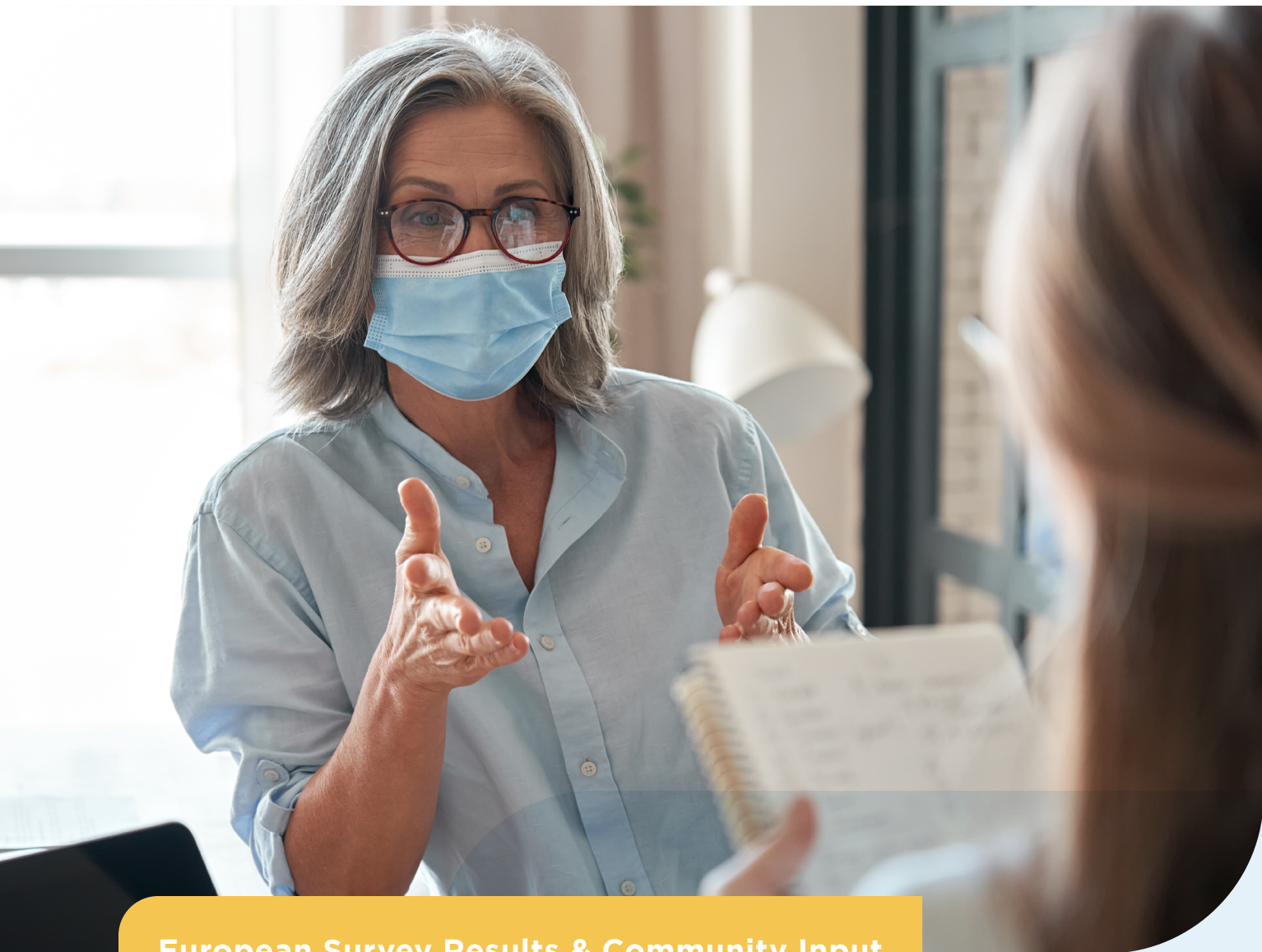


AUTOIMMUNE DISEASE & COVID-19 INFORMATION



European Survey Results & Community Input

MARCH 2022



Introduction

Two years into the COVID-19 pandemic, autoimmune patients are still unsure how to best protect themselves.

From rheumatoid arthritis to multiple sclerosis, lupus to pemphigus, autoimmune diseases occur when a person's autoantibodies mistakenly attack their body's own tissues. Some medications for autoimmune diseases suppress the immune system, increasing patients' COVID-19 risk. These people may be more likely to develop serious illness if they contract COVID-19, more likely to spread it to household contacts and more likely to die from COVID-related complications.

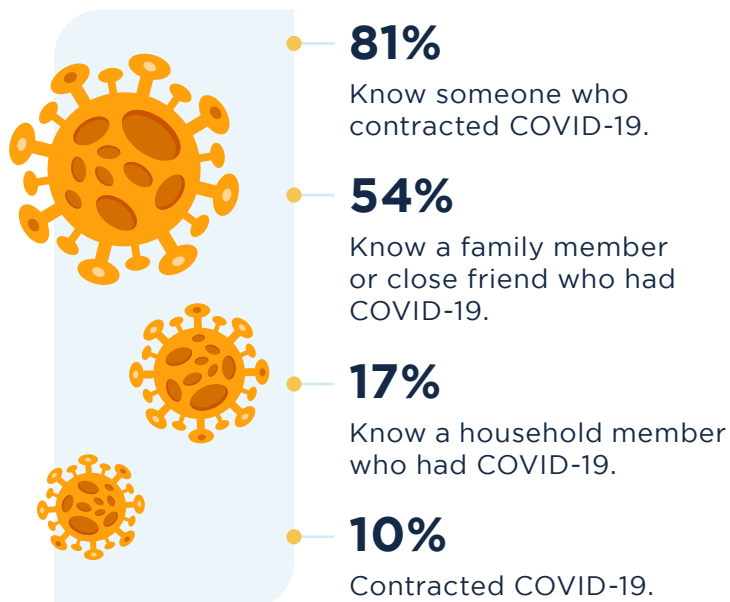
As the world begins to settle into a new normal, autoimmune patients must adjust. Many patients, however, are confused or uninformed when it comes to important guidance specifically for immunocompromised populations about risk and vaccination.

Through international survey data and insights from key patient advocacy organisations, this report explores the struggles faced by autoimmune patients in Western Europe and identifies how policymakers can help.

Living with an Autoimmune Disease during COVID-19

The Pandemic Has Affected Most Autoimmune Patients

As the COVID-19 pandemic and resurgences of the Delta and Omicron variants swept across Europe, patients with autoimmune diseases felt the virus' impact in their daily lives.

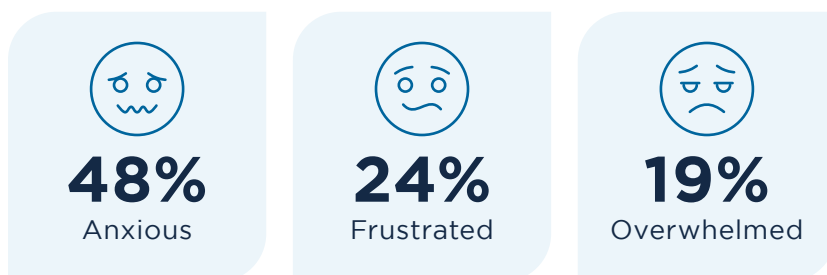


“
Patients are tired of the pandemic.”

– Souzi Makri,
EULAR PARE

The Pandemic Has Taken an Emotional Toll

Managing an autoimmune condition while also attempting to navigate the threat of COVID-19 was emotionally draining for many patients. A majority of participants reported an emotional toll:



Understanding Risks & Taking Precautions

Autoimmune Patients Lack Awareness

Many autoimmune patients are still unaware of specific details about the risks they face. When presented with information from the European Centre for Disease Prevention and Control and other health organisations, only about a third of patients conveyed high awareness about basic risks.

37%

Very Aware



“People taking medications that weaken their immune system may not be fully protected from COVID-19.”

32%

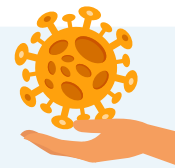
Very Aware



“People with compromised immune systems may need additional COVID-19 vaccine doses.”

28%




Very Aware



“Immunocompromised people who contract COVID-19 are more likely to transmit the virus to household contacts.”

Autoimmune Patients Continue Precautionary Measures

Patients do recognize the need to take precautions. The majority continue to take protective measures even after receiving a vaccination.

Precaution	Pre-Vaccine	Post-Vaccine
 Wearing A Mask	77%	76%
 Social Distancing	74%	76%
 Avoiding Social Gatherings	70%	63%

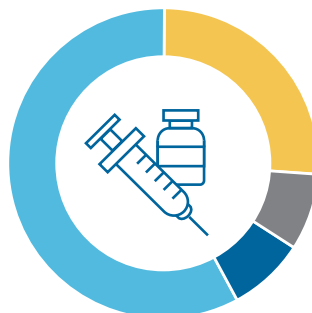


Navigating Vaccine Decisions

Most Surveyed Autoimmune Patients are Fully Vaccinated

Patients who reported being unvaccinated or partially vaccinated said their hesitation stemmed from:

- Concerns about side effects or safety
- Concerns about triggering a flare-up
- Concerns about potentially having to suspend autoimmune disease treatment



- 58%** Fully Vaccinated & Boosted
- 26%** Fully Vaccinated
- 8%** Partially Vaccinated
- 8%** Unvaccinated

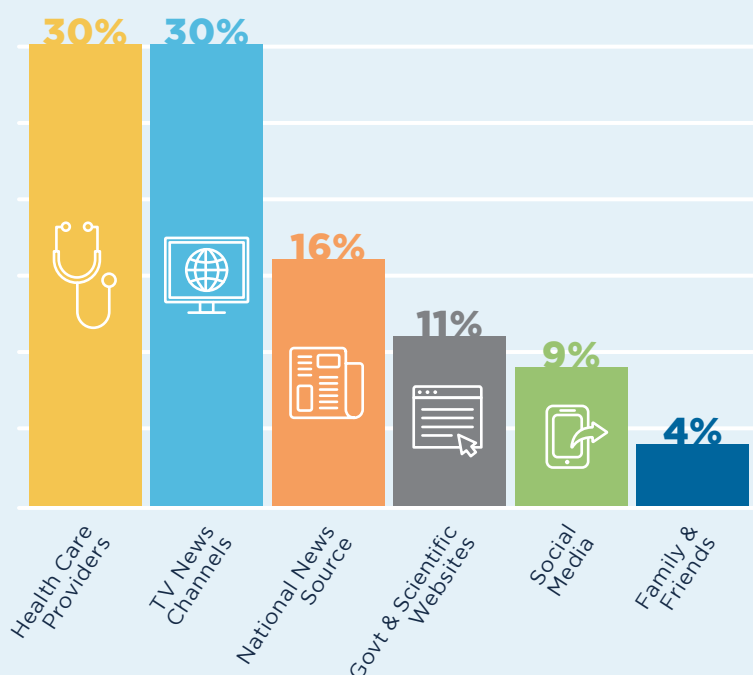


At some point, the amount of new information about COVID-19 was really just overwhelming.”

- Lucja Wanicka,
Lupus Europe

Patients' Information Sources

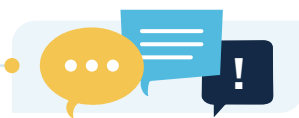
Autoimmune patients have different sources of information when it comes to health care concerns, though health care providers and TV news are the most common.



Mixed Messages Make Vaccine Decisions Difficult

Most patients expressed that evolving messaging about COVID-19 and vaccination made it harder to make vaccine-related decisions.

85%

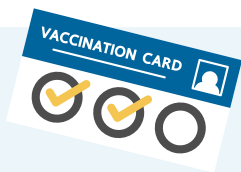


Mixed or unclear messages from the media and government complicate decisions about vaccination.

Battling Uncertainty

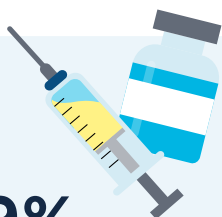
On Vaccination Details, Confusion Persists

From brands to booster shots to third doses, navigating COVID-19 vaccination decisions is a complicated process. On top of all that information, autoimmune patients must also consider their condition and medication. Many struggle with identifying the best path forward.



41%

Are uncertain about whether they need a third vaccine dose or when to get it.



59%

Are uncertain about the difference between a third vaccine dose and a booster shot.



48%

Don't understand if a third vaccine dose needs to be the same vaccine brand.



58%

Don't understand if a booster is needed some time after a third dose.



Patients Want Personalized Care

To better protect themselves from COVID-19, autoimmune patients want to know their options and how each pertains to their personal circumstances.



55%

Say COVID-19 vaccines are more effective with some autoimmune disease medications than with others.



82%

Want to explore which medications for their specific condition are most compatible with the vaccine.

How Policymakers Can Help



As a community, we have to have a very clear ask of what people need to make sure they don't get ignored."

- Anthony Woolf, Rheumatologist, Arthritis and Musculoskeletal Alliance

Patients Want Clear Information

Providing support and information for autoimmune patients requires a clear understanding of what they need: **clear, consistent information tailored to individual conditions and medications**, preferably housed in a central location.



82% Agree

"People who live with autoimmune diseases need greater awareness of the importance to get a third dose."

85% Agree

"People living with an autoimmune disease need easy-to-understand, factual information to guide their decisions about vaccination."

85% Agree

"Government policies on vaccination should reflect the unique needs of people living with autoimmune diseases."

What Patients & Health Care Providers Can Do

The survey collected free responses that highlighted patients' **experiences, frustrations and suggestions**.

When asked what policymakers can do to protect autoimmune patients, participants shared recommendations for the government, as well as guidance for patients and providers.

"Pass on clear guidelines for treatment."

"Personalized information from a family doctor."

"Talk to a doctor you trust."

"Ensure that health providers keep patients updated, and be clear and concise at all times."

"Link in with specific consultants for those conditions, so those consultants can pass on the correct advice directly."

Needs Assessment

To best manage their condition and make decisions about vaccinations during the pandemic, autoimmune patients need information that meets certain criteria.



Clear, correct and concise information about vaccines.

When it comes to information on vaccines and diseases, autoimmune patients communicated frustration and confusion about what information is accurate and relevant. They want guidance that is clear, correct and to-the-point.



Information that is accessible in a central location.

With so many sources of information, autoimmune patients demonstrated a desire for information that is not just clear, correct and concise, but also easy to access.



Vaccine information customized to specific autoimmune conditions and treatments.

Each autoimmune condition is different and requires different treatments. To make informed decisions, patients need information on how their disease and its medications will respond to vaccines and COVID-19.

Autoimmune patients also expressed a desire to rely on health care providers as a main source of information. Many want collaboration between policymakers and health care providers to improve the distribution of information.



We want people to be getting the right information. All of it needs to be conveyed in clear language."

- Neil Betteridge,
*European Alliance
for Patient Access*



Survey Demographics

In total, 400 people living with autoimmune diseases participated in the online survey between January 12 and January 24, 2022.

Gender



59%
Female



41%
Male

Country



33%
Germany



13%
Italy



25%
Spain



12%
United Kingdom



17%
France

Age Range

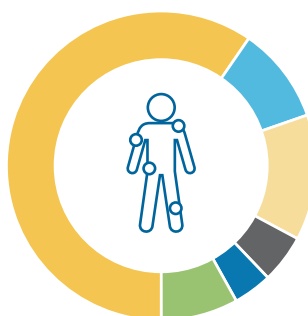
16%
18-29

23%
30-44

31%
45-64

29%
65+

Autoimmune Diseases



59% Rheumatoid arthritis
10% Lupus
13% Multiple sclerosis
5% Systemic sclerosis
4% Pemphigus
8% Graves' disease

Meeting Participants

On February 23, 2022, organisations that represent people living with autoimmune diseases met to consider the international survey data and the challenges facing patients during the COVID-19 pandemic.

**Arthritis and
Musculoskeletal Alliance
(ARMA)**

EMD Serono

EULAR PARE

**Global Alliance for
Patient Access**

**Italian National
Association of People
with Rheumatic and Rare
Diseases (APMARR)**

Lupus Europe

Merck

**Polish Rheuma
Federation**

ReumaNet

**Swedish Rheumatism
Association**



About the European Alliance for Patient Access

The European Alliance for Patient Access is a division of the Global Alliance for Patient Access, an international platform for health care providers and patient advocates to inform policy dialogue about patient-centered care.

GAfPA.org

