

Statement of Consensus on **Support for Autoimmune Patients in the United Kingdom**

For autoimmune patients across all four nations of the United Kingdom, navigating life during the COVID-19 pandemic was challenging. From the outset, immunocompromised patients knew that they would be vulnerable in the face of a disease that was barely understood. As guidelines and recommendations about vaccination emerged, the information was often conflicting and confusing. Autoimmune patients were left to wonder how they might be impacted and what they should do.

As the UK emerges from the worst of the pandemic, the autoimmune patient community now faces questions about how to navigate a potential future pandemic. Reviewing lessons learned during the COVID-19 pandemic can help patients, health & care providers and policymakers better address ongoing struggles and prepare for future challenges.

Several key principles and strategies should guide future care for autoimmune patients in the United Kingdom.



Policymakers and healthcare professionals should proactively identify who is at risk and offer tailored support, information and advice. While the specific nature of any next pandemic cannot be anticipated, understanding who is vulnerable is the first step towards providing protection, support and optimal care when the time comes. To be able to do this in an efficient way requires the development now of effective data capture and sharing systems between primary and secondary care.



Communication among providers, patients, patient groups and policymakers must be proactive rather than reactive. Relevant and accurate information, such as vaccination guidelines, must be communicated in a timely, accessible manner. Content should make clear to vulnerable groups which specific issues they should consider.



Autoimmune patients need clear, specific guidelines that acknowledge the differences among diseases and care pathways. Different autoimmune diseases, and some of their related treatments, impose different levels of vulnerability. Patients need guidance that is tailored specifically to their condition and care pathway. Policymakers will need to invest resources into evaluating risk levels, creating customised vaccine guidelines and conveying clear information quickly.



The healthcare system, policymakers and the government must ensure ongoing access to care for autoimmune patients. Autoimmune patients will need support as they continue managing their condition in the midst of the additional challenges posed by a future pandemic. With continued monitoring of, and access to, access to new treatments, physicians can ensure patients stay informed and better protected.



Patient organisations should be seen as trusted partners, alongside government and the NHS in supporting people who are immunocompromised. By working together in a collaborative and coordinated manner, we can ensure that this vulnerable population receives the best possible care and support.

Future pandemics may threaten the well-being of everyone, but autoimmune patients will face heightened challenges. Information must be clear and easy for patients to access.

We, the undersigned, commit to helping autoimmune patients prepare for future public health emergencies. As patients manage their conditions and well-being, we can play a meaningful role in developing and distributing tailored, actionable information that speaks specifically to the needs of the autoimmune community. With appropriate recognition and support from policymakers and clinicians, we can work together to proactively engage and support vulnerable autoimmune patients across the United Kingdom.

Signatories

European Alliance for
Patient Access

AiArthritis

Arthritis and
Musculoskeletal Alliance

British Society of
Rheumatology

British Thyroid Foundation

European Multiple
Sclerosis Platform

Lupus Europe's Patient
Advisory Network

Lupus UK

MS Registry

MS Society

MS Trust

National Rheumatoid
Arthritis Society

Patient Information Forum

Versus Arthritis



GAfPA.org

