

Call to Action by the Immunocompromised Community in the Wake of the COVID-19 Pandemic

Background

Although the world has moved into the endemic phase of COVID-19, people living with compromised immunity remain at high risk of severe disease course and resultant health complications, long hospitalisation, and even death after catching the virus (1). This puts an enormous burden not only on the immunocompromised and their families but also the healthcare system and economy of their countries (2). It is therefore of utmost importance that new policies and practices around COVID-19 prioritise the needs and protection of the immunocompromised, at the same time benefiting the whole society.

Over fifty international representatives of immunocompromised communities gathered in Barcelona and virtually from 16th to 18th of June 2023 at the Immunocompromised Patient Advocacy Exchange to discuss the needs, experiences, and patient advocacy ideas in relation to COVID-19. While participants came from various primary disease areas, the common issues they all face as immunocompromised people in trying to return to life after the pandemic were strikingly apparent.

We – the immunocompromised people – are now announcing this Call to Action to state our unmet needs and challenges in the wake of the COVID-19 pandemic and to propose positive solutions to policymakers and other relevant stakeholders. These changes have the potential to bring substantial socioeconomic and health benefits not only for the immunocompromised but for the entire population globally.

Call to action

We call for a comprehensive model definition of who is considered immunocompromised.

During the COVID-19 pandemic, it became apparent that there is no comprehensive, inclusive, and well-researched definition of being immunocompromised. The underlying causes for a compromised immune system vary greatly and this heterogeneity must be captured within the definition. An evidence-based overarching model definition which can be adapted by each country, along with the assessment of the corresponding risks associated with COVID-19, would allow countries to ensure that any policies, treatment options, research, and recommendations targeting this group will reach the appropriate audience of interest in an inclusive manner.

We call for researchers to determine the number of immunocompromised people.

Relying on a comprehensive definition of the condition, the number of immunocompromised people must be determined in each country, and this community is prepared to lead on such research. It would build accurate statistical data and allow for reliable analysis of the socioeconomic and medical impact of being immunocompromised to both the immunocompromised people as well as the economy and healthcare systems of their countries. Being immunocompromised carries a burden not only to the people experiencing the condition but affects also how their families and close ones are able to participate in the society. The number of these affected individuals and the impact on their lives should also be assessed.

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We call on governments to invest in research to improve COVID-19 vaccines and medicines for the immunocompromised.

Current vaccines do not provide sufficient levels of protection for the immunocompromised leading to an unacceptable inequality of protection (3,4). Vaccines of improved effectiveness and wider treatment options for COVID-19 in the immunocompromised are urgently needed to avoid hospitalisations and prolonged treatment. These would facilitate our return to normal life and society reducing the financial toll on healthcare services and budgets and therefore benefitting the wider population.

We call for improved access to COVID-19 vaccines and medications for the immunocompromised.

Robust policy and recommendations, strengthening of pharmaceutical systems as well as enhanced education of healthcare providers are needed for timely and straightforward access to COVID-19 vaccines and medicines for immunocompromised people. As exemplified by the vaccine rollout during the pandemic, new assessment pathways must be put in place urgently so new drugs are available as soon as possible after development, not only for COVID-19 but also to combat avoidable delays in treatment of primary conditions. Effective access to these vaccines and treatments, which implies compliance with the recommendations of the health authorities by healthcare professionals, is a necessity that must be guaranteed for the immunocompromised. Considering the rising COVID-19 infections and the evolution of circulating variants, we need such vaccines and drugs now.

We call on policymakers to define clear strategies to protect the immunocompromised.

There must be clear, inclusive, timely, and evidence-based recommendations for the immunocompromised both in relation to COVID-19 and any future public health emergencies (5). Policymakers must be aware of the immunocompromised community's needs and of their responsibility towards these communities – we need determined and considerate actions, generation and acceptance of relevant scientific evidence and implementation of solutions. Protecting the most vulnerable must remain the ethical foundation of our society.

We call for recognition of the importance of non-pharmaceutical interventions in preventing COVID-19 infections.

Combined non-pharmaceutical interventions (NPIs) including masks, distancing and air purification systems were proven to be important in avoiding COVID-19 infections (6,7). We call for policymakers to recognise the importance of these measures, particularly in healthcare settings such as hospitals and pharmacies where masks should be mandated. We also call for awareness and acceptance of the general public regarding the need for masking to protect the immunocompromised community. Mask mandates must be recognised as a collective solidarity effort to protect the most vulnerable populations.

We call on governments to keep publicly reporting true levels of COVID-19 infections, hospitalisations, and deaths in their countries.

Only accurately and timely reported national data can allow for appropriate public health recommendations and efficient measures against worsening of COVID-19 globally, providing protection to immunocompromised people and the society in general. These data should be accompanied by an assessment of risk for immunocompromised people.

We call on patient communities, healthcare providers and health authorities to engage more in patient education and health literacy.

It is essential that healthcare providers, health authorities, and patient groups furnish the immunocompromised and their families with reliable information to enable them to assess their individual risk levels and ensure they know the pathways to access necessary treatments and care.

We call for recognition of the psychosocial needs of the immunocompromised community.

We need inclusivity, awareness and understanding of immunocompromised people's needs in the workplace and to provide them with equal societal opportunities without stigma but with empathy and equity. We also need improved awareness about the psychosocial care needs of immunocompromised people and to ensure that health and social care systems provide appropriate support to the affected people and their families, e.g., access to free counselling.

We call for stronger coalitions across the immunocompromised communities.

Coalitions, joint projects, and coordination actions are needed across the communities of the immunocompromised living with different diseases and conditions, as only these can ensure that the unmet medical and psychosocial needs are stated and tackled effectively. Strong leadership and defined goals should emerge to strengthen advocacy efforts as a community.

Why do we ALL need these actions? – Solutions that offer a benefit to everyone

Let us journey back to 2020 and think about how lives of the general population were impacted by the COVID-19 pandemic, with fears of infection, losing loved ones, losing jobs, being unable to support families, not having access to appropriate healthcare and avoiding hospital appointments to lower the risk of catching COVID. This grim reality continues to hold true for millions of immunocompromised people and their families worldwide as they face a 4th winter under these restrictions.

Whilst the general population has begun to grow tired of hearing about COVID-19, we – the global immunocompromised community – remain at high risk of long hospitalisation and unfavourable outcomes from catching COVID-19 and the threat to global public health is still considered to be high (8). This prevents us from leading normal lives; participating in society and going to work. Access to basic healthcare for primary conditions as safety measures against catching COVID-19 in healthcare settings have been lifted is now a high-risk activity. These obstructions do not end with us but extend to the lifestyles of our families and loved ones carrying a substantial burden to theirs and our mental health (9,10). These inequalities fuel our collective inability to participate in and contribute to society, putting an enormous burden on the economy of countries globally while our long hospital stays after catching the virus halt the efficiency of healthcare systems (11). Moreover, due to the inability to efficiently fight off COVID-19 infections, lack of appropriate protection and treatment of the immunocompromised increases the risk of viral mutations and new variants which can be dangerous to the whole population and result in further lockdowns (12).

Considering all above, it evidently serves the best interest of the entire population to bring the needs of immunocompromised people to the forefront of healthcare recommendations, policies, and research priorities as a matter of urgency. The adoption of these actions serves to benefit governments, health services, the economy, and the wider population. They will help to reduce the strain on valuable health resources and budgets, to facilitate healthcare access for others, to reduce the risk of virus mutations and enable a significant part of the population to return to the economy in terms of employment and spending. It is now time for governing bodies, policymakers, researchers, the pharmaceutical community, healthcare professionals, patient communities, and the general public to do their part in ensuring that the immunocompromised people and their families are given a chance to lead, what to others is a normal life, and eliminate this inequality while benefiting the whole society.

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