bgWitness Name:
Statement No.:
Exhibits:
Dated:

UK COVID-19 INQUIRY

WITNESS STATEMENT OF Mark David Oakley

I, Mark David Oakley, will say as follows: -

1. I am the Co-Leader of the UK wide patient campaign group Forgotten Lives UK, along with Nikola Brigden and Professor Martin Eve. Prior to this the group was called Evusheld For The UK, which was set up in June 2022 (02/06/2022), however the name of the patient group has been changed to give a better reflection of the present situation those affected by the issues are in and to also support the wider call for protective drugs for the immunocompromised and immunosuppressed (herein referred to as I/C)

2. The patient group was set up with the intention to campaign for the swift introduction of monoclonal antibodies to protect the immunocompromised and immunosuppressed population across all 4 nations of the United Kingdom. The people within this classification cover a wide spectrum of medical conditions such as solid organ transplants, blood cancers, cancers, kidney failure and chronic illnesses such as Lupus, Sarcoidosis, Multiple Sclerosis and many more.

3. In many cases, the effects to their immune system due to the illness or the medication taken to control or treat their illness means their immune system is unable to generate an antibody response to the Covid 19 virus through the use of present vaccines, or the response is too low for it to be effective. As a result of this they are largely unprotected, and due to the issues with their immune system they

are recognized as being at a much higher risk of severe outcomes if they contract Covid 19.

4. The campaign group has approximately 2050 members on Facebook and over 4000 followers on Twitter covering a wide range of illnesses and conditions of those affected. The campaign group is a non-funded patient-led and run group, and since its inception it has worked with representatives across the political spectrum, national charities, clinicians, and the media.

5. The group is the appointed patient group for the All-Party Parliamentary Group for Vulnerable Groups to Pandemics, and a recognized stakeholder in both the NICE assessment processes and with the DHSC and the now defunct Enhanced Protection Panel Stakeholder Forum. Since the group's inception, it has also taken on a role of advice, care and support for the members as issues faced by members during the pandemic have arisen, it has also been a focal point for communication for the associated political, medical, health and mental health issues.

6. The evidence submitted in this statement is based upon my own personal experience of issues as an immunosuppressed person living through the pandemic and shielding, evidence from members of the group through personal accounts, and through large evidence gathering questionnaire, to a representative sample of 229 members. The percentages displayed and quotes referred to in this statement have come directly from the questionnaire. The questionnaire was placed on our private group for members to answer and submit questions listed and was only open to those within the group and could not be circulated to a wider audience. The questionnaire was open to any members who were I/C and had been shielding, or for family members or carers to answer on their behalf. The content and questions of the questionnaire were based on areas of concern raised by members over the period of our group's existence. The aim of the questionnaire was to gather both data in terms of numbers and lived experiences of those affected by the issues arising from shielding. The questionnaire and accompanying answers are submitted as (**MO/1 – INQ000216917)**

Commencement of shielding

7.At the start of the pandemic, it became quickly clear to myself that there was a very high risk to myself due to my condition of Pulmonary Sarcoidosis and immunosuppression. The images of the horrifying scenes from the ICU wards in hospitals in Italy were a very sobering warning of what was inevitably to come. I personally took the decision to begin shielding before the official start date set by the government and began shielding 14th March 2020. This was echoed by members of our group who have shown that 71% (Q10) began shielding prior to the start date of the 23rd of March 2020 set by the government. It was extremely concerning to see the way the virus was being treated before it was confirmed it had hit the shores of the UK, with the Prime Minister still insisting he would shake hands and large meetings of people such as the Liverpool v Real Madrid Football match and the Cheltenham Festival being allowed to continue.

8.The initial messaging before lockdown appeared effective as 80% (Q8) received information from the government informing them of the need to shield, albeit it most was released via the press prior to the official announcement on 23rd March 2020, however it still shows that just under 20% (Q8) had to make a decision for themselves and had to make efforts to ensure they were placed on the shielding list. Both personally and as a group the conclusion is that the shielding should have started earlier. There was also little information as to why those in these cohorts were so vulnerable. I can recall assuming that my vulnerability was due to the nature of my illness and didn't realise at the time that the level of immunosuppressants I was taking would be the larger cause of vulnerability and received no real information regarding this.

9.For some I/C it was a battle to ensure they were properly recorded as such for the official systems to ensure they could benefit from perceived forthcoming benefits and for many it became an issue during the Pandemic to get added to the lists as they were diagnosed with new conditions that put them should have put them into this category. Some 20% (Q9) raised this as an issue.

Direct quotes from Evidence group: -

"I became immunosuppressed in the middle of covid so at first was not included and had to find information myself".

"GP didn't recognise CLL even whilst being treated as immunocompromised. So coding was not applied."

"Everyone with CLL was accidentally excluded from one of the rounds of letters".

"There was an issue with coding for CLL patients. I wrote to many people and eventually received a letter of thanks for highlighting the issue".

"I have a Primary Immune Deficiency. There was very little focus on that. The focus was on the immunosuppressed. I do not and never will have an intact Immune system. We were left out in the cold."

"At first, people were tolerant of my forced shielding, but, over time, increasingly, I felt that I had to justify myself. People I knew adopted a 'get over it' attitude and began to think I was overreacting and should 'return to normal."

"NHS digital's algorithm missed my particular condition from the list, and this took 6 weeks to be corrected."

"My GP even when sent information that I was immune suppressed (I had received from my specialist consultant) would not add me to the list in the end my specialist consultant got hold of them and they eventually added me to the list"

"Had to contact GP to get health record updated to show my hospital prescribed and administered immunosuppressing drug Rituximab clearly shown (was mentioned in correspondence from consultant to GP) but not showing on my Patient Access

medication list. This was to ensure correct code for me put on Covid dashboard and so I could access booster vaccines and antiviral treatments."

"Struggled to get the Gps to realise we were at high risk of being severely Immunosuppressed ! they argued just old people "

Continuation of shielding after first shielding period

10.The first shielding period ended in early August 2020, as the first wave began to subside. The overwhelming majority who answered the evidence questionnaire complied with this shielding instruction, well in excess of 90%. (Q11) Despite the shielding program running officially until 17th September 2021 when the Government closed the program, those in the shielding cohort were not officially advised to shield again, even when the next more virulent waves began. There was lots of mixed advice mainly on local levels or from clinicians or GPs to individuals, however the decision to shield became an individual one, with no further support after the first period ended in August 2020. There was at least some advice from these sources, as advice from Government and NHS was woefully lacking, with no clear direction as to what to do.

11.Evidence from our sample group shows that over 54% (Q12) still continued to shield, with many of those having no choice but to still shield to this day, with a further 35% (Q12) shielding as and when they have felt it necessary to protect themselves as rates have increased. Those that are still shielding are now into their 4th year of shielding or living very restricted lives in order to protect themselves.

12.From a personal perspective I shielded myself until I paid for the prophylactic drug Evusheld on 1st November 2022. This was a total of 963 days. This included periods of having to live separately from my family in a summer house in the garden for an accumulative total of 7 months, when the risk was too high due to members of my family contracting covid, my children being identified as possible infection contacts, awaiting 3rd primary vaccine, or when other members of my family undertook activities that were deemed to put them at high risk of exposure. This meant living at distance from my wife and youngest child, unable to have any personal contact with them.

Physical effect on families and homes of shielding

13. As with so many others in this situation in our group, I was unable to physically cuddle my eldest 31-year-old daughter who lived separate from us locally, to ensure she did everything possible to protect me. Other examples of this are children who had to go into student accommodation at university, when they would have normally commuted. This was done to avoid putting family at risk rather than coming home, or children moving out to live with other relatives so they could continue their education. This is not an unfamiliar experience with 33% (Q35) of the evidence group living apart from family members during their shielding periods, in some cases some actually had to pay for separate accommodation, or even going to the extent of dividing the existing accommodation so that no communal areas were used.

14. Further examples of people's situation direct from the evidence group, underline how difficult it was for many families to adapt both in physical terms to effectively split their homes into two to ensure a level of safety so they could protect a loved one and allow some level or normality, and on an emotional level with the shielding process often splitting families completely - Some examples of direct quotes from our questionnaire below.

“My partner lived in the garage for most of 2020”.

“My son ended up living with his grandparent, so he didn't have to shield anymore”.

“My son was staying in a caravan on the front lawn”.

"I stayed in a separate house on my own while my wife looked after kids on her own, working full time and homeschooling. My children still struggle if I am not home for bedtime as they panic that I have left again".

"Separate bathrooms, separate bedrooms, not sharing a car journey, no sharing mealtimes or watching tv together in the living room".

"I lived in the house with the family but totally separate - we are a family of four and until this month lived wearing masks in the house, not having any social interactions indoors (still the case) , no eating together, no sleeping, no socialising - since 2020 "

Shielding advice and Government advice

15. The amount of time and periods that I/C have spent shielding and the decisions to shield is plainly in stark contrast to the range of restrictions that applied to the normal population, that still in many cases allowed them to carry on parts of their life, such as work and socialising, even if only in restricted numbers and the length of times it was implemented by the government. After the end of the first period of shielding in August 2020, no one was officially told to shield again, even though the program was still in place. This was despite the fact that the UK saw another lockdown in November 2020, and the further extended lockdown in Jan 2021 with the much higher incidences of Covid 19 and deaths during these periods. I/C patients were left to make their own decisions with no official Government advice and no communication.

16. From my own experience before the national lockdown began on 6th January 2021, I spoke to my GP who advised me that the covid rates and the risk to me was so great that I should live separately from my family if my children went back to school. We took the decision to not send the children back to school on 5th January 2021, and the following day the 3rd National lockdown began. Had we sent our children back to school, it would have left me with the stark choice of living separately or risk catching the virus from my children. The advice and decisions from the government at this time seemed ill thought out, chaotic with no thought to the risk it placed people in.

17. Once again, the I/C seem to bear the brunt of ill-thought-out decisions, made at the last minute, with no thought of the consequences. This typifies the situation that many of our members and other I/C found themselves in then and now. Only 44% (Q15) of our evidence group felt that the shielding program followed the science, with the rest feeling that it was used to manipulate the political messages and had any further official periods of shielding been announced it would have sent the wrong political message. It seemed that the economy took a much higher precedence than the protection of the most vulnerable. This was typified by the "Eat out to help out" scheme introduced in summer 2020 on August 3rd, whilst the most vulnerable were still shielding with the program only paused 2 days before. Time and time again we watched in disbelief whilst cases and deaths rose, whilst decisions were delayed or action was ignored, often leading to ineffective advice and restrictions. It seemed to be the norm that they were put in place too little and too late, putting the vulnerable at further heightened risk, both of contracting the virus, and of not being able to access effective healthcare due to the high demand in hospitals. In that way many of the evidence group felt their situation and safety was used in an effort to reassure the public rather than to protect them.

Direct quotes from Evidence group: -

"It appeared that decisions were guided by economics more than by public health considerations".

"Shielding should never have ended for the most severely immunocompromised until they were given covid protection - why shield us and then say we no longer needed to when the infection rate in the community was higher than it was in 2020 and we still did not have protection? The government knew the vaccine didn't work for us but ended our shielding programme anyway whilst also removing community mitigations."

There was strong scientific advice that severely immunocompromised needed something more than the vaccine and in vitro and real-world scientific data showed Evusheld was 92% effective in preventing severe illness and hospitalisation for this cohort - despite this scientific evidence and scientific advice to provide it the UK government refused at odds with 33 other major nations including the entire G7"

"Shielding (and all related challenges) has been paid lip service by government (and society) throughout. It was officially ended (surreptitiously) far too soon - very clearly, given there are still thousands shielding (as of May 23), and alongside this, the little support given, and the acknowledgment that it was still necessary for many, was withdrawn. This has left a significant number of CEV/IC abandoned and struggling on multiple levels, and informed public perception of risk to our cohort."

"Shielding was introduced to 'protect the NHS' not individual patients. Lifting it put previously shielding patients in a very difficult position as risk from covid still very high, but expectation was to return to work/ 'normal life' etc with few mitigations"

"I think the government response was slow to act and was done for political/economic expediency. They were very slow to protect the vulnerable but very quick to open up."

Practical effects of shielding and access to food and medication

18. The period of official shielding led to many practical problems on a daily basis for those having to endure it. For many I/C this meant their family also had to endure the shielding in order to protect them. Our evidence group showed that 180 out of 229 79% (Q30) I/C had someone in the household shielding with them. This also included school age children, with 12% (Q31) having school age children as part of the family shielding with them. This had severe implications on many levels for those in this position.

19. From the outset when the shielding was announced there was little practical advice on how those who were ordered to stay behind their front doors and not go out were to manage practically. At one point I received one of the few text messages from the shielding program, telling me I should not go outside to put the bins out and stay inside to protect myself. For those that were shielding they had to consider how to access food, medication, and other day to day needs.

20. I was initially contacted by my local council and offered food parcels as were 45% (Q6) of our evidence group. The setup of this service in my area took approximately 2 weeks. Although the delivery of them was welcome, there appeared to be very little planning as to the content and the needs of those receiving them. An average box contained a loaf of bread, 2 large onions, 2 packets of biscuits, a few tinned goods such as soup, tomatoes, baked beans, some fruit, and vegetables such as apples, potatoes, and toilet rolls. We received no contact as to what was required and to the size of our family. Whilst the effort was appreciated, and it was set up quickly at a time where the supply chain was struggling, it did not represent anything other than some basic items to top up a food cupboard, and I am unclear as to how anyone was supposed to survive on just this delivery at a time when so many couldn't leave their houses, let alone put themselves at risks in large shop queues.

21. Due to the perceived risk from the messaging, we received, no member of my family felt safe to go to the shops and this was replicated for many I/C who were shielding and were reliant on deliveries. The supply of the food boxes seemed ill thought out in what they contained with regards as to what would actually be needed, around 27% (Q6) were reliant on members of the community dropping food and shopping to them. We initially made use of supermarket deliveries, as some decided to deliver only to the most vulnerable, however this was an informal arrangement, and it was often a struggle to book slots. These would often be released late at night, which would involve having to make many attempts during the night to secure a delivery slot. This situation was improved after the larger supermarkets put in place the delivery scheme for the vulnerable based on the government shielding lists and allowing one delivery slot to be booked on a recurring basis once a week. This noticeably improved things and was well

organised by the supermarkets and to their credit they kept this scheme going long after the government ended the first shielding period.

22. There were however instances of patients who had to go through too many hurdles to be placed on the lists to get access to this service as they had been missed off due to administrative errors. It should be noted for many of the most vulnerable the position of having to rely on deliveries meant increased costs in deliveries and goods they purchased. When other non-food items were purchased, they were largely from online retailers as they had no option to do normal shopping, for items such as clothing and household goods, which again meant increased costs in paying for delivery fees. In other cases, they were left with no alternative but to order more than they would normally spend on a weekly food budget, to ensure they met the minimum spends for a food delivery and pay for the delivery slot, until the supermarkets put in place free delivery passes for the vulnerable. A situation that still remains for many adding to the costs of their household budgets.

23. A further issue faced due shielding was access to prescription medication. Only 113 (Q6) of the evidence group were able to get their prescriptions delivered by their pharmacy during this period. It has to be borne in mind that many I/C patients need very regular deliveries of medication, and if these were not delivered, this placed them in the position of having to collect it themselves, at a time when they were told to stay indoors. From a personal viewpoint I was declined deliveries from my pharmacy as they had insufficient staff, and no further capacity to take on more deliveries and it was only when I spoke to the manager who was an acquaintance, that this service was put in place for me.

24. The overriding evidence from our group points to the fact that there was precious little put in place to ensure they had adequate deliveries of food or medication. In too many cases, people were reliant on friends and family, and it is noted that a significant amount felt the first 6 weeks of lockdown were particularly difficult in obtaining supplies which added to the stress of their situation. My elderly father-in-law was also classed as vulnerable and received absolutely nothing. We had to rely on having his food delivered as part of our shopping and then transporting it down to him. The feeling of those who were shielding in our group and personally,

is that little was put in place to ensure those in this situation could remain shielding, and they had to implement their own arrangements to ensure they could eat and ensure they had their medication.

25. This did not appear to get rectified throughout the first lockdown. After the initial period of shielding ended in August 2020, food parcels were ended. Those that were still remaining shielding had nothing put in place to assist them from then on. The supermarkets carried on the scheme to ensure they had access to free delivery slots and once these slots were put in place, they worked well ensuring a fixed regular weekly delivery, and there was good communication from the supermarkets, with priority for those on the list. But many found that their deliveries of medication subsequently stopped, even though they were still shielding as pharmacies cut back on deliveries, again leaving them with little choice but to arrange collections via friends or family or having to visit the very types of places they were told to avoid.

Direct quotes from Evidence group: -

"I was offered but received nothing, due to poor implementation."

"I was offered nothing, I received voluntary support from my community or other organisations."

"Had to fight for everything, given letters for shielding arrived late which caused issues with employers."

"The Government form asked if you had anyone who could go shopping for you. If you answered yes, then your name didn't go on the list. Found this out when speaking to Tesco to find out why I didn't have priority shopping. Redid the form and was on all lists!
Yes, technically I did have someone who could go shopping, but then I would have had to shield myself from my own husband!"

"The food parcels were not good; they were a waste of money and were donated to food banks."

"I was not offered shopping delivery slots for a while. We were becoming seriously concerned."

"Local chemists were hit and miss on delivering prescriptions, and then withdrew the service altogether as soon as they could. Had to spend incredibly long hours waiting in online queues to secure a home shopping delivery slot, sometimes only 1 in 3 weeks and have no family or friends nearby to help support with ad hoc deliveries."

"I did receive a food box requested from the council, but the quality and quantity were extremely poor".

"No delivery of medication available
No food parcels so sometimes had limited food.
Felt isolated and alone".

"It was very difficult to get my medications delivered by my nominated community pharmacist. I ended up paying for a delivery service but most of the time there were problems with it. Some of my specialist medications have to be delivered by a national pharmacy company who holds the NHS contract. There were several months where it was impossible to contact them, and my medication deliveries were delayed and therefore my treatment was late. The only way I could contact them in the end was via their Facebook or Twitter accounts."

"It was all good in first lock down then it all STOPPED .. then absolutely nothing other than inappropriate government recommendations such as avoiding people you might think are infected.
I had to pay for medication delivery."

"Supermarket delivery services were overwhelmed and the vulnerable were not prioritised."

"Until the supermarkets prioritised those shielding it was chaos. I ran out of lots of things. There was mental health help, but a long waiting list meant nothing was available for over a year."

"Abandoned is the only word I can use."

"My rheumatologist put me on English shielding list but I live in Wales and the lists were not compatible, so I couldn't initially get a delivery slot (for 6 weeks), I had to get my GP to manually add me to the Welsh shielding list (it is fortunate I knew about this)"

"Initial access to priority supermarket slots was appalling and took weeks. Food box (which was nutritionally deficient and inadequate) provision was patchy. There was limited to no check in regarding mental health or practical support. No provision was made for medicines delivery."

"I was officially offered nothing (from the Government), although eventually received letters) but fortunately there was a local Covid support hub set up to provide assistance, food and medicine deliveries, etc. I managed to get groceries delivered, luckily. And once it was permitted, my partner was able to get things for me."

Access to employment and financial implications of shielding

26. The decision to have to continue to shield apart from the first lockdown has been and continues to be a personal one, based on each patient's situation and advice from their GP's and clinicians. For many in the evidence group, the situation has not changed since the first lockdown. Many in this situation have had to face financial hardships because of this. There has been no financial support for those that were shielding from the government. Some were fortunate to have been placed on furlough if they were working prior to the pandemic, and only if their employer chose to use the scheme.

27.Prior to the pandemic I had a successful small landscaping company employing 4 people, and I was the main income source for my family. As soon as I had to shield it became apparent that the business would no longer be able to function. We initially placed our staff on furlough, but information through the coming months on whether it would be extended was unclear and not forthcoming. The furlough scheme provided precious little income for those who ran their small businesses as a limited company and a company director. It then became clear that the company could not continue to run and pay its overheads, whilst unable to generate income and I took the decision to close the company with the loss of four jobs.

28.This situation was reflected across 3% (Q16) of the evidence group with further business closing down as a result of shielding. 8% (Q16) have taken early retirement to avoid exposing themselves to further risk and 5% (Q16) have been made redundant and over 11% (Q16) have simply quit work as they did not feel safe in the work environment. Over 43% (Q16) are now simply reliant on their savings to finance their continued shielding. Nearly 19% (Q16) have been able to adapt their work life to be able to work from home in a changed capacity, and a further 10% out of the evidence group have had no choice but to return to work and put themselves at risk due to their financial position.

29.We have also seen instances where the partners of those shielding have had to give up employment or substantially change the way they work, due to the danger it posed to the partner they were trying to protect.

30.At no point during the shielding program or since has the issue of the financial support been addressed by the Government. The only financial support has been statutory sick pay, which was limited to 28 weeks and on 1st April 2021 the ability to claim that was halted, in stark contrast to the furlough support scheme which ended on 30th September 2021. Many in this position have lost all income and are now watching their life savings dwindle. Many have had to place themselves in the situation of choosing to struggle financially or putting their health at risk.

31. A teacher in our group saw all the mitigations in her classroom removed even though she was vulnerable. This left her with a choice between going to work and risking her health every day or resigning from her job. This also needs to be considered in relation to the increasing household expenditure that many now face due to rising inflation, fuel costs and rent and mortgage costs. On top of this many that shield or are still shielding have had to change shopping habits and have become reliant on home deliveries for all manner of items. This has led to higher costs, delivery charges and more limited choice. Many of this group also have conditions that mean they use more energy also (dialysis etc) or have special diets, which incur higher costs. Even now as the situation continues this element is completely ignored by the government and too many have fallen through the gaps created by this situation. It has also forcibly removed a significant proportion of I/C people from the workforce who prior to the pandemic were engaged in the workforce and would still be able to return to work if the protective drugs were in place for them.

Direct quotes from Evidence group: -

"I have been unable to continue in my employment due to lack of protection."

"I have had to put myself at risk and return to work due to my financial position".

"I worked until March 2022 at home but when we were being forced as civil servants back into the office, I took early retirement at financial cost to me as I didn't apply for medical retirement."

"My wife had to leave her job as a teaching assistant."

"Due to needing to avoid indoor (shopping) spaces, we pay a premium for always shopping online".

"I lost income streams for my businesses and found others. I stopped attending stall events to sell at and I went digital, selling my art internationally via a print to order platform. It was hard and I lost money on prepaid stall fees, but I've made it through."

"Had to pay 2nd rent as partner had to move out".

"I have been unable to return to work in NHS/ academic settings due to risk."

"I have not gone back to work and my partner lost his job and felt that his ability to continue remotely was impossible. With his line of work, it would be extremely difficult to find a job that didn't require a lot of face-to-face events and meetings. People aren't understanding of particular situations as they believe that people need to 'live with Covid". The government has made no provision to protect immunocompromised individuals or their families in work situation".

"I've had to refuse to do work due to it not being a safe environment and hence reduced my income".

"Now on one salary due to still shielding. Husband took a new job working from home so we can shield as a family. Income as a household dropped over £30,000".

"I had to take one year's unpaid leave and it has been extremely stressful not knowing if my employers would allow me to continue working for the company. I have had to negotiate a new role working from home, getting my union involved."

"Cannot return to work which is NHS and no progression in my career".

"I had to fight for my job every single day. My employer behaved very badly, and I had to threaten legal action. Had the government acknowledged that there are many people who remain at high risk and are unable to respond to vaccination I think I may have received more support."

"We have no income currently, apart from my partner's redundancy pay. There is no help."

"I lost a profitable successful business that had been running for 15 years. my partner had to become the main income source and we had to use our limited savings. Absolutely no financial support, whilst others have been furloughed or received sick pay".

32.It was however not only the I/C person who was affected in their incomes and workplace because of shielding. Due to the need for family members to have to live under this regime, they often had to adapt the way they worked or give up working in order to be able to protect their loved one in the same household. 26% (Q32 were able to work from home at the discretion of their employer, with 5% changing employment to a safer job. 6% were unable to be accommodated in their needs by their employer with 9% simply unable to continue to work.

Effect on those working in healthcare.

33.There was another impact surrounding the restrictions shielding caused with regards those who were working in healthcare and due to their I/C statues had to shield. Within the questionnaire we saw 14 positive responses from either healthcare staff, or those that worked within the healthcare industry, who were unable to carry out their role or had it impacted in some way, which limited their ability to fulfil their role.

Direct quotes from Evidence group: -

"I am a doctor and normally work in a busy hospital seeing patients. Since March 2020 I have not been into work in person due to my immunocompromised state. I have continued to work in a modified way remotely."

"My wife was unable to work as a Registered nurse due to me being immunosuppressed and high risk."

“Yes, I had to stay off work for one tear of shielding then returned and working in full Ppe since.”

“Yes, I am a counsellor and no longer see face to face clients. I have had a huge decline in clients because of this.”

“No, I had just retired in 2019. I was automatically placed back onto the HCPC register without a need to pay but since I was shielding and all my ex-colleagues were telling me there were no precautions in place in my old department, I did not feel safe to help out in any capacity.”

“Yes. I stopped working and was shielding at home. I was unable to "work at home". I ventured back into work for one day when shielding officially finished but found it was too unsafe to be able to continue. Eventually a change of role meant I could work at home for a short period before retiring.”

Children and access to education

34. As previously mentioned, 12% (Q31) of the evidence group had school age children shielding with them. The effect on children in this situation has been immeasurable. It placed a strain on children having to reconcile what was happening in their life as it was to all other school age children, with the added anxiety of the thought that their loved ones were at a high risk of the virus and that they could be responsible for infecting them and possible death. As the restrictions were eased it placed more and more strain on children and parents as hard decisions had to be made. The desire to allow your children to return to some sort of normality and mix again with their peers is overwhelming, but extremely difficult to reconcile with the risk of them doing so to a person that is shielding.

35. This became even harder when schools reopened. Many schools did their utmost to protect the children under their care and also adults in this situation. My youngest child's primary school gave her a tour of the school before it reopened to show her the precautions put in place to put her mind at ease, and both schools

ensured their computer systems recorded the family situation. This meant we were alerted quickly of any cases and the circumstances so we could make judgements. The burden and stress encountered every day for an I/C parent or guardian waiting for their child to come home safe and not get pinged as a contact was immense. My youngest was pinged several times and inevitably contracted covid. The anxiety for her having caught it, and fearing she had passed it on was a huge burden. She steadfastly refused to come out of her room in isolation to protect me even though she was really poorly. At this point I was living separately from the family to protect myself. This was echoed by many, and a lot of people saw it as their only option to allow their children's education to continue.

36.A member of our group rented a flat across the road from her family house to allow her children to return to school, the only contact being through a window or masked and in the garden socially distanced. It is difficult to explain the drain of emotions for a parent not to be able to cuddle your child or do normal everyday activities with them. To have to do this on a protracted long-term basis is nigh on impossible to comprehend unless you have lived through such a situation and have created issues for many families and children that they will have to struggle to deal with for many years to come.

37.For many parents the issues with children attending school versus protecting a household member has been a long running problem, with some parents choosing to elect to remove their children from school completely as they saw protective measures rolled back. It also made life difficult for those with children in higher education.

38.Residential higher education facilities such as universities were seen as incidences of high levels of Covid 19 among students who attended physically. This meant families had to put in place systems to protect themselves if their children returned home. For many this meant testing and periods of isolating when returning to ensure they were covid free. For many it meant the family remained split with children not returning in breaks to avoid the problems.

Direct quotes from evidence group: -

"My daughter was at university at the start of the pandemic. Her mental health suffered as she was extremely worried about me. She had no support at Uni and the stress took a toll on her. She lived at her summer job to protect me which meant I was alone for the entire duration. It was very lonely, and I was very isolated. Both my daughter and I continue to suffer with anxiety and depression which came about during this time. "

39.Once again, all these difficult practical situations put more stress on all members of the family. For many as time has worn on, their vulnerability has not changed, but many have experienced fatigue from their loved ones placing more pressure on them to try to reduce their level of shielding placing them in a very difficult practical and emotional situation. Many have seen contacts with friends and other family members outside the household reduce or stop. Again, they have faced a lack of understanding with assumptions being made that the danger to them has passed.

Access to healthcare and associated problems

40.We have seen evidence from our group that the shielding program has had a direct effect on their physical and mental health and their ability to access healthcare during both this time period and up to the present day. During the period of 1st March 2020 to 28th June 2022 95% (Q1) needed to access healthcare, however many struggled at all levels of health to gain access to healthcare. Some 31% (Q2) stated they had critical healthcare appointments cancelled. This included issues such as routine injections of Rituximab used to control rheumatoid arthritis being cancelled leaving patients in pain and the condition worsening, a wide range of surgeries delayed with resultant complications or worsening of the conditions due to the time delays, chemotherapy sessions being stopped early rather than running the full intended course. Many had investigative procedures or review appointments cancelled, meaning they had to continue dealing with a condition on no or unsuitable courses of treatment. Again, the burden on their mental health was huge, due to the anxiety delays for treatments created.

41.Some of the evidence group resorted to switching to private healthcare in order to keep their treatment going. Many stated they felt abandoned and had increased levels of pain and anxiety of not knowing when and how they would be treated. Some now undoubtedly have conditions that have been made worse and incurred irreversible effects due to delays incurred. On a more basic level many have struggled with GP appointments and dental appointments. This is a concern as many patients require frequent consultations with their gp to deal with lower grade issues surrounding their condition. There has been praise for the way that video consultations have been introduced which has given reassurance and safety, but also frustration as it has also precluded many from physical examinations and some gps only offered telephone consultations.

Direct quotes from evidence group: -

"My rituximab infusions were totally cancelled for over 1 year. I used to have them every 6 months, so my rheumatoid arthritis then came back".

"Long delays/clinic not running for: eye clinic, lumbar puncture & MRI/PET scan and neurologist redeployed to the ward. I was completely left in limbo resulting in almost total hearing loss and ultimately requiring plasma exchanges, then chemotherapy followed by immunotherapy, and now biologics because I didn't receive treatment in time."

"Cancellation of renal transplant clinic during a rejection period in my transplant. Unable to get an appointment at the GP to get emergency bloods taken. 19 hr wait in A&E for transfer to ICU where I was out immediately onto ventilation and was deemed critical condition "

"Long waiting times to see Arthritis consultant, had to go private for cataract surgery as I was on the verge of not being able to do my job due to sight".

“I needed to see my GP, but they were not doing face to face appointments, only telephone appointments. I had to wait 8 days before I got a phone call back.”

“Lack of measures made it impossible to access healthcare in the way you would like as I felt unsafe when I did due to lack of masks and ventilation.”

“Access to GP was a nightmare; nothing face to face and took days and repeated calls to speak with anyone at all. Was finally given a cancer diagnosis 9 months after the definitive biopsy was taken and didn't commence any treatment until 12 months post biopsy. Had to fight for everything, GP initially told me I wasn't at increased risk from Covid despite my knowing that I was.”

“4-week delay to treatment due to huge covid rate in hospital, led to relapse of disease. Brand of immunoglobulin changed as unable to obtain regular treatment, this led to dreadful side effects for 7 months until regular brand could be obtained. Difficulty obtaining treatment when I contracted covid via GP & 111, who had no knowledge how to access treatment. GP blocked access to join shielding list & consultant had to write to them explaining my condition; GP unhelpful in obtaining vaccination on a number of occasions, unable to have locally & resorted to a 200-mile round trip to hospital on some occasions.”

“Delay in having cancerous growth removed and then a delay after a positive bowel test.”

“Delays of over three years in an operation I still need”.

“Had to be referred for a lump in my throat, waited 5 months after being referred urgently and still didn’t get an appointment after the 5 months, was told by the hospital it wasn’t urgent and would have to wait longer. Ended up having to go private”.

“Progression in my disease and new treatments made available I was eligible to start treatment but due to high Covid rates the start was delayed by 15 months. This added to my anxieties.”

"My chemotherapy was stopped because of covid. Decided by the cancer team".

"My usual yearly scan was cancelled for 2 years. My medication was constantly delayed reaching me."

"Delay to tests needed to check for progression of cancer. Unable to get a bed initially when first admitted for biopsy (during 1st omicron wave) and had to return a second time for this when there were still problems getting a bed. Also, the risk of catching omicron was a major concern when in hospital. These problems all delayed the start of chemotherapy."

"Waiting area for chemo ward in the public corridor made me very uneasy with people not wearing masks and coughing."

"Progression in my disease and new treatments made available I was eligible to start treatment but due to high Covid rates the start was delayed by 15 months. This added to my anxieties."

"Lack of GP appointments. Unable to have many face-to-face hospital appointments. Anxiety about mixing with others due to my CEV status"

"Was told not to attend the children's ward as even though my son would usually have been admitted being so ill, we were told it was not a safe place for him and he'd be safer at home. First time in his life (14 now) that I had been told the NHS was not there for him. All regular hospital appts done by phone not even zoom so no one could physically assess him even by sight."

"Dentist refused to wear a mask correctly.
Verbally abused by another patient at doctors
Hospital staff not wearing masks, told I was paranoid".

Inequality of care for I/C and lack of mitigations to ensure adequate protection.

42. Many have felt vulnerable and scared to visit healthcare settings due to the chance of exposure to Covid-19. 54% (Q4) felt that the safety and availability of healthcare either in the form of home visits or healthcare settings had been compromised by inadequate infection control measures and the availability of PPE. The issue of overcrowding in hospital waiting rooms is an issue that has frequently been referred to, as was the issue of mask wearing. Evidence from the group points to issues with many patients not wearing masks when it was mandatory, and in many cases, staff were either not wearing them or they were worn improperly, even at consultant level. There is also one case of a member of staff working in primary health care who was given out of date PPE, with a new date sticker placed over the top.

43. There was much concern expressed in the questionnaire from members of our group regarding lack of infection control, with many citing problems in waiting rooms in areas such as phlebotomy and even chemo wards, with patients who appeared to have covid symptoms being allowed to mingle with other patients or vulnerable patients finding they were sharing wards with covid positive patients. In some cases, staff made best efforts to protect immunocompromised patients, but it was clear facilities were inadequate to accommodate this. In one case a patient from our group contacted us to tell us he was taken to A and E and was sat in a store cupboard for 8 hours, to keep him separate from other patients.

44. Many in the evidence group reported feeling that their condition wasn't taken seriously by reception staff. I myself had to try to explain my position to my gps receptionist when attending for a blood test and was treated with a total lack of concern. I ended up waiting outside of the surgery in the rain for my appointment. This would appear to be a regular occurrence with people in the group, often choosing or being asked to wait outside whilst waiting to be seen. Waiting outside in all weather conditions simply to access is not a pleasant experience and the problems are exacerbated for those with physical conditions and places a further

stigma on them as being treated differently and with a lower level of consideration than others.

45.Whilst there was an accepted shortage of PPE during the early part of the pandemic and a learning curve, it appears there has been a waning of interest in infection control measures as the pandemic has progressed in some settings, as a fatigue from the situation has set in. Examples of a district nurse coming into a home with no mask and no handwashing, a nurse not wearing a mask or hand washing during a cannula procedure, a GP visiting with no hand washing or mask, and numerous similar examples along with masks being worn under the chin. I personally attended my dental practice with my family for a routine appointment. My wife came back out having gone in to check to find no mitigations were in place. When she explained our situation, she was told it didn't matter anymore by the staff. We were unable to have the check-ups carried out due to this.

46.This is in sharp contrast to the treatment I get from my local veterinary surgery. They are aware of my condition, and it is recorded on their computer system. Upon arrival they greet me in the car park masked and take the animal from me. The consultation is carried out with the vet over the phone and the animal returned back to the car park where the vet or nurse gives a summary, and any medication is bought out and social distancing is still observed. Poor examples such as these have led to many patients feeling extremely fearful of entering healthcare settings and doing all they can to avoid attending. Many feel it is the last place they wish to go and has led to them voluntarily cancelling appointments or procedures. This has also extended to them having their covid vaccinations where many feel the risk of attending a vaccination centre where no mitigations are in place, far outweighs the limited benefit of having a vaccine which for many immunosuppressed patients offers very little return.

47.Yet simple steps can still be taken to protect I/C patients that take little effort. Another dental practice now has me recorded on the computer system as I/C, offers me the first appointments of the day, is happy to allow me to wait in my car in the car park and call me in and the dental staff have agreed to wear masks when I am in the examination room, and the surgery has deployed Hepa air filters in the building for the benefit of staff and all patients. Cheap and effective measures that work to put I/C patients at ease, lower their level of risk and help to stop them feeling excluded, but which are too uncommon. As a patient group it is simply beyond belief that a busy veterinary surgery can put in place better protocols to protect vulnerable visitors and their staff and treat I/C patients with more dignity and care, than many healthcare settings, whose very existence is to care for the health of their patients.

48.There is a perception of health inequality for those in this group with 32% (Q5) feeling they had experienced this during the time period. Many felt that the removal, downgrading or general ambivalence to mitigations simply excluded them from accessing treatments leading to the inequality, with a general lack of awareness of the situation or a willingness to cater for it. When an I/C patient has to consistently explain their circumstances to health staff and has to fight for their entitlements and to be taken seriously, and when the staff display a lack of understanding, it very much feels to those patients like there is an inequality of healthcare. That feeling can only be exacerbated when they have to queue up outside in the rain in the winter months in order to protect themselves and access basic healthcare. The feeling of inequality of healthcare has been massively magnified by the fact that so many are still effectively shielding and feel like they have been left to rot, when they could have had drugs that lots of other countries were using, that would dramatically improve their situation. The general feeling for I/C patients is that they are having to fight for every piece of protection even at a basic level, access to healthcare is becoming harder and they are stigmatised by continuing to wear masks and asking for simple adjustments to be made in their care and treatment.

Direct quotes from Evidence group: -

"I was CEV but also pregnant during this time. My maternity care was shocking during this period with no measures in place for patients or staff. This was in 2022 and by then the hospital seemed so fatigued with safety measures that they gave up. Because I couldn't avoid my appointments, I had to ask for a separate waiting room every time or wait outside."

"Lack of masks from other patients. At one appointment the person taking my blood took her mask off to sneeze and wipe her nose. It was a small room and there was no ventilation".

"I had to attend a general phlebotomy dept, which was terrifyingly overcrowded. It was dreadful and I ended up in tears.
In the biologic clinic there were no issues. At the GP surgery there were few infection controls once the lockdowns ended. One practice nurse even refused to put a mask on when giving me my flu jab - even though my notes have a red banner on the screen that reads immunosuppressed."

"Being put in a COVID positive area despite being immunodeficient felt awful. Couldn't wear a mask as I was having to use nebulisers all the time."

"I had to visit a hospital to receive a Sotrovimab infusion after contracting covid in early 2021. I was put on a chair in a corner of a two-bed ward occupied by two seriously ill dialysis patients who also happened to have covid 19 - neither wore masks and one was coughing explosively. I was forgotten about until I went to find someone,
so, I spent much longer exposed than I needed to be."

"In Cancer treatment areas some evidence of people not wearing masks and policy not being encouraged. In vaccine centres no facility in queues for distancing, no masks by staff and many attendees, in GP settings no masks by staff or reception. Dental care was best regarding safe space and ventilation."

"Lack of social distancing and masking among patients. Poor or non-existent ventilation. Most staff wearing surgical masks, some incorrectly. Being told to change my FFP2 mask for a surgical one (I refused). Being told it was ok, I could remove my mask. Lack of hand sanitiser."

"When I attended the hospital for an iron infusion, one of the respiratory nurses' colleagues came into the department from the Covid ward and complained of feeling all "Covidy" because they had not changed their scrubs after leaving. And there they were standing wafting their Covidy scrubs around the room with a clinically vulnerable patient there. This type of thing has severely affected my anxiety levels. I am still vulnerable, and things have gone back to almost normal as far as they're concerned."

" During lockdowns felt hospital had good infection control, but during 2022 felt I was put more & more at risk of contracting covid; had a friend of 13 years contract covid at our infusion unit when guidance was left to slide, a patient & two persons came in with no masks & additional persons were not allowed & she had to point this out to staff, she felt she contracted covid from them as next to her. My friend was travelling directly by car, so the only time she could have got covid was on the infusion unit. She messaged me from hospital a number of times, with the last message saying they had exhausted all treatment options & she sadly died."

"On the chemotherapy ward the infection control measures were excellent. However, more generally in the hospital and in particular when collecting medications in the pharmacy it was extremely worrying because my husband had to wait with other patients who were not following guidelines. He complained to the hospital, and they arranged to deliver his medicines instead."

"Lack of PPE, lack of social distancing, alternative mask required to be worn that was low level protection, general lack of understanding by staff of CEV".

DNACPRs

49.The inequality of healthcare also has to be called into question with the consideration of the issue of DNACPRs. Out of our group only 3.1% were spoken to directly by their GP or Clinician regarding this, yet it appears the decision to use these for vulnerable patients was much more widespread than this and the lack of communication and discussion regarding these decisions is both chilling and disturbing.

Mental health issues as a result of shielding for I/C and family members

50.As well as physical health there is an overwhelming feeling that the mental health of this group has been affected by the shielding program. The vast majority in the evidence group are still shielding and accept it is necessary to protect their vulnerability, but only 74 out of the 229 32% (Q13) felt it struck the right balance between physical protection and mental wellbeing. Some expressed the view that shielding was fairly easy to begin with as most of the entire population was in a similar position. I can personally recall feeling reasonably safe with my family behind the front door, as a regime of precautions were put in place which everyone adhered to. Many found that the mental aspect of shielding became harder as they started seeing restrictions being lifted at the end of each lockdown and life for most went back to normal. It very much gave a feeling of being left behind to those in our evidence group as more things returned to normal and they were left unsupported and with little information. This position was made much more difficult for those who had partners who had to try to return to work, and even more difficult for those with children.

51.The anxiety for those shielding of trying to allow their children's education to return to normal whilst still trying to protect themselves has been immense. It has also been difficult for the other members of the family, especially children who have felt equally conflicted and anxious about the possibility of bringing the virus back to their loved ones. I personally witnessed this first hand with my family, and it became much harder as time progressed and normality returned.

52.We sadly have one example of a family that shielded for 3 years, and the daughter unwittingly passed the virus to her father, who subsequently died within a few days in hospital. She now has to deal with not just the loss, but also the guilt of passing the virus onto her dad. The prolonged periods of shielding that many have had to endure and many still are, has left them struggling to reintegrate into society, when circumstances have allowed them to end shielding, or they have taken the decision to end shielding due to other pressures.

Direct quotes from the evidence group: -
"I am still shielding, and my mental health is suffering."

"No, the shielding programme was woefully inadequate, and devastating for mental health".

"Shielding didn't affect my mental health, it was the lack of easy availability to treatments, and now the removal of patients on anti tnf biologics on the Covid treatments list and badly affected my mental health, as the government acknowledges we are high risk but has removed treatments for me. They acknowledge my risk but don't care if I die, therefore they think I'm worthless to society."

"986 days of shielding affected my mental health massively - I struggle to go near people and feel normal again."

"Shielding was fine for me when everyone was in the same boat. After so-called 'Freedom Day', it has been much harder."

"The measures were essential, particularly once the rest of the population were 'back to normal "

"My mental health has suffered as a result, and it has been hard to comply with it"

“In many ways, I'm still shielding. I risk assess each and every situation. Removing shielding and then setting criteria for antivirals I don't meet has damaged my mental health. Lack of general understanding re the risks of infection to people like me impacts on my mental health Even today, my mother-in-law thought it was acceptable to say she's impatient with the time it's taking for her to be able to hug and kiss me, and how she "wants to do it, even if she has to pin me to a chair to do it". It's a nightmare how people don't respect my immunity situation and the right to protect my survival from threats such as this.”

53.There is a general feeling from the evidence group that the physical aspects of shielding, although difficult were tolerable to a degree, the mental problems caused by the ongoing situation have led to depression and anxiety for many. I was fortunate to have the prophylaxis drug Evusheld in November 2022, which I paid for privately, and the adjustment from shielding to a more normal life has taken me approximately 6 months. The fear of walking into busy places still remains, and at first, I was extremely cautious and fearful. If I walked into a small shop, I was still constantly risk assessing and looking for ways out. There has been virtually no mental health support offered for those in this situation. During the initial lockdown, only 8% of the group were offered any sort of mental health or well-being support, but yet nothing has been offered as the shielding has continued. We have one instance of a member who is suffering depression and having contacted their local mental health support services have been told they can't have any counselling, as they can't attend in person.

54.Over 75% (Q17) felt their mental health suffered as a result. Only 13% (Q17) have managed to obtain some sort of mental health treatment through the NHS. 7% (Q17) have been told the waiting list is too long and many have either tried to just battle through, or turned to private counselling or help from charities. Some have turned to GP’s and medication to help through this difficult period. For the I/C their lives have been on hold since the start of the pandemic. Many have seen family events pass them by. Too many have not even been afforded the joy of holding a new niece or nephew or a treasured grandchild. Many have grown separated from family and there have been family rifts due to those not living with the daily reality of the situation taking the view that they have become fixated with the measures they must take.

55. Comments in the press and social media regarding covid being over or just a cold have reinforced these viewpoints. Many have had no respite of a holiday or a break away from home or enjoyed the simple pleasures of a family meal in a restaurant. Some will likely face their 4th Christmas alone. Other life events have passed them by. In August 2021 my mother had her 90th Birthday. I had to witness this from afar and was not even able to cuddle her on her birthday. I can recall the day vividly where I struggled to hide my tears of desperation and disappointment. In June 2022 I lost one of my best friends of over 30 years to cancer. Due to his illness, he had also been shielding. In his last weeks I was unable to visit him as he knew shielding was pointless, but I couldn't take the risk as he was saying his last goodbyes to various friends and family. I spoke my last words to him on the weekend of the Queen's Platinum Jubilee celebrations, sitting in my car looking at a local green where it seemed the whole world was celebrating the event. I sat watching with tears streaming down my face as I had my last conversation with him and felt totally alone and excluded from the world. I was unable to attend his funeral as the crematorium was unable to provide any mitigations to help keep me safe. Watching a funeral over a video link by yourself is no way to say goodbye. I have missed watching my daughters perform in school productions, I have waved my family off on holiday and waved them back, before going into isolation because of the risk from them travelling. These are everyday occurrences for people still in this situation and are repeated day after day for so many. This is no way for them to have to live a life. They have been denied these moments and they can never be regained, some of these people also have a life limiting diagnosis, which makes the loss of these precious moments even harder. When they are faced with living like this every day and seeing the outside world carry on, it is no wonder that their mental health is slowly eroded day by day as they live in isolation.

56.There is little doubt that the mental scars of having to live a protracted life like this will have a long-term effect on many I/C patients. It should be borne in mind that for many, stressful situations and mental health issues can have a direct and detrimental effect on their physical condition. It appears that this is inevitably storing up problems for the future that will place a further burden on both the patient and the healthcare resources.

Direct quotes from Evidence group: -

“I have made arrangements to receive treatment privately/Charity organisation due to inability to have it provided through NHS/GP”.

“I have sought support through NHS/GP but have been refused or told waiting list is too long”.

“I agreed with the GP to increase my existing antidepressants.”

“Don’t feel comfortable attending for hospital appointments so tend to limit the times there and refused the routine health appointments including breast screening and other checks and podiatry etc., because of still shielding…Everything is kept to the minimal…Taking my own rein on my mental health rather than going into another medical setting”.

“My GP suggested I buy herbal remedies from the pharmacy for my anxiety. Other than that, there has been no further assistance offered.”

“I have had countless blocks of counselling throughout the last 3 years. It's nothing more than a new sounding board. Counselling cannot change my situation and keep me safe”.

"Mental health suffers because we have no social life. Because I'm immunosuppressed my husband has to shield also. We no longer go to cinema, dine out, visit pubs, clubs or use public transport, planes, or trains".

Vaccinations, organisation, access, and associated issues

57. Vaccinations have been a central issue to members of our group, due to the unfortunate situation many are left in with the vaccinations being of little or no effect due to their bodies inability to produce antibodies, due to their immunosuppression or immunocompromisation. This has been the whole reason that many have had to, and still continue to shield. In the middle of 2021 evidence started to emerge that vaccines were less effective for people in this situation, and it was clear that those in this position were at a higher risk. From our evidence group only 23% (Q21) were made aware through some form of Government communication, with a further 15% (Q21) being updated through their GP or clinician. The remaining 52% (Q21) gained this crucially important piece of information through the media, social media and charity information.

58. On 1st September 2021, it was announced that an additional primary vaccination would be required for those in this situation. Only 36% (Q22) were made aware via the NHS vaccination service, and a further 11% (Q22) through their GP's or clinicians. A further 38% (Q22) found out only through media reports or social media. 7% (Q22) of our evidence group did not even realise it was actually a 3rd primary dose.

59. Many faced problems with trying to arrange getting this vital 3rd primary dose booked. Despite the decision being made on 1st September 2021, the roll out was slow to begin, and the booster roll out overtook it with many elderly getting the boosters before the 3rd primary was arranged for the immunosuppressed. Many had trouble booking the vaccination, despite being told it was important. 20% were not able to book via the online or telephone service and 29% (Q25) tried to book through their GP's only to be informed that the GP's had no information regarding the 3rd primary dose. I personally tried all 3 options and was unable to book the

vaccine. At the time my children were back at school and because of the risk to me, I lived separately from my family in the summer house in the garden, until I could get my 3rd primary dose. During this time my daughter was pinged as a possible contact and subsequently contracted covid during this period. I was only able to return to the family home after I had acquired my vaccination, which was only carried out as I was speaking to a friend who worked at a doctor's surgery in another town and the doctor arranged to get my dose administered in the vaccination clinic she ran.

60.We have similar incidences of where desperate I/C patients had to try to work around the system to get the vaccine they needed. Many were told incorrect information and there appeared to be a general ignorance as to the need for the 3rd primary dose and confusion with some GP's and vaccine clinics telling patients they had to wait 6 months from their last dose. My own GP surgery did not send me an invite until January of 2022, as they had been given no information until that point. I also raised the issue with my local MP who contacted the local health trust who apologised in writing for the delay.

61.Further problems were caused with regards to record the 3rd primary dose on the NHS records system also, as there was no provision to record it. 26% (Q25) tried to get it recorded as a 3rd primary dose but were told there was no way to record it and some 8% (Q25) eventually went through NHS records corrections to get it subsequently amended. This episode in the administration of the vaccinations highlights the problems surrounding this cohort of patients. The information appeared slow to be rolled out, was badly communicated, and implemented, even though it was identified as a priority by the JCVI, with many having to wait for other cohorts to get their boosters first, even though the booster roll-out started well after the need for additional primary doses for the most vulnerable was announced.

62.The delivery of vaccinations has been a source of anxiety for many within the evidence group and shows good and bad examples of its implementation. From my own experience I used a vaccine clinic run by a local GP surgery, with the use of volunteers in a village hall. The protective measures such as masking, social distancing and hand sanitising were always scrupulously enforced and they were knowledgeable staff, overseen by a GP to deal with any queries. Unfortunately, this has not been the case for so many. One of the biggest stumbling blocks has been the ability to be invited for or book vaccines. Many have experienced frustrating call after call to the 119-booking service, GP surgeries and vaccine clinics when trying to arrange vaccinations for themselves or for their family when household members have been eligible. In many cases staff dealing with the booking have been unaware of who has been entitled to what vaccinations. This has been replicated when they have visited vaccination clinics. It should also be remembered that for many who are shielding, a visit to the vaccination clinic has been a source of worry due to entering an environment that is often busy, the very place they have been working so hard to avoid. Many had experienced more questioning of their need and entitlement for the vaccinations due to the I/C status and in some cases, they have had to argue their case or have simply been told they are not entitled and refused.

63.The issue of the 3rd primary vaccination dose not being recorded also caused subsequent problems with vaccine clinics confusing that for a booster and again attempts to refuse vaccines due to the wrong recording have caused more problems. It has been an all too familiar story of those in this position, having to be proactive to get their vaccinations booked and having to often fight to get what they are entitled to. Our evidence shows on so many occasions that those who are I/C are acutely aware of their condition and what they are entitled to with more knowledge than those in positions where they should know. Even in my vaccine clinic where it has been so well organised, it still gave me a feeling of being a second-rate citizen being taken to one side and having to show my documentation to prove that I was eligible. Many have also experienced poor levels of protective mitigations in vaccine clinics, with overcrowded venues, lack of ventilation and masking. As time has gone on the desire to implement these mitigations appears to have faded in some places, in stark contrast to the measures put in place at the start, with often long queues of people outside the clinics.

64. For the most vulnerable to visit a vaccine clinic is a difficult choice. Many are aware that the benefit to be gained from having another vaccination is minimal or non-existent, but they continue to attend in the hope that the accumulation will increase the levels of protection. It is however a case of weighing up the gains against the risk and the simple lack of regard for their situation means some are now declining further vaccines as they are not prepared to enter an indoor setting where they stand more risk of contracting the virus than being protected from it.

Direct quotes from Evidence group: -

"Each vaccine I had found out by ringing around and asking various agencies as there was very little knowledge with GP staff or vaccine hubs."

"The episode had me in tears. I had to book time off work and travel to this place. And then have to explain to 3 different departments as I was moved through the stages. Frustrating and upsetting. I eventually got it but not without a huge amount of stress".

"I never received invites, so I always booked myself in, lying to the online system if I had to bypass the system to access booking then took all my paperwork with me to prove my eligibility."

"My health board and GP were totally useless and unprepared. I had to involve a kidney patient advocacy charity to step in and write formal letters. It was very stressful."

"Problem booking the first booster as 3rd primary had been recorded as a booster so the system would not allow me to book. Eventually managed to persuade nurse at GP clinic to vaccinate me".

"Had great trouble accessing my third primary dose and this was very common. The GPs were initially very badly informed and knew very little about it, they kept calling it a booster and telling me i had to wait 6 months from prior dose. My renal unit who was supposed to pass on their patient details to the third primary dose programme were equally behind the game. I had several emails with my consultant who did his best to get things moving from the hospital side and managed to provide me with a personal letter confirming eligibility. He was as frustrated as me with the whole situation."

"Even though I had eventually booked a booster appointment and had evidence I was eligible the chemist would not administer it because he said I was not entitled, and I was sent away".

"I had to wait an excessive long time to receive a text invite for my third primary dose and did not receive an invite for my autumn 2022 booster and still no invite for Spring 2023 booster. I have just booked through the NHS website as an invite too slow or does not even get sent anymore."

"3rd dose -corridor to get checked was crammed and no ventilation, once in the queue there was no way to get out, complained to gp afterwards. Nurse was very stroppy when I asked for the 3rd dose to at least be correctly recorded on my card."

"I felt quite stressed when I had to prove I was entitled to the booster having to prove it with paperwork. I was questioned and not believed because I didn't' look' unwell".

"I couldn't resolve the issue with my third primary dose via NHS phone or online. The call taker didn't say he didn't believe a primary third dose was an initiative at all - he said I must have misunderstood a news conference & I was just due a booster. My GP surgery knew I was entitled to a third primary dose but couldn't resolve it either. I got lucky, I received an immunosuppressive therapy in hospital that made me eligible, so my hospital trust was able to arrange my third primary dose & booster at that hospital trust (a different trust than my GP's)."

"For one booster, 06/05/2022, my GP surgery was refusing to answer phone enquiries about vaccinations, so I travelled some distance to a pharmacy clinic where the pharmacist refused to vaccinate me even though I took all my evidence with me. I complained to the clinical commissioning group, and they apologised and arranged for me to have a jab at the local surgery. At all the community clinics I went to I had concerns about safety. Volunteers consistently did not observe distancing. I felt very vulnerable when told to sit and wait for 15 minutes after the jab with many other patients with barely adequate distancing".

Antiviral treatments and associated problems with timely access

65. In late 2021 access to antiviral treatments for many I/C was announced, with Covid Medicine Delivery Units (CMDU's) being set up to deliver these to patients. The delivery of the range of drugs was however time sensitive and relied on them being administered within 5 days of the onset of symptoms developing. A PCR home testing kit was sent to the cohort of patients identified as being I/C with instructions to log any positive result on the NHS site and they would then be contacted for assessment and to arrange access to the antivirals. In the evidence group 75% (Q27) of the replies showed they had received one of the kits when first sent out. 7% (Q27) did not receive a kit despite being I/C and a further 8%(Q27) only received a kit after they chased up the issue with the NHS/GP or Clinician to resolve the matter. The introduction of the antivirals certainly gave some peace of mind in that there was a level of treatment available if you were I/C and contracted Covid. I personally recall quite clearly receiving the email message from the NHS outlining this one evening and bursting into tears. The thought that if I did contract covid that it might not be as feared was a definite comfort, and after such a long period of bad news it felt like some hope and progress. In our evidence group 69% (Q28) never needed to make use of the service. This can best be summed up by a quote from one reply "Shielding is effective - Neurologist said covid would probably kill me-makes you very aware of the risk" Very few in this position changed their protective habits on the basis of the introduction of the antivirals. This meant that the majority carried on shielding and avoided the need for access to the antivirals. Some 12% (Q28) also reported that they used the system and that it went smoothly. Some 15% (Q28) tried to use the service and were either denied it or had to go through a lot of problems in order to access them successfully. The comments from the evidence group paints a very similar picture to what was encountered with the vaccines. Patients who were well aware of the system and their entitlement with their condition, encountered problems with the system when they reported the positive result. In some cases, they received no contact and then had to make follow up calls to try to get the process moving. In many cases it took multiple phone calls with one patient reporting they had to phone 11 times to the 111 service over a period of 5 hours, then found when they arrived at the CMDU, they hadn't been booked in and then spent 2 days chasing

actually getting the drugs, all of this done whilst being very poorly with Covid. There appeared to be a disconnect between how the system was supposed to work and how those on the front line dealing with the initial calls and inquiries dealt with them, with knowledge very much lacking.

66. In many cases people contacted their GP, only to be told they weren't aware of the system, or that they were not entitled to access the drugs. This often resulted in urgent follow up calls to Clinicians or charities who advocated for the person to resolve the situation. When my close friend who had terminal cancer had the same problems, these were only resolved when he contacted his hospice support team. My wife spoke to our GP practice to find out what provision they had in place if I did catch covid and what would be the procedure. The receptionist had absolutely no knowledge of what was in place. It was only when my wife insisted that she find out, that there was actually a GP who was the covid coordinator for the practice, and that if it did occur, he would oversee the issue. This point was raised some 6 months after the antivirals were introduced.

67. In other cases, there were problems with accessing CMDU over weekends, as many didn't operate over this time period. This caused additional problems when the critical 5-day time frame for the effective deployment is borne in mind. There were also staffing issues that caused difficulty in accessing the drugs. During the wave of high covid infections, one of our members could not access the antivirals as the nurses on the unit had contracted covid and the unit was not staffed. This meant they and others could not access the drugs, as no one was put in their place to ensure the unit stayed open. There have also been cases of the best option drugs for a patient's condition not being available and, in some cases, the administered drugs being out of date. The issue of access to antivirals and problems encountered with gaining them quickly has to be seen from the perspective of the I/C person to be fully appreciated.

68.For a I/C person who has spent the last 2 years shielding as they have been told they are at exceptionally high risk, they face serious illness or morbidity, contracting Covid 19 has become the most frightening outcome they could face. Having spent so long shielding and taking so many precautions to stop the contracting of Covid 19, on top of their normal pressures associated with their medical conditions was massively frightening. To then have to face a number of telephone calls to try to access the service, or to be told that a drug they could rely on wasn't available to them or couldn't get to them in time was devastating and extremely worrying. It should also be remembered that those trying to access these drugs were ill. Having to deal with stressful telephone calls is difficult for many I/C patients and stress can result in their physical condition worsening. To have to do this with the symptoms of covid on top of this is unimaginable. As a patient group we are still seeing issues such as this now some 18 months after the system was put in place, and we have grave concerns as to how it will operate going forward as responsibility is passed to ICB's (individual care boards) and how the ICB's will ensure a good supply of the drugs and access to the drugs out of hours.

Direct quotes of what was experienced from our evidence group: -

"Took 11 phone calls to 111 lasting over 5 hours. Was booked if. Then wasn't"

"Had to spend nearly 2 days chasing. Incredibly stressful on top of being stressed about covid. Dreadful service"

"I waited 56 hrs for the CMDU to call me back after spending 3hrs trying to report it to the NHS 111 number as I couldn't get through. In the end my husband went to the renal clinic and refused to leave until he had the prescription in his hand and then drove 30 miles to collect it from a hospital in another county. I almost ran out of time for them to work."

"Molnupiravir was 3 months past expiry date"

" There is no fast track service for receiving the antiviral covid treatments - the process was confused - each service (GP, hospital, 111) was not clear as to the procedure - each one said to call the other - once at 111 it was the same running through of questions and then upon receiving the treatment there was no one to answer questions whilst on it - it's a shambles - the process needs simplification."

"111 & GP had no knowledge of service but was offered an ambulance due to severe breathing difficulties; finally assessed by specialist nurses at the hospital I attend."

"GP said I didn't qualify and would probably be okay without it. Out of hours doctor prescribed them via 111 service."

"Left messages on the call line but not called back. NHS 24 being unaware of vulnerable people being given antivirals only after demanding to talk to a supervisor was it acknowledged. Complaint was raised and a call back with an apology made."

"Had to chase for 3 days".

"I had to chase up for 4 days and only got antivirals after a neighbour was good enough to go and pick them up for me".

Monoclonal prophylactic antibody treatments

69.In March 2022 I/C patients were given hope of their situation ending with the approval by the MHRA of the monoclonal antibody drug Evusheld, which could be used as a prophylaxis to give I/C patients a good level of protection against Covid 19, and allow them to return to a more normal lifestyle, similar to that of the normal population that had benefited from the vaccines. The drug was quickly adopted by many countries across the world including the United States, Canada, France, Italy, Spain, Germany, Poland, Japan, and many smaller countries such as Singapore, Qatar, and Thailand. It was adopted for use by every other G7 country. The UK government however was seen to drag its feet and was unable to decide on this. Despite appeals from clinicians, politicians in the House of Commons, national charities and our patient group, the calls for the fast introduction of the drug through the rapid C19 process which was a viable route for the rapid assessment and introduction of this drug went unheeded. This was in stark contrast to the recommendation made by the Vaccine Task Force 2020 future strategy report, which recommended the development and use of Monoclonal Antibodies as a way of giving protection to the I/C. This view has also been echoed by Dame Kate Bingham who was responsible for the Vaccines Task Force and has publicly said that provision was made to order the drug, only to then be told that it was considered a cheaper option not to order it and leave the I/C still shielding.

70. The delay was further compounded by the resignation of the health minister at the time Sajid Javid and followed by the collapse of Prime Minister Johnson's administration. We witnessed a stagnation in the government over the summer months and a total wall of silence on this issue, with no contact from any Government department or Ministers, until August 10th, 2022, when a decision to refer the drug to the National Institute for Health and Care Excellence was published. This meant that the drug would go through the normal assessment process, lasting nearly 9 months. There was on the part of the government a total lack of urgency on this matter and a failure to communicate with any parties calling for the drug to be deployed.

71. We are aware that there was a view in some circles that giving such a drug to the I/C would result in them taking too many risks and placing themselves in danger resulting in more cases. This is in sharp contrast to the realities experienced in other countries that have rolled out this drug, where I/C patients value freedom, but also value their health more and continue to be cautious. Personal experience of having reduced health through illness has shown me that I value my health and I cannot afford for it to become worse. The last thing I would do having had this drug is take unnecessary chances, and still continue to evaluate every situation for risk and take precautions such as wearing a mask wearing, an air filter at home and avoiding many situations. This is an attitude that is echoed by many in our group and is a totally disingenuous assumption to make.

72.If this train of thought is followed through, it would mean there is no other option but to force the I/C to be closed away for the rest of their lives. Many written and oral questions were submitted in the Houses of Parliament, pressing for answers on the progress of the decision to deploy the drug and issues surrounding it. The drug was showing good protective results in other countries and more importantly reductions in hospitalisations. This was highlighted in an EPP Stakeholder Forum where a member of the JCVI spoke about the forthcoming winter vaccine program. He commented that whilst it was accepted that for many the vaccine boosters would afford little or no protection, something was better than nothing, yet in the same EPP Stakeholder Forum meeting the Antiviral task force spoke of their concern about the efficacy of Evusheld, still offering a high level of protection. This simply highlighted the illogical arguments being used to hold back the use of this drug and the total inequality in how the efficacy of vaccines and Evusheld were judged. Following debate in parliament in October the minister of State for Health, Robert Jenrick agreed to push NICE to shorten the review process, with the first draft guidance being issued in February 2023. Following a change in its effectiveness against some variants, NICE exercised caution denying the authorisation of the drug to the many thousands, so desperate for it after such a long agonising wait.

73.NICE themselves concluded in their draft guidance that “that there is an urgent unmet need for an effective prophylactic treatment for people who do not have an adequate response to vaccination”.

Inequality of access to treatment and its effects

74.The drug was then released privately by the manufacturer at the end of October 2022, which gave the option for those that could afford it of funding the drug privately. Despite efforts by the drug company AstraZeneca to keep the price of the drug as low as possible, by the time pharmacies added their administration cost and consultation costs were added, it put the costs as high as £2380 in some cases, which was out of reach for so many, especially when it had to be repeated every 6 months. This has undoubtedly added a further unfair inequality of healthcare to this cohort of patients with those who cannot afford the ongoing costs of this drug have to stand by and watch as others have been able to access the drug and return to some form of normality.

75.I was lucky enough to have been able to use some savings to pay for the drug privately in November 2022. And it has made a massive difference to not only my life, but also the lives of the rest of my family, not only in terms of having some protection, but allowing me to live a more normal life, whilst still exercising caution. I spent just under 1000 days shielding, often living away from my family, not seeing many relatives, and only meeting friends outside at a distance, even in the midst of winter. I was also denied Christmas with my eldest daughter for 2 years. With two children in education, it has proved massively difficult for the family to deal with and to cope physically and mentally. It has placed untold strains on all of us, and I am being treated for depression as a result of this.

76.The change from shielding to being freer, has not been a simple change to make overnight. After 3 years of constantly wearing masks, risk assessing had become a routine, as had avoiding so many places such as cafes, restaurants, school concerts and many other simple pleasures. I have suffered anxiety when entering even small empty indoor settings and anxiety when meeting family again in groups after such a long time.

77.Relationships have had to be built up again and the courage to enter places after such a long time has taken months to build up. I would estimate it has taken 6 months to get to some semblance of comfort in sitting in a cafe, but I still get anxious to be able to ensure I can sit near a door or a window and to make sure no one around me is displaying any symptoms. Even taking limited public transport such as a train to London for a hospital appointment, is still a planning exercise, meaning selecting a train for a quieter time, ensuring first class tickets are booked in advance, so they are not so expensive, so I can sit in a carriage that has more chance of being emptier and screened off from many of the passengers to give some degree of safety.

78. I would never even consider buying first class tickets prior to the pandemic, but it now seems the only way to travel with more safety. But even doing this means as an I/C person I pay more for my travel and I am tied to particular trains rather than the simple freedom of jumping on any train, with the anxiety of how crowded it would be. This is just a typical extra financial burden are faced with in order to be able to carry on part of their lives safely, tied in with the additional stress and complications entailed with something as simple as travelling on public transport.

79. The effects of the change after having the drug and the caution displayed have been repeated by many in our group who have been fortunate to be able to obtain it, and the stories of how long it has taken for them to adjust are all too familiar. There is also a form of what can only be described of survivors' guilt, in that I and others have been fortunate to have been able to afford it, and yet we feel very guilty knowing that so many are unable to afford this essential drug and are still left in the seemingly never-ending situation of shielding.

80. There have been instances of great generosity within members of the I/C community who have paid for those less fortunate than themselves to have the drug also, but there have also been other heartbreaking stories of many who have felt at their wits end and suicidal after seeing the drug made privately available, but unable to afford it. We are aware from our group of one person who considered turning to prostitution in order to fund it for another family member. This truly has become an example of a totally unfair inequality of healthcare.

81. I personally have been very lucky, to have seen the effect on my family and the weight of worry and anxiety lifted from my wife and children's shoulders, and to be able to cuddle my eldest daughter again has made the sacrifice to fund it worthwhile. The chance also to be able to cuddle my 91-year-old mother after nearly 3 years, when at many times during shielding I feared I would never get to hold her again due to her age is one you can't put into words, but the question has to be asked why so many been denied this simple freedom.

82.In the evidence group the overwhelming response was that 50% (Q29) would have ended shielding and still limited contacts and activities and 44% (Q29) would have ended shielding to return to a more normal life. Only 2% (Q29) felt they would have remained shielding. The decision to delay the introduction of the drug denied so many the chance to have some semblance of a normal life. And the long-term mental health effects of this could be seen for years to come.

Direct quotes from patients in the Evidence group: -

"I had to fund raise to access this privately it was very embarrassing to beg for help given in all other g5 countries feel very let down Evusheld is our vaccine !!"

"It would have been a game changer, a release from prison."

"I was very disappointed that, unlike most other countries, the UK did not make Evusheld available on the NHS. It would have made an immense difference to my quality of life."

"I was so looking forward to being able to mix with people and see my grandchildren. I have missed them for all of 3 years for fear of infection with Covid."

"It would've saved my job. I would've been uncomfortable but having it was better than losing my job and risking my home being repossessed."

"I would particularly have liked to have been able to meet up more easily with family members and to attend my church (perhaps take Communion again). I would have liked to have attended a special party for a friend in a worse situation health wise than mine. I would have liked to have felt my spouse could have had more freedom - for employment and socialising and other 'normal' things too."

"I would have been able to attend Christmas events with my children, do a lot more in education settings in my role as a school governor."

"I can't go anywhere without an ffp3 mask. I can't go to visit relatives, can't go to church, or see anyone without a lateral flow test. It's appalling so bloody lonely."

"I and my husband who both work in the City of London would have returned to our role's vs continuing to work from home full time. We would be able to start meeting family and friends and travelling again with a level of confidence."

"It would have also enabled my family to return to a more normal life. My eldest son is now under the doctor and on medication for mental health problems caused by shielding to protect me, imagine how that makes me feel."

"I thought it would end this awful time of shielding and give us some sort of life back. Unfortunately, that wasn't to be. I cried in despair".

"It would have transformed my quality of life and that of my family - I feel as if we were totally abandoned. As soon as the shielding was scrapped from public life no one was here to protect us - it's been very difficult."

"I would have my life back and not be utterly depressed and anxious. I spend most days in bed crying. I pray I don't wake up these days as living like this is torture."

"The refusal for Evusheld just added to feelings of being forgotten. It was extremely challenging. To know over 30 countries were protecting their CEV whilst we were refused this. Those lost months could have allowed me to see my grandson, to have hugs. I live alone so the provision of Evusheld could have enabled some carefully chosen socialising with family and friends and helped the feelings of loneliness that I experienced."

"Without Evusheld I remain fully shielding. I am now in my fourth year of shielding. I was so hopeful of a way back to my life when the MHRA approval was announced and the subsequent months and now year have been very hard. We were given hope and then denied it."

"My wife has also had to shield to protect me and as a consequence she had to give up paid employment as well as her social life. My mental health would have been saved as I could have returned to normal. Other medical issues I had and still have could have been resolved as I would have been able to attend medical settings. Both my wife and I could have returned to being economically active"

"I was fortunate to be able to get it privately in Nov 22. It has made an enormous difference to my life, allowing me to be with extended family and visit other places more normally. I still have to take precautions such as avoiding really busy places, masking etc, but the change to physical and mental health has been enormous. To many denied it when it could and should have been available as a matter of urgency"

Overview of the shielding program

83.The shielding program was set up with good intentions to deal quickly with a large-scale problem facing both those who needed protecting and the NHS to prevent it being overwhelmed. Its secondary role was to buy time for both, until suitable vaccines and or medication could be developed to take them out of the position. As many are now in their 4th year of shielding or living a very restricted life it is clear that despite some drugs being available, which could have significantly impacted the lives of the I/C for the better in terms of alleviating the problems of having to shield, but also giving them the much needed protection from the virus, there has been a clear lack of will or incentive for the Government, the DHSC, UKHSA or the NHS to deliver anything but the most basic level of protection and in many cases it has now been withdrawn below the bare minimum.

84.The Government has simply relied on avoiding the issue by relying on the stock answers that they are providing free lateral flow tests and vaccine boosters and that they will do all they can to protect the most vulnerable. Sadly, the view of our group and many of the charities that support other patients is very much that this is a hollow pledge. If vaccines were the answer, then the I/C would simply not be in this position. Free lateral flow tests are appreciated by the I/C, but they have limited value since the I/C needs to know the people they are interacting with are not positive rather than themselves.

85.For someone who is shielding the thought of a plumber coming into the house who has to repair an urgent leak, and who refuses to wear a mask and the I/C person has no knowledge if they are covid positive is a frightening prospect, after they have protected themselves for 4 years. It leaves them with stark everyday choices, where they have to decline everyday normalities of life such as this, and it becomes massively draining. The communication and implementation of the shielding program has been poor from the start. Whilst this may have been acceptable in the first weeks, it is deplorable that nothing was done to address its failings. People have had to make their own decisions to protect themselves, with a myriad of different advice to interpret. Those shielding were left un-provisioned during the initial shielding period and had no financial support, whilst watching the majority of the population benefit from the furlough scheme. Over 11 million jobs were furloughed, yet those shielding had nothing to financially rely on, forcing many to make the stark choice between work and safety. In all aspects those shielding were an afterthought. As each lockdown was lifted, little if any information was passed to those shielding and what was passed was untimely, leaving them in limbo. Those shielding watched further subsequent waves occur, with more virulent strains of the virus, and yet shielding was not implemented officially for them and no guidance as to what to do was issued. When the vaccine issue arose the problems were slow to be communicated putting those I/C who thought they were safe at further risk. They then sat and watched the shambles of a 3rd Primary vaccine rollout for what was at the time viewed as an essential dose, whilst seeing other cohorts be invited to get their boosters. They had to fight and argue to get the vaccines booked and have stand up arguments with staff to prove they were entitled, and a similar picture has emerged for many with the access to antivirals. Time and time again questions have been raised by all parties in Parliament, and the Government has done all it can to avoid giving any direct answers.

Ongoing issues for I/C still shielding after removal of mitigations.

86.As restrictions have been rolled back for the rest of the general population with much political fanfare, the I/C population has been further left behind and forgotten about. The issue of access to Evusheld in 2022 has shown a startling inability for the Government and any department to have the ability to work with any haste or immediacy to counter the problems. Time after time letters have been ignored or responded with the same platitudes, and requests for meetings to try to press the issue and find solutions have simply been blanked. When replies have been sent, they have made promises of engagements and assurances that the welfare of the I/C is a priority, but far from doing anything, more and more support systems and protections are removed.

87.My own MP, a government backbencher of some standing, expressed his complete surprise and annoyance at the way the issue had been ignored along with requests for meetings. This is a situation repeated with many of the group's own MPs with whom they had discussions, resulting in their MP's raising questions on this issue. The rollout of Evusheld has resulted in the most questions raised in the House of Commons on a single drug, showing the level of concern over this issue. The decision to push the drug down the NICE route showed a complete disregard of the issue the I/C find themselves in, a system woefully unable to deal with the rapidly changing variant challenge that Covid 19 presents. The DHSC has also been very slow to move on many of the issues. At present the CMDU's are set to be passed to ICB's in June 2023. The issue of access during out of hours and weekends and a unified policy on access, was raised by ourselves in a meeting in November 2022. In a further meeting in April 2023 the issue was again raised and still no answer could be given. The only certainty they could give was that with the move to ICB's patients would have to pay prescription charges for the covid antivirals. This is yet another health inequality compared to the normal population, as the normal covid vaccines are not subject to a prescription charge.

88.The problems with the ongoing vaccine boosters have been mentioned, but as more and more clinics roll back the use of masks and social distancing, more I/C patients are beginning to consider the risk is too high for the benefit. The feeling of protection has further been damaged by the decision by the JCVI not to provide boosters to the household members of the I/C leaving them further exposed and questioning the scheme. Again, the communication on the latest booster rollout for spring 2023 has been extremely poorly communicated with many I/C patients being unaware and having had no communication informing them of the boosters' availability, but also there has been low uptake as many I/C patients are now very frightened to go into vaccine clinics where the staff are not wearing masks. As it stands at present the take up by the I/C has only been around 27% for the booster, highlighting the problems.

89.Since Freedom Day was announced in February 2022, we have witnessed the NHS have an off and on policy for masks and protective measures with some health boards using social media to promote the fact they were gleefully no longer wearing masks. Some have had to rapidly reassess this policy as they have watched their staff sickness levels rise. For an I/C patient the prospect of having to attend a critical healthcare appointment with no masking or no infection control measures in place apart from certain wards dealing with the I/C has become a frightening prospect. Many have evidenced that even in those wards there have been instances of nurses, Drs and Clinicians not wearing masks, until the patient has challenged them. Many have been on the end of an attitude of the issue has gone away and it doesn't matter anymore. Many have witnessed a total fatigue or denial of the very real issue. Many have found themselves now being placed on general wards when staff are aware of their vulnerability, only to find they are in a bed next to a covid positive patient and having to fight to get moved to a safer location. They now find themselves going into healthcare settings where the very staff supposed to protect and treat them are being told to come into work if they are asymptomatic. Many are so frightened that they are cancelling routine appointments, and some are cancelling surgeries and procedures as the reality of catching covid in healthcare settings is now too great. This has left many facing a total inequality of care that looks set to continue into the long term and is very concerning, as we see daily reports of issues being raised by our group members, and the incidence of these is only rising.

Government communication and stakeholder engagement

90. As a stakeholder we have seen more provisions withdrawn and a total unwillingness to engage. After a protracted fight we managed to become a recognised stakeholder on the Enhanced Protection Panel Stakeholder Forum. The purpose of this was to allow a form of two-way communication between the UKHSA, NHS, DHSC, JCVI and others. It consisted of fairly regular video conference meetings where updates were given, and questions could be asked. It had limited use as many questions were sidestepped often with promises of answers at a later date. In April 2023 a meeting was held, and despite numerous comments by the Chair Dame Jenny Harries about how useful the meetings were, in the last 5 minutes it was announced without warning that it would be the last meeting, removing the last face to face method of contact with the various agencies.

91. This has sadly been a regular feature of contact with both the Government and various Government departments. In August 2022 we submitted a letter calling for the introduction of Evusheld, alongside 19 National charities, supported by a consultation document collated by the APPG for Vulnerable Groups to Pandemic, which was supported by 200 clinicians. We were not given the courtesy of a direct reply, only a copy of a letter that was sent back to some charities and passed on to us. We contacted the Prime Minister, The Chancellor and the Health Secretary directly in September 2022 concerning this issue and requested a meeting and received no reply again, with letters sent to the minister with responsibility for health Robert Jenrick in October 2023, again with no reply. In January 2023 we did receive a reply from the DHSC on behalf of the minister Will Quince, although in the true style of these communications it was sent on an email address that could not be replied to. We subsequently hand delivered a letter to Number 10 Downing Street on March 2023 and have had no reply.

92. It has been a fight to get communications established with virtually any department within the DHSC. We requested that we take part in the EPP Stakeholder Forum held with the charities, and at first were turned down. It was only after standing our ground and a supporting letter from the APPG for Vulnerable Groups to Pandemic that we were allowed to take part. Subsequent to this we did have a couple of meetings with some members from the DHSC, including the Antivirals Taskforce. Although accommodating, the meetings highlighted the slow pace and unwillingness to consider ideas to help alleviate the problem, such as pilot schemes for the roll out of Evusheld and the suggestion of the provision of certain antivirals (Paxlovid which is administered in tablet form) being dispensed to some I/C, to allow them to have the drugs in their possession ready to use under instruction should they test positive. Every conversation was always met with promises to consider and consult further but such consultation never materialised. In one instance we highlighted a case of an individual's problems with accessing the antivirals and a promise of an investigation was made by the DHSC. This took 6 months of constant chasing by us on the patient's behalf until this was investigated and resolved. At the point of writing this we are still awaiting any details and communication as to how the switch from CMDU's to ICB's for the provision of antivirals to patients is to be implemented, with the switch over deadline only 4 weeks away.

93. The poor communication from the DHSC has been highlighted amongst many issues, by their long-drawn-out decision on the refusal to use Evusheld. The lack of open, transparent, and timely communication of the decision reached on Evusheld by the DHSC meant that MPs and Lords did not have access to factual information that was known to the DHSC and which they had asked for and, as a consequence, debate and future questions on this topic were not accurately informed. The timeline of this is highlighted in the exhibit document **(MO2 – INQ000216918)** which summarises a timeline of the events and decisions regarding the decisions surrounding the procurement of the drug Evusheld. This is supported by Exhibit **(MO/3 – INQ000216921)** which details a list of the Parliamentary questions and answers timeline regarding this issue.

94. As a group we have worked alongside many national charities and they have been open and willing to help and share information, in the face of the poor and ever decreasing communications. If it was not for the good work done by all involved in these charities to work together to protect their patients and provide information, many patients would be unaware of many of the issues and changes affecting them.

95. Following the disbandment of the EPP Stakeholders Forum we were told to resort to communications with DHSC, NHS, JCVI Dept's in the normal way by e-mail only. Many requests for the e-mail contact details were made and finally received for departments some 4 weeks later. This just underlines the slow pace of the simplest delivery of information. In the same meeting the disbandment of the antivirals monitoring team for the DHSC was announced, along with the message that everything was returning to pre pandemic footing in relation to dealing with the virus. This included the suspension of the ONS survey data which provided daily followed by weekly updates as to the prevalence of the virus and the monitoring of variants. When it was suspended, we were informed a new system would be put in its place. We are still awaiting this to materialise. The withdrawal of this has been a massive blow to many including the I//C who relied on this to assess how to try and carry on their lives and effectively risk assess.

96. This is the very tool relied on by other institutions such as NICE when evaluating drugs such as Evusheld to gauge its effectiveness. These changes proved a point of massive frustration to ourselves, and our colleagues in various charities and has left those we represent with a massive feeling of total abandonment. Whilst as a group we understand the need for the economy and society as a whole to return to normality, the decisions made in many cases defy logic. It cannot make sense that the most vulnerable patients, who through no fault of their own are the ones who drain NHS resources during a Pandemic and during the normal operations of the NHS, are not better protected to help reduce that strain on such precious resources.

97. When the decision to pass the assessment of Evusheld to NICE was made, our application for stakeholder status was quickly accepted and the liaison staff have been extremely helpful and communicative. We have had no issues with the timeliness, or quality of communications and it is clear from the evidence panel assessments that submissions that we have made with concerns in the appraisals have been noted and considered. They continue to be receptive to the issues of the I/C

98. Since the start of our campaign, we have had the full support of the APPG for Vulnerable Groups to Pandemic and were quickly accepted and appointed by them as their preferred patient group. The understanding, support and advice that has been offered has been outstanding from a group that fully understands the many issues affecting the I/C. As a fledgling campaign group, we have had to find our way, and we have received extensive support and advice, especially from the secretariat for the APPG with whom we are in regular, often daily contact as new issues and developments arise and the introductions they have been able to make to political figures. There is no doubt that without the hard work carried out by them, our campaign would have faced a much harder task.

Overview of issues affecting I/C

99. Nobody who is I/C asked to be in this position, yet every day on top of their own illness or condition they have to still deal with the ongoing situation of trying to protect themselves with no support and no end in sight. The removal of so much of the supportive infrastructure has left both the I/C, patient groups and charities wondering what the plan is to protect the I/C now and going forward, because there simply doesn't seem to be one. For those who are I/C the pandemic has not ended, and in many cases, they feel as if the world is turning its back on them. They are screaming for help, and no one appears to be listening. If it wasn't for groups such as ours or charities offering support, many would be devoid of information and hope. For many in this position just to get up each day and deal with their illness is enough of battle, yet we witness that every way they turn, they have a battle on their hands with simple safe access to treatments for their condition, respect, empathy and understanding for the position they are in, a simple professional

courtesy to be treated in a safe manner by some in healthcare who should know better, whilst they still cling on to the hope that new treatment will be provided for them to allow them to step out from this enforced imprisonment.

100.The shielding program and the protection of the vulnerable has been an unmitigated disaster. It has illustrated time and time again both through personal experience and that of our evidence group and wider group memberships experience, on a daily basis that there has been a total lack of forward thinking and planning across so many government departments. It is simply not acceptable to lock such a large group of people away to protect them, without putting in place systems to ensure they can feed themselves, obtain medicines and medical support when needed. Whilst initial problems are understandable with any undertaking of this scale, the ongoing refusal to deal with the issues raised has shown a callous disregard for the position that so many still remain in. Far from improving, the position has become worse with those affected in more danger and now suffering severely with financial problems and health problems of all types, both mentally and physically as a result. The assumption that the big machine of the Government would swing into action and rely on prior well thought out plans and systems has been shown to be a complete myth. It has shown up, what little planning and systems there were/are still in place for such issues as totally lacking. A total lack of coherent integrated planning and communication has been highlighted, with I/C often having better knowledge, and having to argue and fight every step of the way. There should be no doubt that this will have ramifications on the health of the I/C, how they are treated and the resources of the health service for years to come. The way the whole issue has been dealt with since the start is one which no one involved in its planning, development, evolution, and implementation at any level should be proud of and can and should only serve as a sobering lesson in how not to look after those in most need during a pandemic.

Lessons for the future

101. In terms of lessons for the future, the appalling way in which the most vulnerable have and continue to be treated, serves to highlight that the whole plan needs to be reworked completely from a basic care level upwards.

102. There needs to be a minister appointed with specific responsibility for the I/C as a central information reference and communication point, and more importantly with decision making abilities and can liaise with other ministers.

103. The biggest difference to those in this position is the provision of new protective drugs and treatments. If these are developed and put in place, many of the other requirements will fall by the wayside. It is essential that the Government continues to encourage the development and trials of new drugs in the UK, and monitors those that are available across the globe. It is essential that quicker assessment and approval systems are put in place and maintained for these and any forthcoming drugs. It has been proved such a system can be done effectively with vaccines. This needs to be reimplemented and maintained for Covid 19 drugs and any future pandemic. There also needs to be a plan put in place to ensure that once approval is granted for such drugs, that the delivery roll out to patients is done at speed, rather than within the existing 90 day roll out framework set within the NHS following NICE approval.

104. There needs to be a much better system of recording data of I/C patients. It should be easy to access to ensure any healthcare setting is aware of an I/C patient's status. It should also be easy for the I/C patient to challenge, and have any inaccuracies corrected and it should be permanently maintained to allow it to be updated with new patients, ensuring it is in place for any such future events.

105. There needs to be a centralised care plan for the I/C put in place outlining what protective measures will be implemented to care for and protect them. This has been done successfully in other countries such as the United States of America, where the CDC have implemented their plan. It should reference treatments and preventative measures available, and qualification criteria. Such a simple plan is

an easy reference point for Government departments, Healthcare providers and needs to be put in place across all government departments affected such as DWP, DHSC. The plan also needs to consider the other needs of the I/C, to give a fully rounded care plan, such as financial support, practical support and mental health support. This would also provide clear guidance for I/C as to what they are entitled to and can be referenced in case of any problems. It is essential that such a plan is continually monitored and updated on a regular basis to enable it to adapt to the fast-paced changes of virus and the medical drugs coming on board. There needs to be much more flexibility in the adoption of any such plan and a willingness to make and implement changes quickly and effectively, to avoid missed opportunities as was seen with the roll out of Evusheld and every delay inevitably leads to more pressure on the healthcare systems and bad outcomes for patients.

106.It is unfathomable in this day and age that so many departments appear still so slow to talk to each other and make integrated decisions. There needs to be a much better flow of information and communication between them around a centrally agreed plan.

107.It has been highlighted again and again that decisions have been poorly passed down to frontline staff, who have had no knowledge of new initiatives or treatment that have been implemented. There needs to be a much better effort to ensure those dealing with the public face to face are fully aware, briefed and trained correctly to ensure that patients are not placed in the position of having to fight through endless phone calls to get access to desperately needed medication or other needs.

108.Any plan must encompass a much better level of public messaging to make the target audience aware of exactly what the message is, what is required and what science it is based on. Better awareness of the public as to the issues affecting the vulnerable will help to reduce risks to them and have the knock-on effect of reducing pressure on precious NHS resources.

109.There needs to be greater awareness at all levels of the danger Covid 19 and the many other health issues covid can cause to the I/C, both across the general public and health care providers. The lack of knowledge has been startlingly poor in many healthcare settings. The implementation and maintenance of simple measures and infection control have a greater benefit for all, not just the I/C. Simple infection control measures in the workplace also protect staff, avoiding staff loss and downtime to businesses and the NHS.

110. There must be an acceptance at all levels that the I/C are at most risk and will continue to place the highest level of demand on the NHS resources. Therefore, anything that can be done to protect them in a way that still allows them freedom to carry on their everyday lives and reduce their exposure to needing healthcare should be promoted. Economic cost analysis has shown that the costs of an I/C patient being treated in hospital, far outweighs the costs of preventative measures and drugs. The opportunity costs of an I/C patient being in hospital, in an ICU bed and the number of staff tied up to look after them, and the risks of damage to the patients' long-term health, in many cases after lengthy treatments such as transplants is almost incalculable. By ensuring everything is done to prevent this happening with the provision of steps outlined above, it helps to reduce pressure on NHS resources at busy times, such as during Covid infection waves, leaving more resources free to deal with other cases. It will also avoid causing further complications to an I/C person's health, with the further cost and care implications it can create for the long term.

111. There needs to be an acceptance and creation of financial support for those that are placed into this position. The cohort has been completely ignored and what little conventional existing benefit systems are in place have been inadequate, difficult, and lengthy to claim or in many cases have not applied to some. Just as with the furlough system, there needs to be a support payment put in place to allow those placed in this position to be supported financially.

112. Within the planning there needs to be a fully encompassing shielding plan that will ensure those enforced to shield for their health on the advice of the government, have systems in place to ensure they can access medication, food, and any other needs.

113.There needs to be much better access for the I/C to mental health services, with services dedicated to the unique problems that have arisen for so many in this cohort. The lack of support is telling, and it needs to be available by all methods including virtually as a matter of urgency.

114.One of the biggest issues throughout the pandemic has been the refusal of so many to listen, despite the efforts of so many patient groups and charities to try to engage. It is absolutely essential that there is better communication with those who represent I/C patients, and who are aware from the ground level of the issues being experienced by so many. Many of the issues raised could have been rectified simply, saving time, anxiety, resources, and money. Any planning going forward should ensure that there are patient groups/charities represented to ensure the voices of the patients are heard, listened to, and most importantly acted upon quickly. There must also be a general acceptance that there are many specialists placed outside of government departments, from the commercial, academic, and clinical world, better placed to advise and provide logistic/practical/scientific solutions. An example of this was shown with the organisation and provision of food deliveries by supermarket chains during the pandemic.

115.The most vulnerable need and deserve a much better system in place to protect them but also to reduce the burden they will place on the health services in a future pandemic. Lessons need to be learned and implemented.

Statement of Truth

I 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.

Personal Data

Signed:

Dated: 3rd September 2023