The issue

There are at least 500,000 people in England who are immunocompromised or immunosuppressed. This means that, due to a specific health condition or because they receive certain treatments, they have a weakened (compromised) or impaired (suppressed) immune system. Emerging evidence, from a number of studies, indicates those who are immunocompromised or suppressed may not receive the same level of protection from the COVID-19 vaccines as the general population.

As patient organisations, we are increasingly concerned that many immunocompromised or immunosuppressed people have not been specifically informed of the risk and neither has the general public, the media or parliamentarians. We need immunocompromised and immunosuppressed people to fully understand their personal risk, and we need everyone else to understand how they can continue to protect those that remain vulnerable. Levels of risks will vary greatly amongst and between groups (for example those who have cancer and those using a medication) and so education and information is that much more important.

The available vaccines are safe for immunocompromised and immunosuppressed people, and we are still strongly encouraging our communities to be fully vaccinated if they can, as even those who may have a lower response to the vaccine are expected to benefit from having some level of protection from COVID-19, given the elevated risk the virus poses for immunocompromised people.

How do we know this?

In most cases, we are still waiting for data that shows the extent of this issue. The OCTAVE study is expected to report its findings imminently. However, we do have some early indications. For example, the SOAP vaccine study released data in March 2021 showing that an antibody response was only seen in 13% of people with blood cancer, compared to 97% of people without cancer. We also know that between 12th and 25th March 2021, people with blood cancer accounted for 1 in 20 of those admitted to intensive care with COVID-19. This compares to 1 in 68 admissions between September 2020 and February 2021. This suggests that for people with blood cancer, the vaccine does not provide the same level of protection as it does for other people.

The CLARITY study run by Royal Devon and Exeter NHS Foundation Trust and the University of Exeter Medical School found that 1 in 5 people with inflammatory bowel disease taking infliximab did not make a good level of antibodies after two vaccine doses or where they had one vaccine dose and had previously been infected with coronavirus. The study is due to publish imminently the next stage of findings which look at seroconversion and drop off in antibody levels over time following two doses of COVID-19 vaccine in people with inflammatory bowel disease (IBD) taking infliximab and vedolizumab.
We know that many people classed as clinically extremely vulnerable (CEV) have been continuing to take measures to protect themselves, beyond the end of official shielding. This is often at extreme cost to themselves, their families and mental health, but without this level of extreme caution statistics on the impact of COVID-19 in these groups could have looked far worse.

What next?
We are often hearing that the rising infection rate is not a particular concern because vulnerable people have now been vaccinated. The new Secretary of State for Health and Social Care has said that the UK will have to learn to live with COVID-19. But this ignores the fact that there are hundreds of thousands of people with compromised and suppressed immune systems who don't yet know how the vaccines have worked for them. While we share the urgency to lift restrictions, the needs of people with blood cancer, transplants, auto-immune conditions, and primary and secondary immunodeficiency must be considered as the country gets back to normal. We are calling for the following:

1. Improved Government/NHS communications
   We know from calls to charities’ support lines that, for those who understand their continues risk, many are feeling anxious at restrictions easing and feel they are being left behind. However, we are also concerned that many people who are immunocompromised or immunosuppressed do not realise that they may need to take precautions because their personal risk is or could be greater.

   It is vital that the government and NHS explain what their plans are for communicating with this group, and the wider public, and what timelines they will be working to in order to get this complex and urgent messaging out. We would also like the government to commit to specific and regular public briefings on this issue, and to include this item in Downing Street briefings as standard. The necessary resources should also be available to all immunocompromised and immunosuppressed groups to help improve understanding and support informed decision-making, such as this shared decision making tool developed jointly by professional bodies and the charity Versus Arthritis, with support from NHS England.

2. Future protection
   Given current uncertainties we believe that there needs to be greater thought to the different protections that this group may require in their everyday lives. As we consider the end of social distancing and return to work, we ask that the government set in guidance to employers that:
   - Covid-19 risk assessments are prioritised as a matter of urgency for employees at risk.
   - Employers consider adjustments e.g. flexible start times to avoid peak time travel on public transport.
   - Those most at risk to be allowed to continue working from home where possible.
   - The use of the Coronavirus Job Retention Scheme (open until 30 September) to furlough those who cannot work from home.

   We also ask the government to continue to provide community support for those at most risk in terms of medicines and food delivery.

3. Research into a third booster dose of the vaccine
   We’re pleased that the Government has announced its plans to provide a third booster dose to immunocompromised groups in autumn, pending further data from the research trial, COV-Boost, and advice from the JCVI. However, COV-Boost is only studying immunocompetent people. The Government must ensure it also funds research into the efficacy of the booster for immunocompromised and immunosuppressed people, given that they are the group who will be prioritised for the booster programme.
4. **Investment in other treatments**
   People who are very unlikely to make an effective antibody response (either because they have a primary immunodeficiency or because of their health condition or treatment), will not mount an effective response to the Covid-19 vaccines. If they are to enjoy any of the same freedoms as the rest of the population, they will need protection through therapies such as hyper-immune globulin or monoclonal antibody therapies. Whereas vaccines work by stimulating the immune response to produce antibodies, monoclonal treatments provide an infusion of artificial antibodies. Monoclonal antibodies which provide protection for COVID-19, are currently being tested through studies such as the PROVENT study, and the Government therefore needs to support this research and provide further funding if required, and to ensure that if shown to be effective, these treatments can be made as quickly as possible.

**Providing support to your constituents**
It is likely that you will have immunocompromised constituents who are affected by the issues we’ve highlighted here. If they contact you about their concerns, you may find the collection of our online support pages below useful. You can also help us raise awareness of this issue by sharing this information through your social media channels or raising the matter in Parliament. Equally, if you would be able to write to the new Secretary of State for Health and Social Care to ensure he is fully aware of this issue, and is committed to supporting the needs of immunocompromised people as COVID-19 restrictions lift, it would be greatly appreciated.

**COVID-19 information**
Crohn’s and Colitis UK – [https://crohnsandcolitis.org.uk/support/coronavirus](https://crohnsandcolitis.org.uk/support/coronavirus)
Immunodeficiency UK – [www.immunodeficiencyuk.org](http://www.immunodeficiencyuk.org)
Kidney Care UK – [www.kidneycareuk.org/coronavirus](https://www.kidneycareuk.org/coronavirus)