



Rt Hon Rishi Sunak MP
Prime Minister
10 Downing Street
London
SW1 2AA

CC: Rt Hon Victoria Atkins MP, Wes Streeting MP, Daisy Cooper MP, Eluned Morgan MS, Neil Gray MSP, Robin Swann MLA, DHSC, MHRA, NICE, OLS.

26th March 2024

Dear Prime Minister,

RE: Continued isolation facing immunocompromised people on the fourth anniversary of the UK lockdown

Today, 26th March 2024, marks the fourth anniversary of the implementation of the first legal COVID-19 lockdown restrictions in the United Kingdom. To mark this anniversary, we are writing to you as a coalition of charities and patient groups representing immunocompromised people across the UK to express our concern at the continued high risk that immunocompromised people face from COVID-19 and the lack of speedy access to protective drugs for them, as they now enter their fifth year of facing this.

In February 2023, during the assessment of Evusheldⁱ, NICE concluded that there remained an urgent and unmet need for COVID-19 drugs to protect the immunocompromised, and that faster assessment processes were needed. Despite continued access to booster vaccines, many immunocompromised people still have low and limited immune responses to vaccines due to their conditions or associated treatments. This, combined with declining vaccine uptake among this cohortⁱⁱ, leaves many in a position of having little or no protection.

Based on 2023 autumn/winter COVID-19 booster eligibility, over 2.1 million people have been identified in the immunosuppressed cohort in Englandⁱⁱⁱ; over 126,000 people are classed as having a weakened immune system in Scotland^{iv} and over 106,000 are estimated to be immunosuppressed in Northern Ireland^v. In Wales, immunosuppressed people make up part of the 373,040 people considered to have a clinical risk for COVID-19^{vi}. Across the UK, many of these individuals are still following guidelines to reduce their risk of developing severe COVID-19. The recently published INFORM study concluded that such patients were at a risk of up to 14 times more than of the normal population, while accounting for 28% of ICU admissions and 25% of COVID-19 deaths^{vii}.

Many immunocompromised people across the UK continue to live restricted lives and are often joined by loved ones in this, in order to keep them safe. Others have still not seen or touched loved ones

since they were told to shield in 2020. This has taken many people out of employment and education; some have had no option but to move on to benefits, such as Universal Credit, ESA and PIP. On top of this, one of the worst aspects of shielding identified^{viii} by immunocompromised people was ‘missing medical appointments’ – often for the conditions causing their immunosuppression in the first place. All of this increases the load of already stretched public services.

We have also seen an alarming increase in issues relating to mental health, both for immunocompromised people and their loved ones, which was highlighted by the recent report by Bath and Liverpool Universities^{ix}. It is clear that this small portion of the population continues to carry the highest burden of COVID-19 while the rest of the population has returned to normality.

With module four of the UK Covid-19 Inquiry due to start, and with the stark lessons highlighted from the delayed assessment of the original preventative pre-exposure prophylaxis drug Evusheld, we are deeply concerned that the same mistakes are being repeated with the latest iteration of this preventive treatment. While other countries such as France, who recently granted this new treatment emergency authorisation and have rolled it out to eligible people within a month, in the UK, the assessment and authorisation process is once again at risk of stalling. Not only does this delay protection for immunocompromised people in the UK, but it also risks the emergence of new variants of the virus overtaking the efficacy of the drug before it can benefit the community, as happened with Evusheld. At the same time, immunocompromised people experiencing prolonged infection can also be the source of new, highly mutated variants^x. We are also concerned about the message this sends to the pharmaceutical industry, both in the UK and internationally. Unnecessary delays in the assessment process deters research and investment into new, much-needed drugs in the UK.

We include below comments from some of the immunocompromised people we represent. The contributions demonstrate the community’s resilience as well as their continued struggle:

Angela, living with chronic lymphocytic leukaemia (CLL), a type of blood cancer, North Wales, via Blood Cancer UK

‘As a self-employed consultant, my work, and therefore income, are a fraction (15%) of what I had before 2020 – my quality of life is very poor as a result. My social life is virtually non-existent and I am lonely. I am unable to enjoy the global travel for work and leisure I used to enjoy. In short, it has pretty much devastated my middle age years and my zest for life has declined severely.’

Carer via National Kidney Federation (NKF)

‘I am still concerned re bringing ‘anything’ home to my husband who I care for and who has Kidney Cancer and in Chronic Renal Failure. Neither of us have had COVID, he never leaves the house so I feel the pressure is on me, I mix far less with people since COVID and never attend large functions, in fact I hardly go out.’

Patient via National Kidney Federation (NKF)

‘The government should learn the lessons of the Covid enquiry and fully implement the recommendations made.’

Teresa, acute myeloid leukaemia (AML), a type of blood cancer, via Anthony Nolan

‘I had a stem cell transplant about 2.5 years ago & the hospital was still in lockdown, with no visitors. Fast forward to January 2024 when I had to go back into the same hospital to treat an awful infection, this time visitors were allowed to visit with no restrictions on numbers. I found that time more stressful (anxiety over infection risks) as so many people walked about the ward with no masks

on. As for my family, they also followed the rules given at the time to give me and others the chance to return to 'normal' life. Although a new normal life had to be created, by following the guidelines that were given they all knew they were doing what they could, regardless of what others might do.'

Carole, living with non-Hodgkin lymphoma, a type of blood cancer, Lyminster, via Blood Cancer UK

'We choose to live a "Covid cautious" life, which is navigating a life between full shielding and living like normal. We have not been inside any shops since 13th March 2020.'

Patient via National Kidney Federation (NKF)

'I think protection of vulnerable people is needed such as Evusheld 2, continued booster programme, simple access to antivirals, public awareness of risks to immunosuppressed, legal covid workplace protections and protection of vulnerable patients in healthcare.'

Jessica, living with Waldenströms Macroglobulinaemia, a type of blood cancer, London, via Blood Cancer UK

'The pandemic caused me to lose a lot of social contact and support. I am still very lonely and have long term mental health issues because of the isolation during the pandemic... Spend time with trusted friends who understand your anxieties. [These anxieties] are normal, but try not to let them control you. Do small experiments where you don't wear a mask even for one minute to gently expose yourself to change. Be kind to yourself.'

Patient via National Kidney Federation (NKF)

'Before Covid I was happy in my job and confident in my role. I had been in my job 5 years and never had a day off sick. Being told to shield really knocked my confidence. My employer treated me different when I returned to work. I subsequently decided to take retirement.'

Rob, a trained career carer, looking after his immunocompromised wife and child via Forgotten Lives UK

'I have been forced to shield since the start of the pandemic to protect my immunocompromised family. As a result, I have been forced to give up my career in a sector desperately short of suitable qualified staff and forced onto Universal Credit and associated benefits.'

As these experiences show, while access to vaccine boosters and post-exposure treatments are still in place, the need for an effective protective drug and continued support measures is vital for immunocompromised people across the UK. This is poignantly highlighted by Forgotten Lives UK and the recent death of Stephen Cooper, a multi-organ transplant patient, who having shielded since March 2020, was told his cancer was terminal. Deciding he wanted to have as much as a normal life as possible for his last months to make memories, he went out a few days later for a pub lunch and contracted COVID-19. Despite taking a course of antivirals, the precious time he had left was cruelly cut short when he died a few days later. Sadly, this is not an isolated case.

As Prime Minister, we are asking you to take action to ensure that the regulatory authorities now deal with the assessment of the new pre-exposure treatment (AZD-3152) as a priority, and that, assuming there is robust evidence, the NHS plans and prepares for the rapid implementation of the drug. The communities we represent remain in urgent need of such medicines and are desperate for an end to their prolonged wait. After four years, they have surely sacrificed and waited long enough.

On behalf of all those we represent we look forward to your timely reply.

Yours sincerely,

Helen Rowntree
Chief Executive, Blood Cancer UK

Mark Oakley, Nikola Brigden & Prof. Martin
Eve
Forgotten Lives UK

Bradley Price
*Director of Policy & Public Affairs, Action for
Pulmonary Fibrosis*

Henny Braund MBE
Chief Executive, Anthony Nolan

Hilary Lindsay
Chair of Trustees, CLL Support

Kate Rogers
*Chief Executive, Follicular Lymphoma
Foundation*

Dr Susan Walsh
Chief Executive, Immunodeficiency UK

Fiona Loud
Policy Director, Kidney Care UK

Sandra Currie
Chief Executive, Kidney Research UK

Fiona Hazell
Chief Executive, Leukaemia UK

Dr Sarah Rawlings
*Executive Director of Research and External
Affairs, MS Society*

Andrea Brown
Chief Executive, National Kidney Federation

Clare Jacklin
*Chief Executive, National Rheumatoid Arthritis
Society (NRAS)*

Ceinwen Giles
Co-Chief Executive, Shine Cancer Support

Henry Gregg
Chair, Taskforce for Lung Health

Sue Dimmock
*Trustee, UKPIPS (UK Primary Immune-
deficiency Patient Support)*

ⁱ NICE, September 2023: <https://www.nice.org.uk/guidance/ta900/resources/tixagevimab-plus-cilgavimab-for-preventing-covid19-pdf-82615419952837>

ⁱⁱ NHS England, February 2024: <https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2024/02/Autumn-Winter-2023-24-COVID-vaccinations-for-SIS-and-IS-29-February-2024.xlsx>

ⁱⁱⁱ NHS England, February 2024: <https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2024/02/Autumn-Winter-2023-24-COVID-vaccinations-for-SIS-and-IS-29-February-2024.xlsx>

^{iv} Public Health Scotland, 2024: <https://scotland.shinyapps.io/phs-vaccination-surveillance/>

^v Health Protection Surveillance Centre, 2024: https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/vaccination/covid-19vaccinationuptakereports/2024/Covax_slides_for_HPSC_web_based_report_20240220-v1.0.pdf

^{vi} Public Health Wales, February 2024: [https://www2.nphs.wales.nhs.uk/CommunitySurveillanceDocs.nsf/3dc04669c9e1eaa880257062003b246b/cf7a9a9adcddeb0a8025866b003a51a1/\\$FILE/Wales%20COVID-19%20vaccination%20surveillance%20weekly%20report.pdf](https://www2.nphs.wales.nhs.uk/CommunitySurveillanceDocs.nsf/3dc04669c9e1eaa880257062003b246b/cf7a9a9adcddeb0a8025866b003a51a1/$FILE/Wales%20COVID-19%20vaccination%20surveillance%20weekly%20report.pdf)

^{vii} Evans RA et al. Impact of COVID-19 on immunocompromised populations during the Omicron era: insights from the observational population-based INFORM study. *The Lancet Regional Health – Europe*. 2023 Oct. 0(0):100747. doi:10.1016/j.lanepe.2023.100747

^{viii} Liverpool and Bath Universities, 2023:

<https://www.liverpool.ac.uk/media/livacuk/humanitiesampsocialsciences/documents/Final,APPG,report.pdf>

^{ix} Liverpool and Bath Universities, 2023:

<https://www.liverpool.ac.uk/media/livacuk/humanitiesampsocialsciences/documents/Final,APPG,report.pdf>

^x [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10061940/;](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10061940/)

[https://www.thelancet.com/journals/lanmic/article/PIIS2666-5247\(23\)00336-1/fulltext](https://www.thelancet.com/journals/lanmic/article/PIIS2666-5247(23)00336-1/fulltext)