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On behalf of Clinically Vulnerable Families

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IN THE PUBLIC INQUIRY INTO THE
COVID-19 PANDEMIC

WITNESS STATEMENT OF

Lara Wong

On behalf of Clinically Vulnerable Families

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I, Lara Wong, will say as follows: -

1. I am writing this statement in response to the UK Covid-19 Inquiry's request, dated 25 June 2024, for evidence under Rule 9 of the Inquiry Rules 2006 in respect of Module 7. I provide this written response on behalf of Clinically Vulnerable Families ("CVF") which I founded and lead with the support of deputy leaders, expert advisors, and dedicated team members. This statement gives a voice to our members and throughout, where appropriate, I have provided quotes and examples from many of our members to assist the Inquiry in understanding their real life lived experience.

2. In order to prepare this statement, I have drawn on my own experience and knowledge, including from my professional training and understanding, as well as the knowledge and experience of CVF members. CVF is a volunteer group with a primarily online membership base, as set out in paragraph 8. I am aware of many members' experiences and perspectives because CVF has sought to advocate for members' rights, has provided peer support for members and we routinely discuss the challenges faced both individually and as a group during the Inquiry's defined pandemic period.

   It is noted that for the purpose of this Rule 9 request, that the date range of the pandemic is set as the period between 1 January 2020 and 28 June 2022. Where we refer to the pandemic within this statement we do indeed refer to that prescribed time period. However, we do not agree that the pandemic came to an end on 28 June 2022. As of 2024, the World Health Organisation continues to warn that the COVID-19 pandemic persists. Dr. Maria Van Kerkhove has cautioned that "the world remains in the grip of the COVID-19 pandemic" **[Exhibit LW/01 – INQ000505887]**, with ongoing virus evolution and continued hospitalisations, as a consequence of continued health risks. For many of our members the pandemic remains a very real and live issue, and in some cases still curtails their fundamental freedoms. We highlight throughout this statement examples of our members' lived experiences, stressing that those experiences have not improved since 28 June 2022 but remain unchanged to this day. This situation will likely continue unless immediate action is taken to address their needs. We highlight throughout this statement examples of our members' lived experiences stressing that those experiences have not improved since 28 June 2022, but remain unchanged to this day. We therefore respectfully urge the Chair to consider the impact of the pandemic upon the Clinically Vulnerable people and their families during the defined period, recognising that for many, that challenges persist, as they did at the height of the pandemic.

A. Introduction to Clinically Vulnerable Families

3. CVF is a grassroots organisation; and until 16 October 2024 was not a legal entity. CVF was incorporated as Community Interest Company[1] (a private company limited by guarantee) on 16 October 2024 with me as the Chief Executive Officer. It was founded in August 2020 before children returned to schools for the first time following their closure towards the start of the pandemic in late March 2020. At that time, parents were told that schools were safe and that all children must be in school. We were repeatedly told that children did not catch or spread Covid-19 infections but despite that, CVF remained concerned due to the risks posed to Clinically Vulnerable staff and children in schools and to other Clinically Vulnerable close contacts living in households with children who were attending school. This was pre-vaccination.

4. Clinically Extremely Vulnerable persons had been formally shielded between 21 March 2020 and 1 August 2020, however, many Clinically Vulnerable people and those in households with a vulnerable household member chose to shield informally. To these families, nothing had really changed when shielding was paused; their unaddressed risks remained and consequently they felt exposed with limited options available to them or the protections in place to mitigate their vulnerability. For them, Covid-19 still represented a significant and serious threat to their lives and the health of their families and communities' wider connections.

5. When shielding was again paused in April 2021 and never resumed, CVF extended the offer of support to all Clinically Vulnerable people, without children in schools, living in Clinically Vulnerable households, therefore widening its membership and strategy to incorporate the many more concerns and needs of all Clinically Vulnerable families from across the UK.

6. CVF currently represents those who are Clinically Vulnerable, those who had been identified as Clinically Extremely Vulnerable (before this terminology was retired), people who are Severely Immunosuppressed; and those in their households across all four UK nations. Whilst CVF initially concentrated on risks posed by education it very quickly broadened its focus to other wide-ranging issues such as safety in workplaces and healthcare, access to Covid treatments, and many other issues such as safety during voting or while attending warm hubs.

[1] Company Number 16022972

7. Our support group is limited exclusively to those in Clinically Vulnerable households. Entry questions are used to determine whether applicants / household members meet the criteria as outlined in "Covid-19: the green book, chapter 14a" **[Exhibit LW/02 - INQ000408795]** (or those with household members who have qualifying conditions). At present, the combined membership and following of CVF is approximately at 54,515 and is continuing to grow. The group have a significant online presence, through which most of their work is achieved. As at the date of the drafting of this statement there are 2,680 members of CVF's private Facebook group, 13,657 Twitter followers (now known as X), 1,121 BlueSky followers and 1,161 Mastodon followers. Each member or follower tends to represent a family or household and we can therefore reasonably assume that CVF's reach is at least three times the number of actual members and followers to account for multiple occupancy households.

8. CVF's mission is to support, inform and advocate for those in Clinically Vulnerable households as they face an ongoing threat posed by Covid-19. Our vision is that one day we will have sufficient protections to restore the freedoms of society's most vulnerable.

9. CVF has multiple purposes, and these have evolved since its foundation. CVF primarily aims to support, educate, assist, advocate and campaign for Clinically Vulnerable families in the UK due to the risks posed by Covid-19. To further understand the work of the group I have set out how CVF fulfils its functions below:

    a. Support

    CVF's social media presence grew and was firmly rooted in our four core principles:

    (i) To be scientific and evidence based;

    (ii) To provide peer support and practical assistance (i.e. drafting letters, helping with other correspondence and communications for our members);

    (iii) To address the mental health needs of members by offering weekly check-ins with members; and

    (iv) To operate exclusively for the Clinically Vulnerable and their households. Through communication with our members, CVF are able to identify and address any additional needs that arise from a member's circumstances, such as the need for legal advice and advocacy.

b. Education

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

c. Assist

(i) CVF aims to identify those members with urgent needs and help them by offering peer support. For example, we have helped members access antiviral treatments within the tight timescales of 5 days by providing basic explanations of how to apply, as well as directly making representations to healthcare professionals and members' MPs in some exceptionally challenging cases;

(ii) The group try to support members who have been fined and/or prosecuted, or threatened with the above, for Covid-19 related absences in school. Also those who are at risk of losing their jobs or being made redundant for Covid-19 related reasons;

(iii) CVF have supported people in making requests for risk assessments and reasonable adjustments within school and employment settings.

d. Advocacy and Campaign

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

(i) Clean indoor air;

(ii) Reasonable adjustments in schools and in workplaces;

(iii) Updating ventilation standards to support accessible environments;

(iv) Improved access to treatments;

(v) Removing barriers to living 'in' society through improving Covid-19 safety protections;

(vi) Access to antivirals;

(vii) End to isolation rules;

(viii) Masks in schools;

(ix) Masks in healthcare;

(x) Freedom Day concerns including mask wearing;

(xi) Safe access to healthcare;

(xii) Inequalities for children forced out of schools;

(xiii) Access to Covid-19 testing;

(xiv) Safe shopping / food deliveries;

(xv) Raising awareness on behalf of Covid Orphans;

(xvi) Job losses;

(xvii) Choice between education and lives;

(xviii) Stopping the spread (reducing transmission);

(xix) Masked carriages on trains and buses;

(xx) Exam conditions risking infections;

(xxi) Inequalities for Clinically Vulnerable families in exams;

(xxii) Pressure from school and education authorities on Clinically Vulnerable families which resulted in the removal of children from the school roll;

(xxiii) The general need for reasonable adjustments for Clinically Vulnerable people;

(xxiv) Access to the National Tutoring Programme;

(xxv) 'Ghost Children'[2];

(xxvi) Risks posed by warm rooms;

(xxvii) Continued access to free lateral flow tests;

(xxviii) Access to Covid-19 prophylactics;

(xxix) Access to private Covid-19 vaccines;

(xxx) Continued access to vaccines for unvaccinated populations;

(xxxi) Continued availability of Covid-19 data;

(xxxii) Against changes to Test, Trace and Isolate policy – particularly regarding the end of isolation rules;

(xxxiii) Against the abandonment of Covid-19 wastewater testing;

(xxxiv) Against government adverts encouraging sick children to attend school;

(xxxv) Safe voting;

(xxxvi) Right to protest whilst masked;

(xxxvii) The right for anyone to wear a mask; and

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

(xxxviii) The recognition of Clinically Vulnerable as protected characteristics under the Equality Act with new and distinct needs.

10. To date, CVF has driven policy change through various methods. CVF has:
    a. Shared members' case studies with the local and national media;
    b. Developed and maintained strong links with Parliamentarians who have asked questions in Parliament on behalf of CVF;
    c. Taken part in relevant All-Party Parliamentary Groups ("APPGs"), for example, members of the group were invited to take part in the Coronavirus APPG chaired by Layla Moran. This led to a question being asked in the House of Commons about Clinically Vulnerable people and schools;
    d. Joined forces with other campaign and educational groups, such as Covid-19 Bereaved Families for Justice, Independent SAGE (for example, in relation to 'The Covid-19 Pledge' where as a signatory to the pledge we have advocated for the needs of our members and have worked to raise awareness of the pledge directly with companies and by encouraging our members to raise with their employers and other businesses), Clean Air Classrooms and Long Covid groups. CVF has brought its unique perspective to these collaborations, a perspective which is not available from any other organisation;
    e. Made connections, established awareness, and raised CVF's profile through social media platforms, aiming always for a better future for the Clinically Vulnerable and their families;
    f. CVF is a stakeholder of the National Institute for Health and Care Excellence ("NICE") appraisal for Evusheld and have gathered information to contribute to their recent call for evidence as set out in the exhibited submissions. [**Exhibit LW/03 - INQ000408806** is demonstrative of the submissions made by CVF to NICE].

11. More information about the group and the work that we do can be found by accessing CVF's website, images of which can be found at **[Exhibit LW/04 - INQ000408817]**.

B. CVF Membership: Clinically Vulnerable, Clinically Extremely Vulnerable and Severely Immune Suppressed people.

12. The names of these groups were created by the government during the pandemic, along with the term 'shielding'. These terms have continued to be removed and changed by

the government over the period of the pandemic to the current day. Although the term Clinically Extremely Vulnerable ("CEV") has stopped being used by the government, many who were designated CEV continue to describe themselves as such.

13. The term Clinically Vulnerable ("CV") remains in active use today. It covers all of those who remain at higher clinical risk to Covid-19 and qualify for vaccines based on those risks. The UK Health Security Agency's "Covid-19: Green book, Chapter 14a" **[Exhibit LW/02 - INQ000408795]** p20 states:

> *"Those Clinically Vulnerable to COVID-19 are defined by the JCVI priority groups as:*
>
> *a) children of any age with severe neuro-disability, severe or profound and multiple learning disabilities (including Down's syndrome and those on the learning disability register) or immunosuppression (as defined in table 4);*
>
> *b) adults who have underlying health conditions leading to greater risk of disease or mortality as defined in table 3; and*
>
> *c) those of advanced age."*

14. These individuals have always been at highest risk of poorer outcomes from Covid-19 infection and continue to be into the fifth year of the pandemic **[Exhibit LW/05 - INQ000408828, page 60]** as noted on 31 December 2023 by Dr. Maria Van Kerkhove (Infectious Disease Epidemiologist; Covid-19 Technical Lead, Director ai Epidemic & Pandemic Preparedness & Prevention, WHO, WHE) **[Exhibit LW/06 - INQ000408839].**

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

    a. In March 2022, *The State of Ageing 2022 Summary* by the *Centre for Ageing Better* **[Exhibit LW/07 - INQ000408850]** estimated that 19% of the population were aged 65 and over. Therefore, for those Clinically Vulnerable due to age (aged 65 and over) the figure is almost 11 million people.
    b. NICE released guidance, published on 14 June 2023 **[Exhibit LW/08 - INQ000339319]**, in which it is claimed that the number of severely immunosuppressed people eligible for Evusheld as 1.8 million. Over the period of

the pandemic, the various government lists of CV/CEV and Severely Immunosuppressed have changed. Some people may not be aware of their risk or status.

c. As stated by the BBC News, *'England on track for vaccinating Covid priority groups'* dated 12 February 2021 **[Exhibit LW/09 - INQ000408872]**, the total number of persons identified in the top priority groups in 2020/2021, excluding care home workers, health and social care workers, and those aged 64 and under, but including those aged 16-64 with underlying health conditions, totalled approximately 20.5 million. It is important to note that these figures exclude CV young people under the age of 16.

16. For many within these groups, they remain at higher risk despite vaccination. This is especially true for immune suppressed individuals, some of whom may not mount a response, or an effective response, to Covid-19 vaccination and therefore remain at incredibly high risk from Covid-19.

17. From the final Office of National Statistics (ONS) dataset, **[Exhibit LW/10 - INQ000408875]** people who have 'underlying conditions' versus 'healthy people' have a 9.2 times increase in death from Covid-19. People who identify as 'activity limited by health a lot, by health conditions' versus 'healthy people' have a 5.4 times increase in developing Long Covid **[Exhibit LW/11 - INQ000408796].**

18. CVF was forged from these Clinically Vulnerable groups of people as identified by the government during the height of the pandemic. Shielding, as a public health measure, had never been implemented before. People had never been categorised by the government based solely on their vulnerability to a virus. It was an entirely unprecedented event, with individuals suddenly grouped by health conditions and advised to take action to protect themselves – which was a novel situation, unfamiliar to society as a whole.

C. Overview of CVF's concerns in relation to test, trace and isolate ("TTI") systems

19. CVF did not formally or informally raise concerns with the government in relation to the development of test, trace and isolate ("TTI") systems. However, CVF later took to social media to actively campaign on many issues highlighted in this statement. Our

membership was often more impacted than other groups by decisions relating to TTI systems due to our heightened risks,

a. Policies and strategies developed and deployed regarding TTI and the impact these had on the membership CVF represents including how the effectiveness of TTI policies adopted affected the risk of exposure to Covid-19 for CV individuals and their families.

20. In the UK, public health responsibilities are devolved so each of the devolved nations had different testing and tracing policies; their intended purpose was to track cases and advise on isolation and management of illness.

21. NHS England working with primary care general practice were tasked with reducing the risk to the most vulnerable. The definition and categorisation of the *'most vulnerable'* was flawed from its inception.

22. As explained in a publication by The Health Foundation in 2021 **[Exhibit LW/12 – INQ000505898]**, the NHS derived data sets could only initially identify less than half of those (approximately 900,000) ultimately categorised as most vulnerable. CVF members and their families were therefore disadvantaged from the start. The policies developed, or lack thereof, from this starting point, led to CV/CEV individuals not being protected adequately.

23. Many CV individuals, who were not shielded, were within other groups such as essential workers; NHS and Social Care, teachers or other front line workers for whom working from home and isolating whilst infectious, was less possible. Insufficient financial support often forced these individuals into precarious situations. Despite the introduction of various financial safety nets like the Coronavirus Job Retention Scheme (furlough) and enhancements to social security benefits, these measures were not accessible to keyworkers. The system was hindered by issues such as insufficient financial support for those who needed to isolate but could not work from home, incomplete data sharing, and poor communication between central and local governments. It is CVF's view that these shortcomings disproportionately affected vulnerable populations, leading to increased risks of exposure to Covid-19 and difficulties in effective isolation.

24. CV people were required to attend work with the only advice that was offered being more frequent handwashing, an ineffective tool against an airborne virus. The CV group who were not designated as CEV, comprises approximately 25% of the general population,

represented huge numbers of deaths. For example, as set out in a BMJ article by *Carr MJ, Wright AK, Leelarathna L, et al, 'Impact of COVID-19 restrictions on diabetes health checks and prescribing for people with type 2 diabetes: a UK-wide cohort study involving 618 161 people in primary care'* BMJ Quality & Safety 2022;31:503-514 **[Exhibit LW/13 – INQ000505899]**, one third of deaths were diabetic patients who were not advised to shield, as they were not classified as CEV, and they were given little or no protection.

25. Some CEV individuals were permitted to work from home even outside the formal shielding period. However, CEV teachers and other keyworkers were often made to return to work once shielding was stopped despite their continued high-risks and dangers of contracting Covid-19 from the workplace, with the school environment being particularly high-risk. Many CV and CEV people, and along with household members, faced difficult decisions. They often had to choose between safeguarding their lives and health, by staying at home or risking their wellbeing due to financial pressures. Financial support for those unable to work from home was either inadequate or unavailable. For those CEV individuals who couldn't work remotely, during shielding periods, the only available financial aid was Statutory Sick Pay ("SSP") , which is generally a limited income source, leaving many in a precarious situation. Clinically Vulnerable people did not even have that 'luxury' and so job losses due to resignations became common, with CV people disproportionately forced to rely on Universal Credit. Following the shielding period finally ending a number of CEV people, who were no longer offered work from home by their employers, also felt compelled to leave their jobs.

26. Many CV families chose to temporarily or permanently withdraw their children from in-person schooling due to health risks. However, some felt compelled to send their children back to school despite those risks, as nearly 50% of CVF members surveyed reported that their families were threatened with fines or prosecution for non-attendance. This left many families in a difficult position, torn between protecting their health and avoiding potential imprisonment and financial repercussions.

27. The government did not take into account the family and work units in which people lived and worked when considering TTI policies. A false belief that children were not particularly affected by Covid-19 meant that school policy development reinforced this, and it continues to this day. Children who were either themselves vulnerable or lived within a household with Clinically Vulnerable members were treated as a homogenous group with all children. Little consideration was given to their different risks or vulnerabilities. Multigenerational households were also poorly understood at national

level, even though they often contained a large number of individuals, including vulnerable and elderly members or younger members with clinical risk factors.

(i) **Testing Criteria and Symptoms**

28. One significant challenge faced across the four nations of the UK was the misalignment between the official symptoms required to access Covid-19 testing and the actual symptoms presented by new variants. This discrepancy had profound implications for CV people and their families.

29. Initially, the UK's policies across all four nations were built around a specific set of symptoms:

    a. a high temperature;
    b. a new continuous cough; and
    c. a loss or change to the sense of smell or taste.

    These symptoms were used as the primary criteria for accessing PCR tests. However, as new variants of the virus emerged, it became evident that these criteria were increasingly inadequate.

30. A study, updated in 2022, by Zoe Health **[Exhibit LW/14 – INQ000505900]**, which collected real-time data from millions of users, identified that people infected with a new variant, such as Delta and Omicron, exhibited a broader and different range of symptoms. These included sore throat, runny nose, headache, fatigue, and muscle pain—symptoms that were not included in the official guidelines for testing eligibility. As a result, many individuals with these symptoms did not qualify for PCR testing under the established criteria.

31. A study by ZOE Health in September 2020, **[Exhibit LW/15 – INQ000505901],** also identified that children often exhibited different Covid-19 symptoms to adults. Symptoms such as sore throat, fatigue, and headaches were more common in children than the classic symptoms such as cough or fever. This posed a further problem for families because official testing guidelines were based on original symptoms, meaning that many children with Covid-19 might not have been tested. CVF believes this gap in testing criteria not only allowed the virus to spread more within schools and homes but also

influenced flawed studies that concluded primary infections within households typically originated from adults rather than children.

32. For CV individuals and their families, this mismatch between the official testing criteria and the actual symptoms of new variants significantly increased the risk of exposure to Covid-19. Many CVF members reported that they or their family members experienced these newer symptoms but were unable to access testing due to the rigid criteria. This led to delays in diagnosis and isolation, increasing the likelihood of transmitting the virus within households and communities, particularly among those who were most vulnerable to severe illness.

33. More concerningly, reluctance to update the official symptom list in a timely manner meant that many cases went undetected, contributing to underreporting and exacerbating the spread of the virus. This was especially concerning for CV households, where the risk of severe outcomes from Covid-19 was already heightened. Some CVF members felt compelled to lie about their symptoms, which were actually recognised as Covid-19 symptoms elsewhere, to meet the official criteria in order to access testing.

34. The effectiveness of the TTI policies adopted by the UK's four nations was therefore compromised by this failure to adapt testing criteria to the evolving nature of the virus. By not aligning testing access with the real-world symptomatology of new variants, CVF believes the policies inadvertently increased the risk of Covid-19 exposure among CV individuals. This gap in the testing strategy left CV households more vulnerable and less protected.

b. The development of the TTI systems including adequately disaggregated and robust data pertinent to CV individuals and their families.

(i) **Priority PCRs**

35. The NHS data algorithm could not nationally identify all of those ultimately categorised as most vulnerable due to the complexity and sometimes incompleteness of data systems held nationally and locally. The origins of the priority PCR testing system for accessing Covid-19 antiviral treatments were rooted in an effort to improve the outcomes for the most vulnerable individuals. The UK Health Security Agency ("UKHSA") sent priority PCR tests to around 1.3 million people who were identified as being at the highest risk of severe illness from Covid-19 as stated in a UK government press release

published on 28 January 2022 **[Exhibit LW/16 - INQ000505902]**. This group included those with weakened immune systems, cancer patients, and individuals with conditions such as Down's Syndrome. However, by using what CVF views as a flawed algorithm, relying on using incompletely coded data sets, these tests were only sent out to a limited group of people. This included some who were previously classified as CV, some but not all CEV individuals, and a new category of "Severely Immunosuppressed" that was similar to but still slightly different from those who qualified for the third primary (initial course) Covid-19 vaccination doses. Many CVF members, particularly those who were formerly CEV, did not know whether they should have qualified for antiviral treatments and received a priority PCR whilst others were often equally confused if they had received one unexpectedly in the post. There was a severe lack of general communication around the new priority PCR tests, which led to much confusion around the process. People who received Priority PCR tests were instructed to use them if they developed symptoms. Only a positive test result would make them eligible to be considered for antiviral treatments, which were available to a select group of high-risk individuals.

36. The rollout of this priority system faced significant challenges. A major issue was the timing and accessibility of the tests. PCR test results often took up to 72 hours to process, which was problematic given that antiviral treatments such as Paxlovid are most effective when administered rapidly, within five days of symptom onset. Delays in testing could therefore result in patients missing the critical window for treatment. Additionally, there were logistical challenges, such as ensuring tests reached all eligible individuals promptly and that those in remote or underserved areas had equal access. Also, the communication around eligibility and how to access these tests and new treatments was not always clear, even to many healthcare professionals, leading to confusion and potential delays in treatment for vulnerable individuals.

37. Some CVF members' experience was that replacement PCR tests did not appear to have been sent out automatically once the initial PCR test had been used. There wasn't an obvious process to order replacement PCRs. Some CV people were passed between 111 and 119 whilst trying to order a replacement. This was problematic as the PCRs were the only community-based means to access antiviral treatment. This meant that people who had difficulty obtaining a kit initially or as a replacement would therefore potentially have reduced means to access urgent life-saving antiviral treatments, as well as potentially increasing emergency admissions to hospitals.

38. CVF believes that shortcomings in the priority PCR system highlighted a distinct lack of planning, foresight, and engagement with the target group, required when implementing a new public health initiative. UKHSA failed to communicate effectively with end users or to consider or improvements needed. Given that patient outcomes relied on fast turnaround times and precise targeting to protect these high-risk populations, it was essential to resolve any systemic issues as rapidly as possible.

(ii) General community-based PCR testing

39. The TTI system was repeatedly criticised for being geographically 'blind': asking people to attend for PCR testing at locations many miles from where they lived and without appropriate access for those who needed it. One CVF member reported being asked to drive more than 50 miles, across two counties, to access the only bookable test available at that time. Members also reported failed attempts to book an appointment during peak times, such as during infection surges, due to the limited testing capacity. Covid-19 Testing Site staff lacked training and awareness of the needs of Clinically Vulnerable people. For instance, CV drivers bringing their children for testing were instructed to keep all car windows closed, increasing their exposure risks, even in large open parking areas. Additionally, those arriving at testing sites to pick up lateral flow tests were sometimes required to walk through crowded areas where others were being tested for Covid-19, creating unnecessary exposure risks.

40. Families where more than one person had tested positive found that they were bombarded with calls from different members of TTI staff, seemingly unaware that their colleagues were also in contact. We also found that family members who had tested positive were surprised to find that they were never contacted, which felt particularly concerning and unsafe for CVF members.

41. CVF were concerned to hear from one member who, in 2021, reported a conversation with a TTI representative. During the call, the TTI official mentioned that a significant number of test and trace cases were linked to schools. Other CV families reported that they attempted to conduct their own contact tracing for their children across various settings because the test and trace system simply would not collect their information. A number of our families did share their concerns about transmission in schools.

Quote 1 from CVF Member

"I had the council ring me, she went through the test & trace form. The lady was lovely & was honest in saying virtually every phone call she's made has been linked to schools. I told her how as a parent & a cev parent it is beyond comprehension the logic surrounding the safety measures schools are refusing to implement. She even told me to make my voice heard because she's alarmed by how many cases are coming just from secondary schools"

Kelly, aged 37 (October 2021)

c. Key decisions made by the UK Government and the Devolved Administrations regarding the adequacy of government guidance relating to TTI, in particular for CV individuals and their families.

42. Government guidance appeared to be based on a homogenous view of the population which did not take into account the specific needs of different groups including CV/CEV individuals and their families.

43. Another issue was the inconsistent integration of digital and manual contact tracing, which affected the accuracy and timeliness of tracing efforts. This was particularly problematic for CV individuals who required prompt intervention to minimise risks. Additionally, the centralised nature of some TTI systems in England, for example, often overlooked local needs, leading to delays and reduced accessibility for those in remote or underserved areas. The devolved administrations attempted to address these gaps by tailoring their approaches, but this created a fragmented response that left CV individuals without consistent support.

(i) **England**

44. In England, key decisions regarding the TTI system appeared to be driven by the need to manage the Covid-19 pandemic on a national scale, but these decisions often had mixed results in terms of addressing the needs of high-risk individuals and their families.

    a. **Priority Testing:** Severely Immunosuppressed individuals were given guidance regarding priority PCR tests (as outlined in paragraphs 35 - 38)

b. **Centralisation of NHS Test and Trace:** The UK Government decided to centralise the TTI system under the NHS Test and Trace program. This decision was intended to ensure a uniform response across England, but it led to significant issues with local responsiveness and the system's ability to meet the specific needs of CV households. CVF found that the centralised approach sometimes resulted in delays in testing and tracing, particularly in areas with high demand or less access to healthcare resources.

c. **Guidance on Isolation and Support:** The UK Government issued broad guidance for self-isolation, which applied to the general population, including CV individuals. However, this guidance was not sufficiently tailored to the specific needs of vulnerable groups. Decisions regarding the provision of support services, such as food and medical supplies for those isolating, were left to local authorities, resulting in a "postcode lottery" where support varied significantly depending on the individual's location. **[Exhibit LW/17 - INQ000505903]**

(ii) **Scotland**

45. The Scottish government implemented its own Test, Trace, Isolate and Support ("TTIS") system, known as 'Test and Protect', as a central component of its response to the Covid-19 pandemic. CVF members felt the title in itself recognised the purpose of testing to protect lives.

46. Recognising the heightened risk faced by CEV individuals, the Scottish Government incorporated specific measures within the 'Test and Protect' system:

a. **Priority Testing:** Severely immunosuppressed individuals exhibiting symptoms were given priority access to testing to ensure rapid diagnosis and care.

b. **Support Services:** Those required to isolate, especially CEV individuals, had access to support services and crisis grants from the Scottish Welfare Fund, including food deliveries and mental health resources. Local authorities played a pivotal role in coordinating this support as demonstrated by Aberdeen City Council **[Exhibit LW/18 - INQ000505904]**.

c. **Guidance:** The Scottish Government provided detailed guidance tailored for CEV individuals, advising them on how to minimise risk and what steps to take if they developed symptoms.

47. While 'Test and Protect' played a vital role in managing the pandemic, several challenges emerged:

a. **Capacity Issues:** At certain peaks, there were concerns about testing capacity and turnaround times, which could impact timely tracing and isolation.

b. **'Protect Scotland' App:** As set out in a press release by the Scottish Government on 10 September 2020, the Scottish Government released 'The Protect Scotland' app and First Minister Nicola Sturgeon urged smartphone users across Scotland to download NHS Scotland's new contact tracing app to help suppress the spread of Covid-19 **[Exhibit LW/19 - INQ000505905]**. Although the Scottish track and trace app was a valuable tool, its effectiveness depended on widespread public adoption. Efforts were made to promote its use, but varying levels of uptake influenced its overall impact.

48. Because Scotland and England developed their own contact tracing apps independently this led to issues, as the apps could not communicate effectively across the UK. Over time, backends were integrated, allowing both apps to share exposed 'tokens' from users across the different nations. This integration helped ensure that people using different apps could still receive alerts about potential Covid-19 exposures, regardless of the app used, but this also created security concerns for users and staffing concerns for employers.

Quote 2 from CVF Member

"I did hear employers in Scotland (e.g. shop workers) telling people not to use the app. There were also privacy issues around the exposure notification system as you could record the pings against your location with £15 of hardware and then identify which pings were associated with someone with Covid-19 - so you then knew where and when you may have been exposed. They also easily identified when people were at home and how many were present as the IDs only revolved every 30 mins"

Tim, aged 43

(iii) Wales

49. In Wales, the Test, Trace, Protect ("TTP") strategy was central to the Welsh Government's response to the Covid-19 pandemic. This approach was tailored to the specific needs of the Welsh population, which included CV people and their households. CVF note that the Welsh title of "Test, Trace, Protect" effectively conveys the core purpose of testing as a means to protect lives. This sentiment contrasts with the titles used in some other regions, which were perceived as more technical or procedural.

50. The key decisions made by the Welsh Government reflect a commitment to local responsiveness and community-based support:

    a. **Priority Testing:** In line with the broader UK strategy, Wales prioritised severely immunosuppressed for PCR testing to access early treatment. However, similar to other regions, CVF members felt that there were challenges in ensuring that all eligible individuals were identified, made aware of, and able to access, these prioritised services.

    b. **Decentralised Approach:** The approach adopted by the Welsh Government for its TTP strategy allowed local health boards and authorities to take the lead in implementing testing, tracing, and protection measures. This decision enabled responses to be tailored to the specific needs of different communities across Wales, particularly in rural areas where centralised services might struggle to reach. The decentralised system allowed for more agile responses aligned with local health infrastructure to support communities, including CV people.

    c. **Enhanced Community Support Mechanisms:** Recognising the particular vulnerabilities of certain groups, the Welsh Government made decisions to enhance community support mechanisms and a press release was issued in June 2021 to describe the support to be offered such as providing targeted assistance to those self-isolating **[Exhibit LW/20 - INQ000505906]**. This included food deliveries, mental health support, and coordination with local volunteer networks to ensure that no one was left without necessary support during isolation. These measures were particularly important for CV people, who faced greater risks.

    d. **Clear and Regular Communication:** The Welsh Government emphasised clear and regular communication as a key aspect of its TTP strategy. This included

providing specific guidance for CV individuals and their families, ensuring they understood the steps they needed to take if exposed to the virus or required to isolate. The Welsh Government's decision to maintain a transparent and consistent communication strategy helped build public trust and ensured that vulnerable populations received the information they needed in a timely manner.

e. **NHS Covid-19 app:** Wales also integrated the NHS Covid-19 app into its strategy. However, as with other regions, the success of these tools depended on public uptake and the ability of individuals to engage with digital platforms.

51. Key decisions made by the Welsh Government regarding the TTP system demonstrated a commitment to local responsiveness and support for vulnerable individuals. While there were challenges, particularly in ensuring consistent access to services, CVF feel that the decentralised approach and focus on community support were significant strengths in Wales' response to the pandemic.

Quote 3 from CVF Member

"One issue for me was there weren't local slots available for PCR testing quick enough (pre-antiviral availability) but I could easily get in at the larger test site nearby across the border at Ross-on-Wye. I was exposed to friends 5 times on the day before I tested positive so needed it quite a few times. I don't think it reflects lack of capacity here so much as Monmouth has a small population and the centres were in the valley areas or Newport where more people live. Whereas Ross on Wye has a large workforce for the market garden produce. Luckily I was negative each time so didn't need to report to TTI."

Sharon, aged 67 (Wales)

(iv) Northern Ireland

52. In Northern Ireland, key decisions regarding the TTI system appeared to be shaped by the need for localised control and coordination through the Public Health Agency.

a. **StopCOVID NI app:** The Northern Ireland Executive rapidly developed the StopCOVID NI app but it faced some integration challenges with other UK contact tracing apps. Northern Ireland's app was developed using the decentralised Apple-Google protocol, which was also used by the Republic of Ireland, enabling

cross-border functionality on the island of Ireland. However, as set out in a blog written by Dr Amgela Daly and Professor Maurice Mulvenna for the Ada Lovelace Institute and published on 24 September 2020 **[Exhibit LW/21 - INQ000505907]** , this created challenges with the original NHSX app in England, which initially used a centralised protocol, limiting communication between the two systems. Telephone support was also available as an alternative.

b. **StopCOVID NI app for u18s:** As explained in a press release published on 14 September 2020 by the Department of Health **[Exhibit LW/22 - INQ000505908]**, Northern Ireland uniquely developed a contact tracing app specifically for under-18s, aiming to involve younger users in Covid-19 prevention efforts. While this initiative was generally welcomed by CV families, there were concerns about its effectiveness. The primary issue was that children were often required to turn off their phones or were not allowed to bring them to school, limiting the app's utility as a consistent contact tracing tool during school hours, where transmission risks for our families were at their highest.

Quote 4 from CVF Member

"My older daughter used the under 18 app and we specifically told her to keep her phone on in school. At one point she got a notification that she had been a close contact but the date given was 10 days prior and in that 10 days she had been around her vulnerable little sister. The only place this could have happened was school but there was no notification from school themselves."

Donna, aged 40 (Northern Ireland)

c. **Vulnerable Populations:** The Northern Ireland Executive initially did not prioritise messaging around vulnerabilities **[Exhibit LW/23 - INQ000505909].** CVF would be interested to know whether this approach positively impacted public perception of vulnerable people and overall health outcomes. It was only as the Test, Trace, and Protect program wound down that the focus shifted to those eligible for antiviral treatments, highlighting their needs more prominently, as explained in a press release by the Department of Health on 21 April 2022. **[Exhibit LW/24 - INQ000505910]**

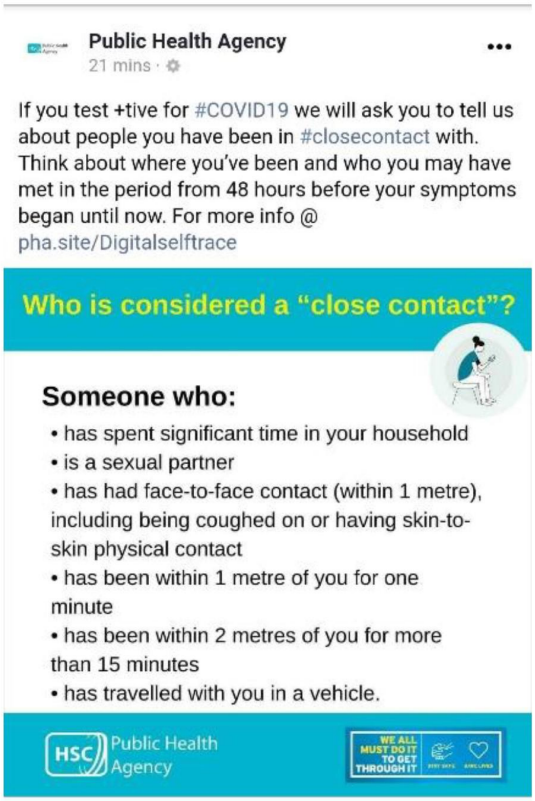


Figure 1

d. **Guidance:** The Northern Ireland Executive issued general guidance to the public on, for example, "close contacts" (see fig. 1 above). They also provided more specific guidance to CEV individuals, offering advice on how to reduce their risk of exposure and outlining the steps to follow if they began to show symptoms.

Quote 5 from CVF Member

"I think at one time it was assumed that if a person was on CEV list they would automatically be contacted if they reported a positive LFT & were sent a PCR test.
But that wasn't the way it worked in practice. It worked for some but not others & it wasn't done by app. It would have been done by phone".

Bernie, aged 66 (Northern Ireland)

d. Overall structure of the system or systems adopted, including the use of private versus public sector providers and the centralisation of the testing and tracing.

53. In any emergency response it is difficult to comprehend why any government would want to start something entirely new and untested rather than relying on the expansion of existing structures and ways of working. These often have the benefit of well-trained staff, used to meeting high quality and audit standards. Most CEV/CV individuals and their families have spent years navigating complex health-related systems. They are also in a sense experts in managing both complex medications and testing equipment necessary for their own health. This autonomy is a vital component of independence for many people. Bringing a multiplicity of new and often untested providers rather than expanding existing and well-tried systems, familiar to patients, makes access much more complex and raises barriers for CEV/CV individuals and many others. It can also increase the risk of unsafe practice.

54. As previously stated, having a nationalised approach which was geographically, disability, and vulnerability blind to the needs of many groups, including CEV/CV individuals and their families, increased risk significantly. This centralisation may have allowed for a uniform response across the country, but it was slow to adapt to local needs, particularly for CV individuals who required more targeted support.

55. The UK Government outsourced significant portions of the testing and tracing efforts to private companies. For instance, large private sector firms were involved in the establishment and management of testing centres and labs, as well as the development of digital contact tracing apps. This reliance on private providers was presumably to scale up operations quickly but some of CVF's members had concerns about efficiency, potential issues around data privacy via private providers outside of the NHS, and the consistency of service delivery.

56. Some CVF members also reported having received false negative results for themselves or their children as part of the Immensa lab scandal, where 39,000 people were incorrectly told that they did not have Covid-19. The Immensa lab scandal was particularly problematic for Clinically Vulnerable people in their homes because false negative test results created a false sense of security. Individuals or their family members, believing they were virus-free, could have unknowingly spread the infection within their households or communities. Given the heightened risk of severe illness or complications from Covid-19 for CV patients, this failure not only increased their chances

of exposure but also delayed necessary medical interventions and protective measures. The result was a significant threat to their health and safety, leading to increased hospitalisations and potentially preventable deaths.

57. Over time, there was a shift towards a more decentralised approach, especially in devolved administrations like Scotland, Wales, and Northern Ireland, where local health boards played a larger role in tailoring services to meet the needs of their populations, including those who were Clinically Vulnerable.

e. Testing strategies adopted as part of TTI including access to testing, access to lateral flow tests, priority PCRs, alternative methods of testing, testing of Clinically Vulnerable children in schools and the use of 'Asymptomatic Testing Sites', sector testing and the reporting processes adopted.

58. As evidenced in an article, '*Covid-19: What is the UK's testing strategy?*' *BMJ* 2020;368:m1222 **[Exhibit LW/25 - INQ000505911]**, the UK initially faced significant challenges in scaling up its testing capacity, particularly in the early stages of the Covid-19 pandemic. While PCR testing was prioritised for high-risk groups like those in intensive care units, people with severe respiratory illness, and isolated outbreaks in settings such as care homes, there was a shortage of testing supplies. This shortage limited the availability of tests for broader populations, including CV people in the community who were not in an area recognised to be in an outbreak. CVF members reported in the very early stages that their families may have had Covid-19 symptoms and knew that they had been in close-contact with someone from an infected region, such as Italy, but were not tested due to very strict limitations on the access and shortages.

Quote 6 from CVF Member

"My daughter had all of the classic symptoms of Covid and so we contacted our GPs. Having discussed close-contacts and my concerns regarding her symptoms I was told that they were only testing people who had been in contact with people from Wuhan. Flights from Wuhan had stopped long before and we all knew that Italy had a massive outbreak, My child had been in contact with a couple of people who had been in North Italy for the half term but they were only testing people who had themselves been to Italy so she was refused a test. The doctor told me how frustrated she was by this, but she simply couldn't help." Tomas, aged 38

59. There were international shortages in essential supplies like swabs, viral transport mediums, and reagents needed to process the tests in the laboratories. These supply chain constraints led to delays and bottlenecks in testing capacity, making it difficult to extend testing to wider groups, including healthcare workers and vulnerable populations which so urgently needed them. **[Exhibit LW/26 - INQ000505912]**

(i) PCR Testing

60. As the pandemic progressed regional testing sites were set up and the general public had access to PCR tests through centralised booking systems. Sometimes CVF members had to travel long distances to access tests. Initially, the UK Government established a network of drive-through and walk-in testing sites across the country, with PCR tests available to anyone displaying symptoms of Covid-19. Attending walk-in centres with indoor sections was risky for high-risk households who may have been more likely to test for symptoms which might or might not have been Covid-19 infections. However, by attending an indoor testing facility, they are likely to be at higher risk to contract Covid-19 due to its airborne transmission. CVF members in urban areas reported more convenient access in some areas but not all: appointments could be offered up to 50 miles away. Later, additional accommodations were made, such as the provision of home testing kits. Mobile testing units were latterly deployed to reach underserved or remote areas.

61. One of the major issues with PCR testing was the delay in receiving results. At various points during the pandemic, particularly during periods of high demand, it could take several days to receive PCR test results. This delay posed serious problems for CV people and people in CV households, for whom timely detection was crucial. A slow turnaround time meant that individuals with suspected Covid-19 had to wait in uncertainty, potentially continuing to expose others if they were infectious and not being able to access vital treatments.

62. In some cases, PCR test results were not returned at all due to technical issues or processing errors. For CV individuals, this created additional stress and confusion, as they were left without clear guidance on whether they were infected. Without a confirmed result, they could not take the necessary steps to access antiviral treatments or inform close contacts, which increased the risk of further spread of the virus.

63. The need for repeat testing due to faulty or non-returned results compounded the challenges. For CVF members who were already at higher risk, having to undergo multiple tests added to their burden. The delays in receiving results from tests meant that they and household contacts had to extend their isolation periods unnecessarily, it hindered contact tracing efforts, and the delay in access to appropriate treatments could also significantly worsen health outcomes.

(ii) Lateral Flow Tests

64. Later in the pandemic, the UK Government encouraged the widespread use of lateral flow tests ("LFTs"), however significant challenges emerged in meeting the surge in demand. This was partly due to a global shortage of LFTs, particularly during critical periods such as the holiday season, when people were planning to meet up with elderly and CV relatives, and also due to peaks in transmission. This resulted in inconsistent supplies across the UK which particularly affected CV people and their households, who relied on frequent testing to monitor their own health and reduce the risk of severe illness if they were to become infected. Regular testing helped CV people to detect the virus in the household early, manage their conditions, and take necessary precautions. For CV households, including family members who were also at risk, the lack of reliable testing supplies left them exposed to the potential spread of Covid-19 within their homes, heightening the risk of severe outcomes.

65. CVF members reported frequent difficulties in obtaining LFTs from pharmacies which struggled to meet high demand. Many members had to visit multiple pharmacies and Covid-19 testing sites, increasing their risk of exposure, sometimes without success. Shortages made it difficult for CV households to regularly access these tests, which was problematic if they were exposed, often repeatedly, to infections through healthcare, schools or workplaces.

66. Such shortages highlighted the strain on the UK's testing infrastructure and the challenges of scaling up mass testing in response to public health needs. CVF believes that the government and health authorities could have predicted surges in demand, especially around expected peaks in demand e.g. during the winter holiday period, but failed to adequately prepare. The worst consequences of poor planning and decision-making were felt by those who were most at risk.

67. Later in the pandemic, LFTs became more widely available and asymptomatic testing became a more significant component of the strategy. CV households found it far more convenient, and safe, to order tests for free via the NHS website and CVF expressed disappointment when this service was withdrawn for most people, particularly for the severely immunosuppressed – the only group still eligible for free LFTs to this day. Tests ordered in this way would arrive, often within 24-48 hours, at people's houses. Even the severely immunosuppressed group are now not eligible to order free tests online but rather have to go in person to a pharmacy to collect their box. This process is fraught with risks for the CV having to go into an often-busy pharmacy. Moreover, the process is often unknown by the pharmacy staff and the CV find themselves having to discuss their medical history and show proof in the busy, and far from private, counter area of the pharmacy. CVF suggest it would be better to provide people eligible for this service a plastic wallet card (akin to the prescription exemption card).

(iii) LFTs for Antiviral Treatments

68. Those who were severely immunosuppressed were prioritised for online ordering and receiving free LFTs even after these tests became less available to the general public. This allowed for regular testing, which CVF members found especially important in situations where frequent PCR testing was not feasible or available. LTS were also easier for people to perform on themselves. Testing by lateral flow reassured people immediately and enabled them to take control of their own risks. Of course, family members of the CV person would also ideally have access to free LFTs to reduce risk of infection of the vulnerable household member, however this need was never factored in as LFTs were increasingly rationed.

69. Despite the increased availability of privately purchased test kits, reporting of positive results through the NHS website required people to enter a code from an NHS-issued test. Given that access to antiviral treatments was contingent upon a positive test being reported, this created a confusing situation where privately obtained LFT positive test results (e.g. LFTs purchased from a local pharmacy), could not be used to access these urgent and essential treatments, even though those tests were more widely available and easier to obtain during peaks in demand or other NHS shortages. This unexpected complication led to frustration and will have potentially delayed, hindered or even prevented access to antiviral medications for those who tested positive using non-NHS tests, thereby possibly worsening their outcomes.

70. There were also reported issues with the NHS Reporting System. Some of our members did qualify for treatment but had to buy an over the counter test at the last minute and therefore couldn't submit their positive report code which meant they couldn't access the treatment that they had qualified for. CVF believes that this obvious gap in the system should have been identified and resolved.

71. The use of home testing via LFTs sent out to severely immunosuppressed individuals was a positive development as these could also be used to report positive tests to initiate faster access to antiviral treatment. However, the more recent changes introduced in September 2023, **[Exhibit LW/27 – INQ000505913]** shifting access to LFTs from simple online ordering to community pharmacies, have created significant barriers to CV people. Pharmacies now require the repeated completion of complex forms in-person and verification of qualification, so individuals have to justify each time. This process not only increases their risk of exposure to infection but also, in some cases, requires traveling long distances to find a participating pharmacy that has stock available. CVF members have expressed concerns about the exposure risks associated with visiting these locations, when compared to the safety and convenience and accessibility of online ordering. CVF believes these barriers may have resulted in eligible severely immunosuppressed people to struggle with, or even be denied, access to both LFTs and antiviral treatment.

(iv) Saliva Testing

72. Saliva testing emerged as a promising method for Covid-19 detection via several university-led trials. Potential benefits included the fact that they were less invasive, easier to administer, and potentially even more accurate than earlier swab tests. These tests could therefore be helpful to test children, people with dementia and learning disabilities and people who could not tolerate the more invasive testing swabs.

73. The University of Southampton was a pioneer in this area, launching a trial that involved weekly saliva tests for key workers, GP staff, university employees and local school children **[Exhibit LW/28 – INQ000505914]**. They demonstrated that saliva testing could effectively identify infections, including asymptomatic cases. The non-invasive nature of saliva testing made it particularly beneficial for those who found nasal swab tests uncomfortable or challenging, which included people who had special needs, babies and children.

74. Similarly, the University of Edinburgh conducted the TestEd project, **[Exhibit LW/29 – INQ000505915],** which ran from April 2021 to December 2022 to detect asymptomatic infections quickly using saliva samples, with results available within 24 hours. The study processed over 168,000 test samples, successfully identifying more than 800 positive cases. The ability to test large groups efficiently and non-invasively was a significant advantage, especially in school settings where regular testing was necessary to maintain safety.

75. Despite the advantages, access to saliva testing was limited so the broader population did not benefit. So, although saliva testing showed promise and unique benefits, CVF question why it did not become widely available or integrated into the national testing strategy on the same scale as PCR and lateral flow tests.

76. After saliva testing proved effective in university trials, they eventually became available for private purchase in the UK. However, the general public remained largely unaware of this option. This lack of awareness will have had a negative impact on testing among groups that could have greatly benefited from the less invasive method. These groups included young children and people with disabilities, many of whom were members of CV households. Although CVF informed its members about the availability of saliva testing, this information did not penetrate the broader public consciousness. As a result, many who could have taken advantage of this more accessible testing method were unaware of its availability, potentially missing out on timely and or regular testing that could have better protected their health and the health of those around them.

(v) Covid-19 Detection Dogs / Biosensors

77. Specially trained sniffer dogs ("Bio Detection Dogs") capable of detecting Covid-19 infected people were explored as an option, but were eventually abandoned, despite supporting evidence for their effectiveness. The Medical Detection Dogs organisation reported that "[t]he highest performing dogs in the trial detected the odour of the virus in the samples with up to 94.3% sensitivity and up to 92% specificity. … This was a far greater accuracy than recommended by the World Health Organization for Covid-19 diagnostics, with the dogs consistently outperforming lateral flow tests (LFTs) across sensitivities between 80-90%, which had an overall sensitivity of between 58-77%" **[Exhibit LW/30 – INQ000505916].**

78. As explored in an article published in the BMJ, *'Scent Dogs in detection of COVID-19:triple blinded randomised trial and operational real life screening in airport setting' Kantele, A et al, BMJ Global Health, Vol 7 issue 5 2021* **[Exhibit LW/31 – INQ000505917]**, they could have been a very useful tool to detect infected cases in transport hubs or hospitals and stream people into safe or unsafe areas and this knowledge could have been used to develop a technological solution such as bio-sensors. This strategy was not pursued by the UK Government.

79. Since Covid-19 case reporting is no longer required and the NHS reporting page was closed down, this has further contributed to the paucity of data on Covid-19 cases. CV/CEV individuals need access to reliable and accurate data to assess their own risk and this has been denied with the reduction in testing, reporting, and the publication of data.

80. Biosensors are analytical devices that rapidly detect the presence of biological molecules, such as proteins or viruses, through a combination of biological and electronic components as explained in an article by Breshears LE, Nguyen BT, Mata Robles S, Wu L, Yoon JY. Biosensor detection of airborne respiratory viruses such as SARS-CoV-2. SLAS Technol. 2022 Feb;27(1):4-17. doi: 10.1016/j.slast.2021.12.004. Epub 2022 Jan 2. PMID: 35058206; PMCID: PMC8720388 **[Exhibit LW/32 – INQ000505918]**. In the context of Covid-19, they can identify viral particles quickly and with high sensitivity, making them valuable for real-time testing. These sensors could potentially allow individuals to get immediate results, reducing the need for lab-based PCR tests and enabling faster isolation of infected individuals. While promising, the biosensors were not integrated the UK's Test, Trace, and Isolate system as they faced challenges in terms of scalability, regulatory approval, and accessibility.

81. CVF believes that additional funding is essential to support further research and development in the field of biosensors. Advancing this technology could greatly enhance the speed and accuracy of Covid-19 detection, making it a vital tool for future pandemic preparedness and healthcare. Investing in biosensor innovation would improve accessibility to rapid testing, ultimately reducing transmission rates and better protecting high-risk populations.

(vi) School / College Testing

82. The UK Government's approach to managing Covid-19 in schools changed significantly over the course of the pandemic, with testing seemingly focused on keeping educational

settings open. Initially, the focus was on PCR testing, but as the pandemic progressed, LFTs became the primary tool for regular screening and testing in schools.

83. When schools re-opened in September 2020, PCR testing was the only method to diagnose Covid-19. However, there were challenges associated with this type of testing. PCR tests required laboratory analysis, which meant that results were not available immediately. The delay in receiving PCR results posed significant challenges. When a student or staff member exhibited symptoms, they were typically sent home and required to undergo a PCR test. The individual and their close contacts were often required to isolate until the test results were confirmed, which could take several days. This waiting period led to considerable disruption, with entire classes or year groups sometimes sent home to isolate as a precaution. Uncertainty and delays contributed to significant concerns among pupils, parents, and staff, and created challenges in terms of teaching and learning.

84. Beginning in early 2021, LFTs were rolled out across secondary schools and colleges. Children and staff were encouraged to take LFTs twice a week, even if they were asymptomatic. The widespread use of LFTs did allow schools to stay open more consistently by quickly identifying and isolating positive cases. If a student or staff member tested positive on an LFT, they were required to take a confirmatory PCR test, however they began to isolate immediately, reducing their risk of transmission. This regular testing also aimed to identify asymptomatic cases that might otherwise go undetected, reducing the likelihood of outbreaks within schools. However, CVF members found that in reality testing was frequently unsupported and not encouraged by many schools who saw isolations as disruptive, and so naturally these efforts rapidly dropped off over time.

85. After holidays, children attending secondary schools or colleges in the UK were told that they were required to test negative twice using LFTs before returning to school. Schools set up impromptu testing centres, often in school halls, where parents and staff were involved in testing pupils. However, while testing was strongly encouraged, it was not mandatory. This led to a situation where some students were not tested, with this population therefore being the least likely to undergo any testing at all.

86. No specific plans addressed the management of potential Covid-19 sickness in this untested group, as it appeared to be the assumption that all children would comply with the testing request. This was concerning for CVF members. Many CVF members also

were not comfortable with the expectation that their children had to remove their mask and test in a crowded room full of other unmasked children coughing and spluttering during the testing process. In response to their concerns, CVF recommended that members requested that their children were tested at home and that they should offer to send photo evidence of the test results to the school. Since schools were not obliged to test children on site, they generally accepted the suggested alternative. Additionally, CVF was concerned that, due to the rapid rollout, volunteers were not always DBS-checked, despite being in close contact with children.

Quote 7 from CVF Member

"I was able to test my child at home before returning them to school. However, I was very horrified to find that my CEV child was made to wait in a group with the children who refused to test or mask, while all of the other children in the school were being tested on that first morning."

Anon CVF member, aged 42

87. LFTs were used as a more practical solution for regular testing in schools. Unlike PCR tests, LFTs provided results within minutes and could be administered on site or at home. The rapid turnaround time made LFTs particularly well-suited for the school environment, where quick decision-making helped to minimise disruption. However, LFTs were significantly less sensitive than PCR tests, which amplify even small amounts of viral material. LFTs can miss early-stage infections, thereby increasing the risk of virus transmission. This raised concerns among CVF members that a single negative LFT result could provide a false sense of security, potentially leading to infected children being sent to school.

88. Testing children was seen as immensely disruptive to schools and the false belief that children are not really affected by Covid-19 put pressure on schools as some families decided that their children should not test and attend whilst unwell due to financial pressures. Caring for children off school was disruptive to work attendance, which was problematic for all workers, but particularly for those on zero hours contracts. This continues to this day. For some children nose and throat swabbing is difficult and although saliva testing has been available since 2020, commercial tests were not made available to children for free via the NHS.

89. Testing in schools was never compulsory and, as it was uncomfortable, the reporting rate dropped dramatically over time. CVF believes that saliva testing would have improved compliance and been a better option for children and adults.

(vii) Wastewater Testing

90. Wastewater testing for Covid-19 was an innovative public health tool that played a significant role in monitoring the spread of the virus across communities in the UK. By analysing sewage samples, public health officials could detect the presence of the virus in specific areas, often identifying outbreaks before clinical cases were reported. This method was particularly useful for monitoring asymptomatic cases and tracking the spread of variants, providing a crucial early warning system for potential hotspots.

91. Wastewater testing is particularly beneficial in several ways:

    a. **Early Detection of Outbreaks**: Wastewater surveillance could detect Covid-19 in communities even when few or no symptomatic cases had been reported. This early detection allowed for timely public health interventions, such as targeted testing and isolation measures, potentially preventing larger outbreaks.

    b. **Monitoring Variants:** As new variants of the virus emerged, wastewater testing became a valuable tool for tracking their spread. By analysing the genetic material in sewage, scientists could identify which variants were present in different regions, helping to guide public health responses and vaccine distribution.

    c. **Community-Level Monitoring:** This method provided a more comprehensive picture of the virus's spread than individual testing alone, as it captured data from entire communities, including those who were asymptomatic or who had not sought testing.

92. Despite its effectiveness, wastewater testing was withdrawn in England as the focus of the public health response shifted. The withdrawal of this surveillance tool raised concerns among public health experts and CV people, who relied on this data to assess the risk levels in their communities.

93. The discontinuation of wastewater testing in England in March 2022 **[Exhibit LW/33 – INQ000505919]** meant the loss of an important early warning system. Without this

surveillance, the ability to detect outbreaks early and monitor the spread of new variants significantly diminished. This reduced the overall capacity to manage and mitigate risks, particularly for CV people, who rely on timely information to avoid exposure. For communities, especially those with high numbers of CV residents, the end of wastewater testing meant they were more likely to be caught off guard by any sudden spikes in infections. It also will have made it harder to allocate resources effectively, such as testing kits and antivirals, to areas where they were most needed. CVF believes this decision has likely increased the risk for CV individuals, as it reduced the overall effectiveness of early detection and intervention strategies. Monitoring was also ended in Wales in August 2023 as evidenced in a news article by the BBC in August 2023 **[Exhibit LW/34 – INQ000505920]**

94. Conversely, CVF understands from an article posted by the University of Edinburgh that in Scotland **[Exhibit LW/35 – INQ000505921]** and from an article posted by Queen's University Belfast in Northern Ireland **[Exhibit LW/36 – INQ000505922]** that wastewater testing continues to play a significant role in monitoring Covid-19 in those nations. In Scotland, the program has been expanded to provide ongoing data that not only tracks the spread of Covid-19 but also offers insights into the long-term health impacts of the virus. Similarly, in Northern Ireland, wastewater testing appears to remain a key component of public health surveillance, helping to guide local responses and identify potential hotspots before clinical cases surge.

f. Contact tracing strategies adopted as part of TTI including concerns regarding the exclusion of children from the 'track and trace' system, tracing in schools and the impact of the NHS app on CV people and consequences to CVF members of the so-called 'pingdemic'

(i) Teething Problems

95. Early in the pandemic, the UK Government decided on 12 March 2020 to halt the initial contact tracing efforts as the testing capacity was shifted exclusively to patients admitted to hospitals. This decision was made due to a lack of resources in the face of rapidly increasing cases, which left the country without a robust tracing system during a critical period. The delay in re-establishing a comprehensive contact tracing system meant that many early cases were not effectively tracked, leading to higher transmission rates, which particularly endangered CV individuals.

(ii) Private Sector Involvement

96. As set out by the Department of Health & Social Care in an independent report 'Chapter 7: contact tracing and isolation' updated 10 January 2023 **[Exhibit LW/37 – INQ000505923]**, the UK Government initially recruited 18,000 contact tracers through both public and private channels. However, the capacity of this workforce was often insufficient to manage the volume of cases, leading to delays in contact notifications. These delays were particularly problematic for CV individuals as it was critical to preventing severe illness. CVF was concerned about the involvement of private companies in the recruitment process with regard to the consistency and quality of the contact tracing efforts.

(iii) Contact Tracing in Schools

97. Initially, contact tracing in schools and colleges was not as thorough as in other sectors. This led to cases where children who were close contacts of confirmed cases were not systematically traced or advised to isolate, increasing the risk of further spread within schools. There was also significant variation in how contact tracing was implemented across schools. Some schools developed robust systems, while others struggled with the logistics of tracing contacts, particularly in larger secondary schools or colleges with hundreds or thousands of students. Inconsistency often resulted in delayed responses to positive cases, leaving more time for the virus to potentially spread.

98. CVF were concerned that headteachers and school staff had not been trained for contact tracing and were often overwhelmed by the responsibility of managing this in addition to all of their regular duties **[Exhibit LW/38 – INQ000505924]**, including during school holidays **[Exhibit LW/39 – INQ000505925]**, on top of the complexities of running schools with new measures and other challenges following lockdown. This lack of training, combined with frequent updates to government guidelines, left many school leaders feeling overwhelmed **[Exhibit LW/38 – INQ000505924]**. Guidance was often released just days before implementation, leaving little time for schools to adapt effectively **[Exhibit LW/40 – INQ000505926]**. The lack of clear guidance and support led to increased stress and workload and so many schools found it difficult to balance the need for thorough contact tracing with the demands of running day-to-day school operations.

99. CVF members found that within schools, contact tracing was inconsistent and often inadequate. Schools were responsible for identifying and notifying close contacts of positive cases, but the effectiveness of this process varied greatly. Many headteachers struggled with the logistical challenges of managing contact tracing, particularly during periods of high infection rates when large numbers of students and staff were affected. This led to delays in notifying contacts and sometimes incomplete tracing, leaving gaps in the effort to contain outbreaks within school settings.

100. Communication between schools and local health authorities was sometimes lacking, leading to delays in decision-making. This was particularly problematic when multiple cases were identified, as schools had to wait for guidance on whether to send entire classes or year groups home. The inconsistent approach to contact tracing in schools was particularly concerning for families with CV members. Families often turned to social media and WhatsApp to share information and updates. This informal network became an important source of real-time communication, allowing families to assess their risk of exposure and make informed decisions about testing their children, their risk of exposure to the virus and the risks of their children attending school.

101. The removal of "bubbles" and the shift to targeted testing rather than broad isolation measures added complexity to the tracing process in schools. While these changes were intended to reduce disruptions to education, they also meant that some cases might have been missed, increasing the risk of exposure for CV people in school, families, and the local community.

102. Older children in schools and colleges across the UK were often explicitly told not to use Track and Trace apps, not even CV/CEV children or CV/CEV staff. When children were sick with Covid-19, their absence was only known to the staff who inputted the registers, and the reason for an absence was often only known to children and teachers if other children told them. Parents and carers were generally not informed of Covid-19 infections unless they were contact traced. Although some schools did publish data on Covid-19 cases in year groups initially, this was ultimately withdrawn. This lack of data put children in CV households, their families and vulnerable school staff at considerably greater risk.

(iv) Exclusion of Children from the 'Track and Trace' System

103. Children, particularly those in school or college, came into contact with a wide range of peers and staff daily. Excluding them from the 'track and trace' system significantly increased the risk to CV individuals. For many CVF households a CV person was shielding at home while a school or college age child attended in-person education. Despite efforts by the vulnerable person to minimise exposure, the child could still bring Covid-19 home from school due to their exposure to a wide circle of contacts. The pressure on schools to maintain attendance, along with policies encouraging children to attend school whilst symptomatic, heightened the risk of infection not just for children and teachers, but also family members, some of whom were Clinically Vulnerable. This situation created a persistent and avoidable risk to already vulnerable populations.

104. Effective contact tracing relies on identifying and isolating all close contacts of a confirmed Covid-19 case. By excluding children from this system, a significant gap is created in the containment strategy. Despite government rhetoric that children cannot catch or spread Covid-19, children can spread the virus to their families and others in the community. This gap undermined the overall effectiveness of the contact tracing system and increased the likelihood of uncontained outbreaks, especially in environments where children congregate, such as schools or extra-curricular activities.

105. Because children were not included in the formal contact tracing process, it led to a false sense of security among parents and carers. Without official notifications, families may have been unaware that their child had been exposed to the virus, leading them to continue normal activities without taking precautions. The lack of awareness would have resulted in delayed isolation, testing, and treatment, further exacerbating the spread of the virus within the household, their school or college, and the community.

106. Excluding children from the 'track and trace' system also had implications for public health data. Incomplete data on who has been exposed or infected means that the true spread of the virus in the community was underreported. This will have led to misguided public health decisions, as the data did not accurately reflect the level of risk or the effectiveness of containment measures.

107. Attitudes and uptake of contact tracing apps and Covid-19 guidance significantly impacted vulnerable households more than others. CV households were more reliant on

clear, reliable information and technologies like contact tracing apps to make informed decisions about risks to their health and safety.

108. There is some evidence suggesting that children with Covid-19 are infectious for a shorter period compared to adults. Studies have found that the median time children remain contagious is about three days **[Exhibit LW/41 – INQ000505927]**, with 18.4% still infectious on day five. However, the UKHSA guidance is that following a positive test result, children can return to school after three days if they no longer have a fever and feel well enough, while adults are advised to isolate for five days. Yet, the exact duration of infectiousness in children is not as robust as it is for adults. CVF believes that further research is needed to ensure that isolation guidelines are both safe and effective, particularly as new variants emerge and the virus continues to evolve.

109. Although Covid-19 remains a legally notifiable disease by medical practitioners **[Exhibit LW/42 – INQ000505928]**, schools in the UK stopped notifying parents about individual Covid-19 cases as part of broader changes in public health guidance. As of February 2022, routine asymptomatic testing in schools was no longer recommended, and the responsibility for tracking and managing Covid-19 cases shifted away from educational settings. This change was part of the UK's "Living with Covid" strategy **[Exhibit LW/43 – INQ000505929]**, which emphasised that Covid-19 presents a low risk of serious illness to most children and young people due to high immunity levels and vaccination rates. However, schools are still advised to notify parents about outbreaks of other infectious conditions, such as chickenpox, slapped cheek syndrome (fifth disease), mumps, rubella, whooping cough, and head lice (nits). While many of these conditions generally pose a low risk to most people, some of them can present higher risks to vulnerable groups, such as pregnant women or those who are immunocompromised or immunosuppressed. Unlike Covid-19, these conditions are seen as a priority for communication in educational settings to help manage their spread and ensure appropriate public health responses **[Exhibit LW/44 – INQ000505930]**.

110. As a result, schools no longer inform parents about Covid-19 cases, and testing within schools is only recommended in residential special educational needs and disabilities ("SEND") settings in the case of outbreaks under the guidance of local health protection teams to counteract the risk of closure due to staff absence.

(v) Track and Trace Apps

111. The use of the app designed to identify potential contacts could have been an invaluable tool for high-risk individuals and their families. It would have enabled them to test more frequently allowing early detection and treatment or providing reassurance that they were not exposed. However, this system's effectiveness hinged on widespread use, meaning it only worked optimally if everyone used is consistently. Scepticism in the media and social media and barriers to the adoption of these tools disproportionately affected the ability of vulnerable people and households to manage risks effectively.

Quote 8 from CVF Member

"Most of our neighbours turned off test and trace as they saw it as punishment and if they were pinged it would stop them from being able to go out."

Jane, aged 47

(vi) 'Pingdemic'

112. The term "pingdemic," which was coined by the media and adopted by politicians, referred to the surge in notifications—or "pings"—sent to individuals by the NHS Covid-19 app, advising them to self-isolate after being in close contact with someone who tested positive for Covid-19. While the term gained widespread usage, it had significant implications for CV people, both in terms of public perception and the actual impact on their safety.

113. The media framed the situation as a crisis of excessive and burdensome notifications, rather than focusing on the underlying cause: a dramatic and uncontrolled increase in Covid-19 cases following Boris Johnson's cancelled 'Freedom Day'. This framing shifted the public's attention away from recognising that this meant there were high rates of Covid-19 all around them. It was regarded as a nuisance and inconvenience, with self-isolation disrupting work (particularly for essential workers) and therefore the economy. For CV people, this was particularly troubling because it minimised the real dangers posed by the virus, especially to those who were at heightened risk of severe illness or death.

114. The loss of confidence in Covid-19 apps, leading to their eventual retirement, left CV individuals without a critical tool to notify them of any potential contacts. This further restricted their lives, increasing their risk of contracting Covid-19, delaying testing, and therefore reducing the speed that they could access treatments. CVF considers that the app was yet another example of something being developed with a one-size-fits-all approach, failing to account for the unique needs of CEV and CV individuals and their families. By treating the population as homogenous, the app overlooked the heightened risks faced by these groups, who would have benefited from more targeted features that catered to their specific health concerns and the need for more frequent monitoring and timely interventions.

115. Politicians' adoption of the term "pingdemic" appeared to serve as a means to undermine contact tracing at a time when there was growing pressure to end pandemic restrictions. By focusing on the disruptions caused by the NHS app rather than addressing the reasons for the surge in cases - such as premature easing of protections and inadequate public health measures - the government successfully diverted attention from its own failings in managing the pandemic. This rhetoric further marginalised the concerns of CV people, who relied heavily on effective contact tracing to avoid exposure to Covid-19.

116. For CV people, the narrative that emerged around the term not only trivialised their legitimate health risks but also made it more difficult for them to advocate for continued precautions in their workplaces, schools, and communities. As the government and media pushed for a return to normalcy, the needs of those most at risk were increasingly unaddressed and sidelined, leaving CV people to navigate in a new world where the tools meant to protect them were taken away.

g. Factors that may have affected compliance with test, trace and isolate regulations. This may include impact and risks related to isolation, the adequacy of financial support including targeted support, practical support and other forms of remote support (such as telephone support) and any other factors affecting compliance or attrition

117. A lack of planning in advance for enforced isolation and the support systems needed meant local areas were scrabbling round to set up support hubs and CV and CEV people and their families were left without access to supplies including essentials like food and medicines. Financial support to allow infected workers to stay at home and isolate was

inadequate and this increased the risk to these high-risk groups. A lack of understanding at government level about the circumstances in which many vulnerable people lived meant that planning for support was frequently inadequate.

h. Enforcement strategies relating to TTI

118. From 28 September 2020, anyone in England who tested positive for Covid-19 or was contacted by NHS Test and Trace and told to self-isolate was legally required to do so. Failure to comply with the isolation requirements could result in Fixed Penalty Notices (FPNs) or prosecution. The FPNs started at £1,000 for a first breach and could increase to up to £10,000 for repeat breaches or more serious breaches.

119. These were complex and poorly understood at all levels resulting in punitive action being taken inappropriately. The enforcement of these regulations lacked clarity, resulting in inconsistent application and confusion among both the public and officials responsible for upholding the rules.

i. Public messaging, in particular the adequacy of guidance and any links between trust in messaging, compliance and the risks posed to CV people

120. From CVF's perspective, the Test, Trace, and Isolate system's public messaging failed to adequately address the needs of CV people. The generalised nature of the guidance did not reflect the higher risks faced by our members, many of whom required more specific and frequent information on testing, isolation, and managing exposure. This failure in communication left many CVF members uncertain about the system's effectiveness and relevance to their circumstances.

121. Moreover, trust in public messaging plays a critical role in ensuring compliance, yet the lack of clear, consistent, and targeted guidance for CV individuals significantly undermined this trust. For many CVF members, the exclusion from early messaging, due in part to incomplete NHS datasets, led to confusion and frustration, as key advice and updates were not reaching those most vulnerable. As a result, many were left feeling abandoned by a system that should have prioritised their safety.

122. The emphasis on digital platforms for communication posed additional challenges. Some members of the CV community, particularly those facing digital exclusion, struggled to access vital information. The reliance on online resources and apps meant

that many CV individuals, without regular access to the internet or digital literacy, were left uninformed about critical updates.

123. Inadequate messaging also had a tangible impact on compliance with testing and isolation protocols. When communication is unclear, people are less likely to fully engage with systems like TTI. This disengagement not only put CVF members at greater risk but also limited the effectiveness of the system as a whole in controlling the spread of Covid-19.

124. CVF believes that the failure to tailor messaging to the needs of the CV community not only increased health risks but also eroded trust in the very systems designed to protect them. Clearer, more accessible, and consistent communication is essential if public health measures are to gain the compliance and trust in the event of a health emergency.

j. Factors affecting compliance with guidance and/or requirements regarding testing, tracing and isolation

125. Several factors influenced compliance with the TTI regulations in the UK, particularly during the Covid-19 pandemic. Understanding these factors is crucial for assessing the effectiveness of the TTI system and identifying areas for improvement in future public health responses:

    a. **Mental Health:** Prolonged isolation had significant mental health impacts, leading to anxiety, depression, and loneliness. These psychological challenges made some individuals less likely to comply with isolation requirements, particularly if they felt unsupported or if isolation exacerbated pre-existing mental health conditions, as reported in an article by Hwang TJ, Rabheru K, Peisah C, Reichman W, Ikeda M. Loneliness and social isolation during the Covid-19 pandemic. Int Psychogeriatr. 2020 Oct;32(10):1217-1220. doi: 10.1017/S1041610220000988. Epub 2020 May 26. PMID: 32450943; PMCID: PMC7306546 **[Exhibit LW/45 – INQ000505931]**.

    b. **Social Consequences:** The social isolation experienced during self-isolation periods, particularly for those living alone or without a strong support network, led to resistance against complying with TTI regulations. This was especially true among vulnerable populations who relied on social interactions for daily support.

c. **Inadequacy of Financial Support:** Many individuals faced significant financial challenges when asked to self-isolate, particularly those without access to sick pay or those in precarious employment. Although the UK Government introduced financial support packages, such as the Test and Trace Support Payment, these were often perceived as insufficient. It was difficult to access and the limited availability of these funds, combined with delays in processing payments, discouraged compliance, as many people simply could not afford to miss work.

d. **Targeted Support:** While there were efforts to target financial support to low-income households, the reach and effectiveness of these programs were inconsistent. Gaps in support led to some individuals choosing not to isolate due to financial necessity.

e. **Access to Essential Supplies:** The ability to access food, medicine, and other essential supplies during isolation was a critical factor in compliance. While local authorities and volunteer networks provided some support, not everyone could access these services effectively, leading to non-compliance. This was particularly problematic in rural areas and among individuals without access to online services.

f. **Support for Dependents:** Individuals with caregiving responsibilities for children, elderly relatives, or disabled individuals often struggled to comply with isolation rules, as practical support for these dependents was not always available. The lack of adequate alternative care arrangements forced some people to continue their daily activities despite being advised to isolate.

g. **Public Perception and Trust:** Public trust in government messaging and the perceived fairness of the TTI system significantly influenced compliance. Mixed messages, frequent changes in guidelines, and high-profile breaches of rules by public figures led to cynicism and a lack of trust, which in turn reduced compliance.

h. **Stigma and Social Pressure:** The stigma associated with testing positive for Covid-19 and the potential social consequences of being identified as a "spreader" also deterred some people from engaging fully with the TTI system. Fear of social isolation or judgment from peers and community members contributed to underreporting and non-compliance.

126. In CVF's view, high-profile cases, such as Dominic Cummings' breach of lockdown rules, significantly undermined public compliance with isolation and other preventive

measures. For Clinically Vulnerable people, this not only increased their risk of exposure but also eroded trust in the government's commitment to protecting the most vulnerable. The perception that those in power were not adhering to the rules made it more difficult for public health messages to be taken seriously, further compromising the effectiveness of Covid-19 policies.

D. Unequal impact of the pandemic on different categories of people across the UK

127. The government approach was focused on the population uniformly and did not consider the distinct impact of policy decisions on Clinically Vulnerable people. This failure placed CV people and their families at increased risk across multiple areas, including shielding (which resulted in prolonged isolation for the non-infected), test, trace and isolation systems, access to antiviral treatments and non-pharmaceutical measures such as repeat testing.

128. Importantly the groups were not mutually exclusive with many individuals falling into multiple risk categories, further increasing their vulnerability. Despite this, the increased risks for those overlapping groups were not adequately assessed. Policies appear to have been developed in silos rather than as part of a unified strategy, making it more difficult for Clinically Vulnerable individuals to navigate the system and for professionals to implement them effectively. A more integrated, targeted approach would have provided better support and protection for these high-risk groups.

129. Initial TTI systems did not adequately consider the challenges higher-risk individuals faced in accessing testing or isolating safely without sufficient support. The rigid testing criteria and delays in result processing, particularly in the early stages, increased the risk for those in CV and CEV households. These groups needed timely and accurate testing to avoid exposure and access treatments, but the system's inefficiencies left them at greater risk.

130. The impact of policies on children and young people was a significant problem for CVF members. By not fully including children in the TTI system, and the use of symptoms for testing eligibility that did not always match those presented by younger populations, put families at risk. CVF believes that this exclusion and mismatch likely contributed to

under-detection of cases among children, which in turn affected household transmission rates and school safety which particularly impacted people in CV households.

131. Financial support schemes were inadequate, inaccessible, and insufficient to cover the full costs of isolation and many faced delays in receiving payments. Workers often felt compelled to continue working despite requirements to isolate, undermining the effectiveness of isolation measures, and increasing risks in poorer communities.

132. Early discharge of Covid-positive patients from hospitals to care homes or the community without adequate testing contributed to outbreaks. These decisions highlighted a critical failure in considering the full impact of policy decisions on the elderly, who are all Clinically Vulnerable, and the risks to households and communities.

133. There was some recognition of the disproportionate impact of Covid-19 on minority ethnic communities, which led to targeted public health campaigns and enhanced data collection efforts. However, the specific risks faced by multigenerational households, particularly those posed by exposure through schools and workplaces, were not publicised.

134. More broadly, the challenges of isolation within households, where members of different generations or different clinical risks lived in close quarters were significant, yet guidance never highlighted or addressed these particular risks and challenges. The lack of advice left many CV households struggling to navigate the complexities of effective isolation, increasing the likelihood of household transmission.

135. Only CEV people were actively given guidance about managing their risks in terms of isolation to manage their risks. However, the guidance proved to be impractical, especially when it was expected to be sustained for long periods, far longer than the general population's lockdowns.

136. CEV people were advised to stay in a separate room from others in the household who were infected or suspected to be infected with Covid-19. If available, they were encouraged to use a separate bathroom from other household members. If a separate bathroom was not available, they were advised to clean shared bathrooms thoroughly after each use. The guidance also recommended minimising face-to-face contact with others in the household. Family members were instructed to maintain physical distance and wear face coverings when in shared spaces. It stressed the importance of frequent

handwashing, regular cleaning of frequently touched surfaces, and good ventilation in shared spaces to reduce the risk of transmission.

137. In smaller homes, it was challenging to fully isolate from other household members, for extended periods, much longer than the national lockdowns. It also had significant impacts on mental health and well-being as reported by CVF members. Many CEV people were also caregivers for others in the household, making it impossible to fully isolate without impacting on their dependents.

E. CVF and the development and implementation of TTI systems

138. Individual CVF members reported several issues with the TTI systems and policies, which often required them to travel long distances to testing sites that lacked suitable accessibility. These arrangements failed to consider their caring responsibilities, the need for accessible facilities, or the financial burden associated with such travel. Many CVF members raised concerns about queuing for PCR tests and being required to remove their masks in near to others, increasing their risk of exposure and regarding the risks associated with attending pharmacies for LFTs.

139. CVF has played a vital role in supporting its members throughout the Covid-19 pandemic, especially in relation to navigating the complexities of the TTI systems implemented across the UK. While CVF was not directly involved in the development or implementation of these systems, we have provided essential advice and resources to help our members manage their health and reduce their risk of exposure to the virus particularly where government support and guidance was lacking.

140. CVF has provided support to its members in the following key areas:

    a. **Isolation and Managing Household Risks:** CVF offered detailed guidance to members on how to effectively isolate within homes during infections. This included practical advice on managing and maintaining physical separation within the home.

    b. **Access to Testing:** CVF helped its members navigate the often-confusing landscape of Covid-19 testing, providing updates on where and how to access PCR tests and LFTs. This was particularly important during periods of high

demand when testing resources were limited. Members understood the importance of testing to reduce risks.

c. **Assisting Members in Accessing Antiviral Treatments**: CVF provided critical support in helping members access antiviral treatments. This included encouraging people to test early and guiding them through the process of reporting positive test results to the NHS and advocating for their eligibility for antiviral medications.

d. **Advocacy on Policies:** CVF contacted MPs and also encouraged members to contact their own MPs to express concerns about changes in policy, such as the replacement of priority PCR tests once used.

e. **Supporting Families During Peaks in Transmission**: During periods of high transmission, CVF played a key role in supporting families by providing resources and advice on how to stay safe. This included information on the latest public health guidance, tips for minimising risk, and mental health support for those dealing with stress associated with their household's risks.

141. Through these efforts, CVF ensured that its members were not only informed but able to take the necessary steps to protect themselves and their families. While CVF did not have a direct hand in shaping TTI policies, we advised and supported members navigate the challenges posed by systems that had not fully considered our needs in Equality Impact Assessments (EIAs), as CV people are not formally recognised as an equalities group.

F. Lessons that can be learned to inform future policy-making and decision making and how consideration can be given to ensuring the views of CVF are considered in that policy development

142. **Recognition of Clinically Vulnerable people as an equality group.** Clinically Vulnerable people must be formally recognised as an equality group in all policy planning, which is especially important during pandemics. Ensuring their needs are systematically addressed through Equality Impact Assessments is essential to prevent discrimination and ensure specific, effective support. Policies should be developed in close consultation with CV communities and regularly reviewed to remain responsive to

change. By prioritising CV people, public health measures will be more inclusive, ensuring that vulnerable populations are not overlooked especially during critical times.

143. **Improve identification of Clinically Vulnerable groups.** Accurate and comprehensive data is essential for identifying all Clinically Vulnerable people. This is vital to ensure they receive critical resources such as priority PCR tests or lateral flows and access to antiviral treatments.

144. **Simplify access to antiviral treatments.** The process for accessing antiviral treatments should be simplified, to remove barriers and ensure timely care for those at highest risk.

145. **Improve the access to LFTs for Clinically Vulnerable people**. This is especially important for those who need to access LFTs for antiviral treatments in the community. Establish an online system for CV people to order LFTs direct to their homes. Provide all eligible CV people with a card, or a QR code on their NHS app, so that they can show proof of eligibility to the pharmacy.

146. **Improve communication to Clinically Vulnerable people in terms of testing and treatments**. Consider providing a dedicated helpline and website during acute epidemic or pandemic scenarios to ensure CV people can receive correct and timely advice. Ensure communication is across multiple channels including, phone, TV, radio, and print, alongside digital platforms to ensure accessibility. Special attention must be given to avoid digital exclusion, ensuring that those without internet access or technical skills are not left without essential, clear information. Alternative media and non-digital methods should always be employed to ensure everyone can access critical updates.

147. **Ensure consistency in public health messaging.** Public health messaging must be consistent and clear to maintain public trust and ensure compliance with TTI systems.

148. **Regularly update testing criteria.** Symptoms should be monitored and testing criteria regularly updated to reflect the evolution of new variants. This must also include any different symptoms identified in children, to ensure timely diagnosis, isolation, and treatment.

149. **Optimise testing timelines and accuracy.** Minimising delays and errors in PCR test processing is important to ensure rapid access to antiviral treatments and timely isolation

of those infected. While LFTs provide immediate results, they lack the sensitivity to detect low viral loads, potentially delaying detection in some cases. In contrast, PCR tests, when processed quickly and effectively, allow for early detection of variants, which can inform healthcare decisions regarding appropriate treatments. Both testing methods offer advantages and disadvantages depending on the population. There is a need for a balanced approach given the different strengths of each.

150. **Address geographical and accessibility barriers.** Testing sites should be easily available to the whole UK population and equipped with appropriate protective measures to ensure that CV individuals can safely access testing.

151. **Improve contact tracing in education.** Effective and consistent contact tracing in schools and colleges is essential to prevent untracked transmission and protect households with Clinically Vulnerable members, especially when in-person attendance is required. Responsibility for tracking and managing transmission chains should be centrally coordinated to reduce the burden on school leaders, ensuring that the heightened risks in these environments are managed effectively. CVF are concerned that, despite Covid-19 remaining a notifiable disease, there is significantly more awareness of head lice outbreaks in schools than of Covid-19 infections. This highlights a critical gap in communication to families, which undermines efforts to keep them informed about potential health risks in educational settings.

152. **Improve testing in education.** Testing in schools should be more inclusive and effective, with options like saliva testing to ensure higher detection rates and compliance, reducing risks of transmission to CV households.

153. **Strengthen isolation requirements for children.** Median infectivity should not be used to determine isolation length for infections given the variability in how different children clear the virus. The risk of transmission with around 1 in 5 remaining contagious after three days, is concerning particularly in school environments where close contact is common. By extending the isolation period to five days, CVF believe we could better protect vulnerable populations and prevent outbreaks, aligning with public health goals to improve school overall school attendance and reduce Covid-19 transmission.

154. **Maintain public trust in contact tracing apps.** Public trust in contact tracing apps must be preserved by addressing issues like the 'pingdemic' constructively, as these tools are vital for to reduce transmission and for CV people to manage their risks.

155. **Provide adequate support for isolation.** Sufficient practical and financial support is necessary for those required to isolate, particularly for those living alone, to ensure they can do so safely without risking health or well-being.

156. **Develop practical guidance for isolation.** Isolation guidance should be practical and consider the realities of household sizes and caregiving responsibilities to minimise transmission risks and reduce risks and mental health challenges, especially for those who are CEV or expected to isolate for prolonged periods.

157. **Enforce isolation regulations consistently.** Isolation regulations should be enforced consistently and communicated clearly to prevent confusion and ensure compliance.

158. **Restore wastewater testing for early detection.** Wastewater testing should be reinstated as it is a vital tool for the early detection of outbreaks, providing essential data to guide public health responses and protect vulnerable populations.

159. **Private sector contact tracing.** The involvement of private companies in contact tracing proved problematic. There is a need for better solutions that prioritise quality, efficiency, and consistency. CVF recommend exploring successful models, such as those used by other countries or public health organisations, and applying best practices to ensure more effective and reliable contact tracing in the future.

160. **Optimise TTI Systems.** Effective data sharing and communication between central and local governments are critical to managing TTI resources efficiently and responding to the specific needs of populations during times of pressure.

161. **Development of technology such as biosensors.** Investing in the research and development of biosensors would improve pandemic response capabilities. Biosensors have the potential to deliver rapid and accurate detection of viruses, such as Covid-19, which would significantly enhance testing efficiency and accessibility. CVF believes that targeted funding in this area could lead to faster, more widespread testing, reducing transmission rates and providing better protection for high-risk groups. This investment would strengthen the overall public health response for future health crises.

Statement of Truth

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

Signed: Personal Data
ara Wong (Apr 24, 2025 17:58 GMT+1)

Lara Wong, Chief Executive Officer of Clinically Vulnerable Families

Dated: 24/04/2025