerns about inappropriate and unlawful use of DNACPRs may be more widespread than previously understood (including by the CQC).[254] CVF is particularly concerned that some CV people may to this day be unaware that a DNACPR has been placed on their record. Existing reviews have not gone far enough, and there continues to be a lack of official data. In the Northern Irish context, Prof. Sir Michael McBride confirmed that no investigations were undertaken to ascertain whether there was a disparity in implementation of DNACPR guidance. He expressed the view that individuals and families had a right to expect that explanations be provided to them.[255] In Scotland, Prof. Sir Gregor Smith agreed that there was an absence of official data on the number of DNACPRs issued during the pandemic, and could not help the Inquiry with why no investigation equivalent to that carried out by the CQC in England had happened in Scotland.[256] Dr Atherton considered that it was not the Welsh Government's *"responsibility or ability"* to monitor whether DNACPRs had been deployed appropriately.[257]

106. CVF therefore submits that the Inquiry should recommend an urgent systematic review of all DNACPRs put in place from the start of the pandemic to now, with specific attention paid to all those who were CEV and disproportionately affected by the issues outlined above. This should be accompanied by an offer of bespoke psychological support for those affected. As set out above, the reviews that have been undertaken do not go far enough, as recognised by Matt

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[250] 8 Oct 2024, 125/25-26.

[251] Dr Mulholland, for example, spoke of informal or formal pressure on GPs (from CCGs) that they had to *"protect the NHS, they should be limiting the number of referrals in to hospital or setting out advance care plans that would say 'I do or don't go in for further care' or 'I do or do not receive resuscitation'"*: 23 Sept 2024, 173/11-25. See further Prof. Simon Ball, re: the increase in DNACPRs (from the community, 4-8%): 7 Nov 2024 23; 48.

[252] Statement of Lesley Moore, INQ000409574_0046, §19.

[253] INQ000493484_0051, §225.

[254] CVF considers that there appears to be a disconnect in the CQC's final report between (a) the many and consistent reports from people, families and carers pointing to 'blanket' decisions having been made and (b) the position of provider organisations apparently not recognising this practice: see the expert report of Prof. Summers and Dr Suntharalingam, INQ000474255_0027, §48. This disconnect is itself a cause for concern in that it suggests that provider organisations may lack sufficiently robust review mechanisms.

[255] 24 Sept 2024, 172/22-25 to 174/1-24.

[256] 25 Sept 2024, 152/9-22; see also INQ000236625_0011, §40.

[257] 30 Sept 2024, 109/6-18.

Hancock, amongst others: *"I certainly think a review like that should be looked at, because it's obvious that there were cases when DNR notices were wrongly applied and I think the issue of consent is so important here. ... I can't recall us looking a review like that, because our absolutely prime motivation was to stop that from happening in the first instance ... now, of course, we're no longer in a pandemic and so now would be an appropriate moment to consider doing that"*.[258] CVF shares the concerns expressed on behalf of the DCC that it has been very difficult to *"get the genie back in the bottle"* even after advice was issued that blanket notices are inappropriate. Mr Stringer considered that there is a *"lingering problem"* with DNACPRs being issued in inappropriate circumstances today.[259]

107. Any potential practical difficulties in checking records (for example those referred to by Prof. Wyllie arising from differing levels of digitisation across the NHS) should not stand in the way of the Inquiry making such a recommendation if the Chair agrees with it in principle. As the development of the SPL has shown us, issues with data can be overcome where there is sufficient motivation to do so.

Decision support tools reduce the CV to a mere number, and cannot be justified

108. Strikingly similar themes emerged in relation to discussions around, and the development of, decision support tools and guidance. It is beyond doubt that *"heartbreaking choices"*[260] were made that resulted in some people being denied the critical care which, absent the pandemic, they would have received.[261] CVF considers that CV people are very likely to have been disproportionately affected.

109. It is clear that those who were vulnerable by reason of underlying conditions were not given sufficient consideration from the outset. For example, the initial published version of the NICE critical care guidance suggested that the clinical frailty scale should be applied to all adults irrespective of age. CVF member Derek describes seeing the guidance online and being *"shocked and particularly worried that an innocent mention of being slower ... might gain an extra 3 or 4 points."* He felt he would have to be *"careful in what [he] said. It reduced trust"*.[262]

110. It took notice of a legal challenges from disability rights groups for the NICE guidance to be amended.[263] As Jackie O'Sullivan put it on behalf of Mencap, it was clear that people with stable disabilities, in particular learning disabilities, *"were not considered as part of this"*.[264] The guidance was amended but, as in the case of DNACPRs, the genie was out of the bottle: Ms

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[258] 22 Nov 2024, 20/4-15.
[259] 10 Oct 2024, 84/5-6.
[260] As Vaughan Gething put it: 20 Nov 2024, 30/24.
[261] Report of Prof. Summers and Dr Suntharalingam, §123; 156, INQ000474255__0051; 0061. See also: IFF research, INQ000499523_3: over half of healthcare professionals surveyed reported that some patients could not be escalated to the next level of care due to lack of resources; Prof. Banfield (BMA), 28 Oct 2024 123/13-19: *"[R]really what you are talking about is a situation in which rationing has to take place, and we saw that quite considerably during the pandemic"*: Matt Hancock, who accepted that *"not everyone who needed an ICU bed got an ICU bed"*, 21 Nov 2024, 43/1-3; Prof. Sir Chris Whitty, who thought it was not unsurprising that *"for the biggest pandemic in 100 years for this country the system was unable to escalate things in the way it normally would"*, 26 Sept 2024, 67/12-14; and the totality of the harrowing evidence of Prof. Fong, 26 Sept 2024.
[262] Statement of CVF, §110, INQ000409574_0046.
[263] As described in the report of Prof. Summers and Dr Suntharalingam, §108, INQ000474255_0045.
[264] 28 Oct 2024, 64/17-18.

O'Sullivan described learning disability services continuing to receive letters that said, *"If anyone in your service gets Covid, they are unlikely to be treated; don't bring them to hospital"*.[265]

111. The commissioning by DHSC of a putative Covid-19 clinical prioritisation model to be used in the event of saturation of NHS critical care resources caused genuine anxiety and fear amongst many CVF members. An early draft of the accompanying clinical decision support aid/tool which was leaked to the media contained numeric scoring. Although it is understood that later drafts did not contain numeric scoring,[266] the draft confirmed what the CV have long feared: that they are particularly vulnerable to being reduced to a mere number, and being discriminated against, by reason of their underlying condition. Prof. Sir Stephen Powis considered that numeric scoring could be used *"inappropriately"* in a way that *"takes away all the nuances and complexities that come out from the care and interactions between a professional clinician and patient"*. CVF welcomes this and other similar reflections,[267] and agrees.

112. CVF remains concerned that, yet again, the genie was out of the bottle as soon as the draft tool was published in the media. Dr Bryden described being sent an early version of the tool by a clinical lead *"and the question was, are we meant to be using this or not ... there was confusion to a certain extent about whether or not there was a central tool being provided"*.[268] The intensive care experts spoke of *"variations in decision-making and conscious or subconscious application of clinical thresholds"*.[269] Caroline Abrahams said she was aware of *"something like"* the draft tool being used in local areas at times.[270] Ultimately, once the DHSC decided not to proceed with publication of the final version of the framework the draft guidance produced by the working group was taken forwards and academically published by the Intensive Care Society.[271]

113. CVF does not support the development in future of **any** decision support tools for the purposes of care prioritisation, even if developed outside of the pressures of a pandemic with stakeholder input. CVF is not satisfied that such tools can be developed in a way that does not embed oversimplified or biased criteria. Nor has CVF in any way been reassured that such tools will not be used more widely than intended in other, non-pandemic times of acute pressure on the healthcare system. Decisions about appropriate medical care should be made on an individual, context-specific basis. They should be made not on the basis of medical records or descriptions of underlying conditions, which may on their face create a misleading picture of a patient's prospects. Decisions should be focused on the particular individual concerned, at the specific point in time, in the light of all of the relevant circumstances, in consultation with the individual patient and their family, and by the treating clinician exercising his or her professional judgment in the light of all of that information. The Inquiry is urged to note and reflect CVF's deep concerns on this vitally important issue.

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[265] 28 Oct 2024, 65/24-25 to 66/1.
[266] As described in the report of Prof. Summers and Dr Suntharalingam, §113; 115, INQ000474255_0048.
[267] See, for example, Sir Frank Atherton, who described a numerical scoring system as being *"too medicalised"*: 30 Sept 2024, 98/1-2.
[268] 8 Oct 2024, 157/1-5.
[269] INQ000474255_0051, §123.
[270] 28 Oct 2024, 45/18-19.
[271] INQ000295282.

F. CONCLUSION

114. 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. In the light of the ongoing threat to the CV posed by Covid-19, there is an urgent need to learn lessons, and to put in place effective protections, so that the CV can once again participate and flourish in society on an equal footing to others. CVF is grateful for the Chair's clear willingness to seek to understand CVF's issues of concern. For many CV people, this is the first time that they have felt genuinely listened to and heard. CVF looks forward to receiving the Inquiry's report and reading the Chair's recommendations, which it knows will be formulated with the care and attention that have defined the approach to this important module so far.

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