



saving the lives of people with blood cancer



5 key tests of the Government's plan for Living with COVID-19: the support required for people at high-risk

Overview

This briefing was produced by 18 charities that support communities that remain at higher risk from Covid-19 (Motor Neurone Disease Association, Scleroderma and Raynaud's UK, Action for Pulmonary Fibrosis, Anthony Nolan, The Arthritis and Musculoskeletal Alliance, Asthma UK & British Lung Foundation, Blood Cancer UK, Crohn's and Colitis UK, Kidney Care UK, Kidney Research UK, Lupus UK, Macmillan Cancer Support, Muscular Dystrophy UK, MS Society, National Rheumatoid Arthritis Society, Parkinson's UK, Rare Autoimmune Rheumatic Disease Alliance and Versus Arthritis).

On Monday 21st February, the Prime Minister is expected to outline a 'plan for living with COVID-19' in England. This briefing sets out 5 key tests the plan must pass in order to ensure people at highest risk from COVID-19 are well supported to live with COVID-19 now and into the future. These include:

1. Directly address the concerns of people at highest risk and commit to improve communication with them
2. Smooth, timely access to COVID-19 treatments
3. Lateral flow tests remain free
4. Improve employment protection and support
5. Set out a plan for the use of preventative COVID-19 treatments and prioritise further research into treatments and vaccines

Why this matters

Everybody wants to get back to normal, not least people at highest risk from COVID-19 who have been among those most acutely affected by the pandemic. However, for that to be possible, Government policy must prioritise supporting them to manage their risk. This is important because:

- **Many severely immunocompromised people do not get as much protection from available vaccines as the general population.** Initial data from the OCTAVE study, published in August 2021, found that a significant proportion of clinically at-risk patients with certain immunocompromised or immunosuppressed conditions, mount a low, or undetectable, immune response after two doses of the same COVID-19 vaccineⁱ; and
- **Many severely immunocompromised people are more likely to suffer severe illness if they catch COVID-19 compared to the general population** i.e. were considered clinically extremely vulnerable. There is considerable uncertainty regarding rates of severe illness, hospitalisation and mortality in this cohort following three vaccine doses and boosters. However, a study from OpenSAFELY published in December 16, 2021 concluded there are potentially several groups who are at higher risk of COVID-19 vaccine breakthrough infection after two doses, including those who are immunocompromised; among the study cohort, comorbidities with the highest rates of COVID-19 related hospital admissions included chronic kidney disease, dialysis and kidney transplant.ⁱⁱ

This means that despite the vaccine programme, COVID-19 continues to pose a serious threat to people that are immunocompromised.

Key tests:

1. Directly address the concerns of people at higher-risk and commit to improved communication with them

We need both a statement from the Secretary of State for Health and a press conference with the Prime Minister, and scientists, directly addressing the concerns of our communities as we enter this new phase with no 'restrictions'.

Too often those at highest-risk have received poor, confusing or no communication from the Government about changes that have huge impact on their lives. They need information about the clinical basis for decisions to end existing COVID-19 measures and what it means for their risk, communicated in terms people understand (such as providing comparison to other risks they take) if they are to have confidence in 'living with COVID-19'. And information about the services and support available to help them rebuild confidence (for example, from the voluntary sector). The public also need to know exactly what steps they can take to support them.

People who were formerly classed as clinically vulnerable or clinically extremely vulnerable should also be addressed, as well as the immunocompromised. We know many still have residual anxieties. None of us would want someone to be taking more precautions than are necessary, to the detriment of their wellbeing, simply because they have not received information and reassurance about their risk.

Finally, the Government must commit to directly communicating with people at high risk regarding future policy change on COVID-19 measures, vaccine programmes, and treatments.

Any guidance designed for them must be available in a full range of different languages and easy read versions, and not be solely reliant on internet access.

Targeting such guidance at the right people in a timely manner requires improvements in the upkeep and sharing of patient data across the NHS. There have been issues throughout the pandemic with poor or incomplete data, resulting in some people being incorrectly told to shield, while others were not but should have been, and it taking too long to identify and invite immunocompromised people for vaccination.

2. Smooth, timely access to COVID-19 treatments

Treatments that help people avoid serious illness and hospitalisation if they get COVID-19 are vital tools to protect people at highest risk. However many people have told us they have struggled with timely access to the drugs since they were introduced, resulting in too many missing out on treatments designed to help keep them out of hospital. The Government must continue to prioritise addressing any barriers to access, so that everyone eligible can access treatment quickly and easily. Specifically, ensuring the right cohort of patients are communicated with, and specialist secondary care teams, GPs, 111 and 119 are all equipped to provide timely information to patients and refer them for treatment. In addition, ensuring the eligibility list reflects the latest clinical evidence over time is very important.

3. Lateral flow tests remain free

Lateral flow tests are vital to making our communities feel safer and able to live more normally. Accessible testing means people at higher risk can establish whether or not someone they want to spend time with has COVID-19 and make decisions about risk accordingly.

Charging for tests would likely increase the risk of people who are severely immunocompromised catching COVID-19, and therefore force them to consider isolating themselves from contact with others, at the expense of their wider health and wellbeing.

4. Improve employment protection and support

People in our communities that are severely immunocompromised and in employment have told us about struggling with balancing risks to their health and their livelihoods.

People whose clinicians advise them not to go into their workplace because of their risks from COVID-19 should have the right to work from home. Where neither working from home or other reasonable adjustment to manage risk are possible, people must have access to adequate financial support while they are off work, for example by making a higher rate of statutory sick pay (ideally aligned to the European Average wage) available in such circumstances.

The Government should continue to provide up to date resources for employers to ensure their workplace is safe for employees, are aware of their legal requirement to provide reasonable adjustments, and of available sources of statutory support. The Government should also demonstrate how they will enforce safety standards without only relying on employees bringing complaints. Alongside this, a much more ambitious public awareness campaign is needed from the Government to ensure people at highest risk from COVID-19 are aware of their legal rights at work, how to raise concerns when an employer does not meet their legal duties and where they can get support to challenge them.

5. Set out a plan for the use of preventative COVID-19 treatments and prioritise further research into treatments and vaccines

The Government must set out evidence-based plans for the use of prophylactic (preventative) treatments for people that are severely immunocompromised, to reduce their risk of catching COVID-19 and give them increased confidence to live normal lives. Further research is also needed into the efficacy of both COVID-19 treatments and vaccines (fourth doses and boosters) in a variety of immunocompromised groups, so that people can have informed conversations with their clinicians about risk and managing it.

Experiences of people affected

Steve had a lung transplant in 2016

"I have been locked down since 4th March 2020. Since then my wife and I have not been inside any building except our house and the hospital/GP. We were very close to our grandchildren (all under 5) before the pandemic, but it's difficult to explain to little ones why you suddenly cannot play inside with them or cuddle them. It's better in summer, when we can play in the garden, but grim in winter with adverse impacts on mental health. Freedom Day last year was lock down day for us! We need prophylactic monoclonal antibodies and anti-virals to put us on a par with the rest of the population, as well as ready access to anti-virals if we do become infected."

Rachael is a kidney transplant recipient

"Like a lot of other kidney patients and others classed as clinically extremely vulnerable, I was shielding from early March 2020. During the first lockdown, I suffered frequent panic attacks and low mood. The fear and paranoia of catching Covid-19 and the potential outcome was overwhelming and made me literally want to hide! Having had a kidney transplant in 2018, and living a wonderful dialysis free life, I couldn't bear the thought of that all being taken away. As restrictions lessened throughout 2021, I continued to make my own risk assessments on a daily basis.

Unfortunately in December 2021, I got COVID-19. I didn't have a fever but I knew my breathing was heavy, the cough was worsening and the fatigue was extreme. My throat and glands were inflamed, and my tongue had strangely swollen too! The nights were the worst because I was too scared to go to sleep in case I didn't wake up.

I follow Kidney Care UK on social media and found it is one of the best ways to get relevant information. They had recently shared about new COVID-19 treatments so I phoned my GP to see if I could access them. Unfortunately they knew nothing about it, nor did my renal team. To say I was disappointed is an understatement so I resolved myself to what will be will be. I updated my end of life plans that I keep at home, and became very practical at what I needed to have in place.

Two days later I received a call from a consultant offering me treatment [later that day]. I thought my heart was going to stop at that moment. Yes I kept saying! This was a lifeline. Within three hours [of treatment] I was on my way home, so grateful that I had received the treatment, but also a sense of sadness that so many other kidney patients have lost their lives."

Sarah has MS. She lives in Norwich with her husband and their two young children.

"I am on a disease modifying treatment (DMT) Ocrelizumab to manage my MS symptoms, which include fatigue, sensory symptoms, and speech and concentration difficulties. Despite being fully-vaccinated, a recent antibody test has shown I haven't developed any COVID-19 antibodies. Due to the pandemic, I am on an extended career break from teaching.

I have a young family and should be returning to the career I love in teaching; instead, I now find myself cautious in hugging my own child as she returns from a school (where case rates

have exploded). We are still waiting for her access to vaccination as a household contact of mine (a programme announced some months ago). In the meantime, I had to quarantine away from my children and husband when she caught coronavirus at school in January.

For people in my position, the latest removal of restrictions means that life will become either more isolated or more dangerous. Basic mitigations to reduce transmission of the virus and suppress case rates had enabled me to tentatively begin participating in society again; now, I feel I am the most restricted and least free I have been in my adult life.

It seems that the safety and freedom of immunosuppressed and other vulnerable people has been sacrificed in the interest of those who already have lower risks. We are a significant and diverse group who were living full and meaningful lives; to an extent, mask wearing, social distancing and isolation periods were enabling us to continue at least some vital interaction with others. It makes me feel angry and ignored. There is no end in sight. The risks must seem low to those who don't have to take them."

ⁱ <https://www.nihr.ac.uk/news/octave-trial-initial-data-on-vaccine-responses-in-patients-with-impaired-immune-systems/28529>

ⁱⁱ <https://www.medrxiv.org/content/10.1101/2021.11.08.21265380v2.full.pdf>