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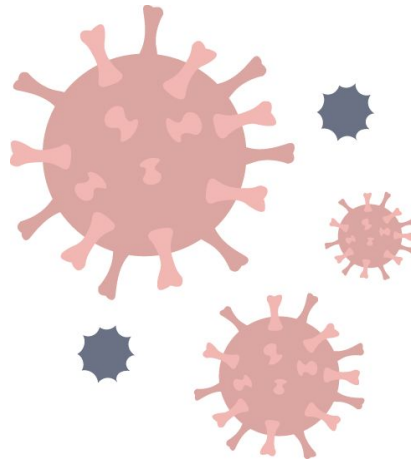
TrialHub

The Patient Communities' Perspectives and Activities during the Covid-19 Pandemic



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Executive summary

The world has been facing trying times, with a pandemic that has threatened the whole society.

Certainly, one of the most impacted sectors during the Covid-19 pandemic has been *healthcare*. Doctors and nurses around the world have been tirelessly struggling to handle virus-affected cases on the front lines of the emergency rooms, hospital visits are limited due to social-distancing measures, many clinical trials are paused or moved outside of the clinics. [Millions of people](#) have been affected and a couple of hundred thousand have died from coronavirus and other complications.

With services responding to high demand for care of patients with COVID-19 there has been increasing concern about the wider health impact of the pandemic. Disruption of “regular” services is affecting many, particularly those with chronic and oncological conditions, patients waiting for planned surgical operations including organ transplantation, and others in need of prompt assessment, investigation, and treatment. Shortage of medicines including steroid inhalers, hydroxychloroquine, vitamin supplements and others are reported across the globe.

For situations of this unprecedented scale, there is an ever-increasing need to understand and join efforts among different health stakeholders to combat this challenge.

Nowhere is this more relevant than in the work of **patient organisations**. They are on the front line of the fight against COVID-19, providing advice and support to the patient communities they serve. In the midst of this global crisis situation, they represent and care for those most vulnerable to the impact of COVID-19, i.e the patients.

In this overview, we explore the perspectives and activities of *various international, pan-European and national patient advocacy groups* and highlight the impact of the coronavirus pandemic on the patient communities they act for.

Patient Organisations and the World's Fight against COVID-19

Patient Perspectives

Apart from the elderly, many who live with chronic and oncological health conditions, have been at higher risk from Covid-19. They are also vulnerable to any failings in the maintenance of “standard” healthcare provision. This is why many patient advocates have taken to social media and other channels to support each other and share their worries, experience, and information in order to help others.

A feature in the Financial Times entitled [“Empty beds prompt fears for non-COVID cases”](#) stated that “A&E attendance fell almost 30% compared with the same time last year”, meaning that people in need of urgent assessment have been delaying seeking help due to the fear and risk of infection.

In such a crisis non-urgent care, including **surgery** has been cancelled, and hashtags such as *#StopElectiveSurgery* became trending on social media not taking into account that definitions of urgency vary and postponing surgery may result in months of pain and disability for many.



"As someone suffering severe neurological symptoms due to my postponed "elective" surgery, I beg all MDs and media to do a better job of talking about this. Please. #StopElectiveSurgery but highlight the profound suffering of those of us who must wait. We do it gladly."

Myalgic Encephalomyelitis patient (USA)

"I've waited 9+ months in agony and was just weeks from seeing a neurosurgeon. There's no knowing when that will happen now. I can only wait and hope that this doesn't result in irreversible worsening of my health. This is profound sacrifice but it's essential."

Dysautonomia patient (USA)

Medicine shortages have been another concern for patients. Those with **rheumatological conditions** who are on hydroxychloroquine have been particularly worried, given the interest in this product as a possible treatment for Covid-19 and the resulting stockpiling of supplies. In countries such as Bulgaria, this therapy was not available even before the pandemic so patients had to order it from other countries like Italy and Greece.

During the pandemic, due to the closure of borders, **Lupus** patients and other rheumatology patients have been left with no alternative. For some of them, no therapy uptake can be life-threatening and this causes further stress, emotional and physical consequences. The European Lupus Patients' Organisation and other organisations have been working with national regulators and industry to address this concern.

"One of the discussed medicines for the treatment of COVID-19 is chloroquine and my basic treatment is based on chloroquine. I use hydroxychloroquine in my daily life to treat myself and stabilize the activity of my disease. Without it, much more alarming symptoms might touch vital organs. People who are not sick and or contaminated have gone to drugstores to buy those medicines without any prescription to self-treat themselves without medical advice and stock for emergency measures. I know several lupus patients and others with chronic conditions cannot find Plaquenil in any pharmacy in France. We must stay confined to be safe, but we also must venture outside to ensure we have enough medicine to follow our treatment and stay healthy. As a result of this constant fear, I am plagued by stress, anxiety, insomnia and fatigue, and I hope these will not lead to more aggressive symptoms. This is how the COVID-19 pandemic is affecting my daily life and I hope that other chronic condition patients are not facing a similar scenario."

Cassandra Alexis, Lupus Patient (France)

There has been widespread concern and fear among people who live with **rheumatoid arthritis** about what Covid-19 will bring. Inflammatory arthritis conditions are heterogenous diseases that are as unique as the individuals who live with them. They are unpredictable and leave a person feeling little control over their health and lives. Covid-19 has only added to that unpredictability and fear. Patients' questions have been related to the level of risk of being infected, the safe ways to get tested, what happens to their medication supply (many of these patients take hydroxychloroquine as well), what additional medical issues they might experience after having Covid-19 and many others. Moreover, the activity of a person's inflammatory arthritis can be significantly affected by stress and the fear of Covid-19 and its potential consequences to a person's life. And this is not only related to medical questions, but also those about having a job, ability to pay bills, etc. Given the diverse range of concerns, people have been wondering

who they even talk to about these fears, and we've seen the arthritis community coming together to help.

"I have never lived through such a global health crisis, and I lived in Toronto through SARS. SARS did not feel like this—I did not feel threatened. I didn't self-isolate, and I did not see the scales of economy that I am currently witnessing."

Rheumatoid Arthritis patient (Canada)



People living with **mental illness** are very vulnerable to disruption of care. For some, stopping or postponing medication can be life-threatening. People with mental illness are also sometimes among the most marginalised in society. Just being able to speak to someone, and not feeling left to cope alone, can be vital.

“Facing my anxiety directly now – at a time when many people are having these anxious thoughts for the first time, is almost, dementedly, comforting. When you have an anxiety disorder and a tragedy occurs, people rise to meet you in that place you usually reside. And so waking up to scary news or uncertainty is, yes, weird and unsettling, but it isn’t far from where I usually dwell. The pandemic almost helps justify my emotions – giving my anxiety something tangible to focus on, and the fact that others are feeling it too makes me feel less lonely in it.”

Mental illness patient (USA)



Patients on disease-modifying therapies have been worrying that their treatment may increase the risk of developing complications from Covid-19, but are aware that stopping or pausing treatment may trigger disease activity.

The **Multiple sclerosis** community has been debating whether certain treatments should be paused during the crisis. Meanwhile, some MS patients have “self-organised” using platforms such as [Shift MS](#) to collate data from government sources and trusted neurologists. Umbrella patient groups, meanwhile, have been speaking up about the need for an equitable, rights-based approach to care and to integrate the views of experienced patient advocates into the response to Covid-19.

"I am used to using the words 'social distancing' when someone has a normal cough or cold. I am used to meeting up with a friend and not knowing whether I will be able to see them again tomorrow. I am used to self-isolating at home while my friends go to concerts. I am used to missing out on things that I love doing. For a person with a chronic autoimmune condition, this is the norm...During these unfortunate times, you have experienced what we experienced on a daily basis...For you it may mean a day or two off work and you can then go about your normal day. For me it means having to come off my biologic treatment for my illness for up to two weeks, which means my illness may flare up while also experiencing the simple flu that you had in a more severe way."

Autoimmune condition patient (Ireland)

Cancer patients have been at particular risk of treatment delay, deprioritization and discontinuation. Those recently diagnosed with cancer, or in the midst of cancer treatment, have been facing disruption for all but the most urgent procedures because of concerns about their susceptibility to the serious risks of coronavirus, and the deficit of personnel, beds, and equipment dedicated to Covid-19 cases. Delayed cancer diagnosis during the last months due to lack of screening programmes and patients not meeting their doctors when having symptoms, has caused a risk of many thousands of cases going undetected and untreated for the years to come. The fear and stress these patients have been feeling in the last month has been all on top of their struggle to cope with fear of the disease.

"COVID-19 is ravaging through our societies. We already see how it affects cancer patients. In the last weeks, we have seen in our Melanoma community that our follow-up appointments and control scans are postponed while patients have been switched to treatments that are less effective but have fewer side effects, can be taken orally instead of IV or are completely taken off treatment. Clinical trials are closed, leaving patients whom all other therapies have failed out of options while Stage 4 cancer patients are not being given permission to self-isolate at home 'because they had no COVID-19 symptoms.' Some patients on forums do not recognise the need to self-isolate and feel that 'cancer was already enough to worry about' and we all possess a high level of anxiety and uncertainty especially when facing rampant levels of incorrect or unhelpful information. We have no reason to believe that this would be different for other cancer communities."

Melanoma Patient Advocate (Sweden)



The novel coronavirus, and the disease that it causes, Covid-19, have triggered significant challenges for millions of people living with **rare diseases**. These patients and their caregivers and family members are seeing their lives disrupted in numerous other ways. According to a [survey conducted by NORD](#), the community is overwhelmingly concerned and impacted by COVID-19; 98% are worried and of those, 67% are very or extremely worried. In addition, 95% have been impacted to some degree at a cost to their immediate and long-term health and well-being. Sources of concern and worry were varied, though a number of people raised concerns about safely accessing health care if or when needed, feeling unsure about the timing of seeking care (not seeking care too early or waiting too long, for example), medications being out of stock or backordered, and worry about risk of exposure while immunocompromised. Technology is being leveraged to provide services while social distancing measures postpone “elective” procedures and appointments, yet only 65% of respondents who saw appointments canceled were offered an alternative via telephone or video.

“Concerned about who will care for our son if we both become ill. Concerned about my son having the virus and requiring hospital care.”

A mother of a rare disease child

“Very concerned about clinical trials in our rare disease...Newest trial just rolled out and now no one can enroll.”

A rare disease patient advocate

"Since blood donations are down, I am concerned that I may have trouble getting my immunoglobulin therapy."

Immunodeficiency patient

Activities

Patient organisations around the world have responded to the coronavirus crisis by providing their communities with guidance and advice on how to get through this. Some have also been working with health professionals to produce information on risks, treatment uncertainties, and trade-offs.

We have compiled a list of popular patient advocacy groups worldwide that have addressed coronavirus-related questions and have launched useful initiatives for their communities in the times of pandemic.



International organisations

- [**International Alliance of Patient Organisations \(IAPO\)**](#) has created a COVID-19 Resources hub on their website to keep patients informed and empowered whilst facing the pandemic. Through a series of articles, their members share their experiences and raise awareness on how the COVID-19 pandemic is affecting their work and the lives of the patients they represent. From a multiple myeloma peer support network between organizations located in neighbouring countries to a legal action that restarted fertility treatments for more than 5000 patients, you will learn about the incredible work their members are doing worldwide. In addition to these stories, they have also created a web page with a summary of initiatives from their members to help fight the pandemic and support patients.

Source:

[Covid-19 Resources Hub](#)

[COVID-19 response activities by IAPO members and partners](#)

[IAPO Members stories on COVID-19](#)

- [**The MS International Federation \(MSIF\)**](#) has shared advice developed by MS neurologists and research experts from MSIF's member organisations. This advice has been reviewed and updated as more information about COVID-19 becomes available. Also, the organisation urges people with MS and healthcare professionals to take part in the COVID-19 and MS global data sharing initiative to help find answers faster.

Source:

[The coronavirus and MS – global advice](#)

[COVID-19 & MS: Global Data Sharing Initiative](#)

- [The International Alliance of Dermatology Patient Organizations \(IADPO\)](#) has compiled a list of resources related to the pandemic from sources including the World Health Organization, dermatological associations, and patient organizations. Information is organized by general dermatological and health information as well as by disease area. A special Organizational Capacity section also lists resources for the new working from home environment as well as self care tips during this unprecedented time. This list is being updated on an ongoing basis.

Source:

[COVID-19: Resources for Dermatology Patient Organizations](#)

- [The International Brain Tumour Alliance \(IBTA\)](#) has assembled a list of COVID-19 links to information for our global community of patients, caregivers, healthcare and allied healthcare professionals and others.

Source:

[COVID-19 INFORMATION FOR THE INTERNATIONAL BRAIN TUMOUR COMMUNITY](#)

- [The CML Advocates Network](#) has launched a CML-specific COVID-19 resource page collecting all relevant information for chronic myeloid leukemia patients in the context of the coronavirus pandemic. The patient-friendly FAQs from iCMLF are available in 7 languages.

Source:

[Chronic Myeloid Leukemia \(CML\) and COVID-19](#)

European organisations

- [The European Patients' Forum \(EPF\)](#) has established a *COVID19 Resource Point* on their website with the most important information and resources people with chronic conditions should have. Also, they have been collecting responses and testimonies from patients with chronic conditions to learn how they are affected by the COVID-19 outbreak. From their unique position at the centre of the European Patient Community, they have gathered invaluable insights from their member organisations covering various conditions, such as melanoma, Multiple sclerosis, Lupus, Spina Bifida, kidney and liver transplant patients, and others.

Given the profound concerns of EPF member organisations regarding the impact of COVID-19 on their communities, EPF shared an Open Memo to health industry representatives outlining the main challenges for patients with chronic diseases and our expectations regarding their on-going commitment and contribution in these unprecedented times.

Source:

[*COVID19 Resource Point*](#)

[*Patient Perspectives*](#)

[*EPF statements on Covid-19*](#)

[*An Open Memo to the Health Industry*](#)

- [The European Aids Treatment Group](#) conducted a rapid assessment aiming to document in a structured manner the perceptions of people living with and affected by HIV and that of organisations providing services to affected communities about the way

in which COVID-19 impacts their health, well-being and access to HIV related prevention, treatment and care. Even though the survey has some limitations (e.g only available online and only in English, limited time the survey was open), the results provide a snapshot of information, concerns and solutions shared by respondents in several countries.

Source:

[EATG Rapid Assessment - Covid-19 ciris](#)

- [The European Cancer Patient Coalition \(ECPC\)](#) has launched a resource hub on their website including guidelines and communication for its members and the larger cancer community with the most current information to ensure the cancer patients are safe and protected during the pandemic.

Source:

[Covid-19 information](#)

[ECPC's communication about cancer and COVID-19](#)

- [Digestive Cancers Europe \(DiCE\)](#) have focused their efforts on collecting information on how their member organisations across Europe are continuing their support of cancer patients throughout the COVID-19 pandemic, i.e COVID-19 Series.

Source:

COVID-19 Series: How our Members are Helping Patients through the Novel Coronavirus (COVID-19) Pandemic

[Part 1](#)

[Part 2](#)

- **EURORDIS** has created a COVID-19 Information Resource Centre for the rare disease communities that includes statements, sources of official information, and activities organised in response to the pandemic that they have received through their network. In addition, the organisation has launched a survey in 23 languages aiming to assess how the COVID-19 pandemic is affecting patients and their families.

Source:

[COVID-19 Information Resource Centre](#)

[EURORDIS Rare Barometer survey on COVID-19](#)

[EURORDIS Rare Barometer survey on COVID-19 - preliminary results](#)

- **The European Lung Foundation** has compiled up-to-date and lung-specific information about COVID-19 for their members, including guidelines, Q&As, Covid Newsroom, the latest research on Covid-19, patient stories. The information materials are available on their website in 11 languages.

Source:

[Covid-19 expert information](#)

- **The European Heart Network** is an organisation helping those that are considered more vulnerable to becoming severely ill with the virus. This includes especially people with cardiovascular disease, such as hypertension, and persons who have had, or are at risk of having, a heart attack or stroke.

On their page they aim to provide links to reliable sources of information. They also follow the activities of their national members across Europe.

Source:

[Covid-19 hub](#)

- [Gamian Europe](#) has created a Covid-19 platform on their website in order to provide the mental health communities in Europe with useful and up-to-date information during the pandemic. The platform consists of international and national resources and guidelines, COVID-19 helplines and services per country, resources and input from their national members and useful articles.

Source:

[Covid-19 platform](#)



American organisations

- [The National Organization for Rare Disorders \(NORD\)](#) has created a resource center for people living with rare diseases. NORD's **Rare Action Network (RAN)** is organizing a Virtual COVID-19 Discussion Group in each state. The NORD RAN is hosting these

meetings to enable the rare disease community to come together during this difficult and unprecedented time. These groups allow patients and their families to exchange stories and experiences with respect to the impact of the COVID-19 pandemic on the lives of those living with and supporting those with rare diseases. Discussion topics include how this pandemic has affected patients' rare disease treatment, medication access, and access to telemedicine. The goal is to address any topics of concern to people living with rare diseases.

Also, NORD launched a **COVID-19 Community Survey** and shared the results revealing the far-reaching impact the pandemic is having on rare patients and families. **The findings reflect a community directly affected and overwhelmingly concerned about the COVID-19 crisis.** 772 participants responded to the survey conducted by NORD's research team from April 1 through April 8, 2020. Respondents represent 49 of 50 states and Washington, DC, and multiple disease categories, including genetic conditions, primary immunodeficiencies, neurological, blood, metabolic, movement, eye, skin and other types of rare disorders.

Source:

[*Rare Action Network COVID-19 Virtual Discussion Groups*](#)
[*COVID-19 Resource Center*](#)
[*COVID-19 Community Survey Report*](#)

- [**Arthritis Foundation**](#) stays in touch with the top experts and gives updates on this quick moving story, with a focus on what people with suppressed immune systems need to know.

Source:

[*Coronavirus and Arthritis*](#)

Many other arthritis patient organizations have responded with blazing speed to develop resources for their communities. An online community of patients have started the #HighRiskCOVID19 social media campaign aimed at sharing with the world what it feels like to be at high risk for Covid-19 and to remind people that their lives are important. There have been patient- and patient organization-led tweet-chats, and Q&A sessions on Facebook and in blogs.

[COVID-19 Global Rheumatology Alliance](#) was an idea set up in March and through the hard work of Philip Robinson (a rheumatologist in Queensland, Australia) and his colleagues, is now a full-fledged collaborative effort that includes volunteer hours from and support of rheumatologists and their associations, patient organizations, industry, academic and health care organizations, and journals. With over 80 supporting organizations at this point, the Alliance's mission is to create a secure, de-identified, international case reporting registry and curate and disseminate the outputs from that registry. The idea is to take advantage of this extraordinary opportunity to study Covid-19 in the global rheumatology community, and to learn how to best help patients through this time.

- [The National Kidney Foundation](#) has provided answers to the most common questions among kidney disease patients and transplant recipients as well as information about the latest coronavirus developments.

Source:

[Coronavirus \(Covid-19\) information](#)

- [The American Lung Association](#) has been hosting a weekly 30-minute webinar to review the latest updates and recommendations for individuals living with chronic lung diseases and their caregivers in regards to COVID-19. Recordings of the webinars are available on their website so patients can access them anytime. Also, their Lung HelpLine is answering questions about COVID-19. All important frequently asked questions and guidelines can be found on their website as well.

Source:

[COVID-19 information](#)

[COVID-19 and Chronic Lung Disease Webinars](#)

- [American Heart Association](#) provides current science-based information about coronavirus to patients with heart problems through various ways on their website helpline. The hub includes helpful resources, safety tips, ways to control stress, coronavirus news, F&Qs and many more.

Source:

[Coronavirus and heart health – information for all](#)

- [Parkinson's Foundation](#) is addressing the top questions about the virus and Parkinson's disease (PD) through a FAQ section on their website. Their Helpline specialists are also there for patients and caregivers to help. What is more, on March 18, 2020 Michael S. Okun, MD, Parkinson's Foundation Medical Director, and Fred Southwick, MD, Infectious Disease Expert and Author, both from the University of Florida Health, a Parkinson's Foundation Center of Excellence, answered the top COVID-19 questions from their community. The event is recorded and available online.

Source:

[FAQ on COVID-19 and PD](#)

[Ask the Experts: Coronavirus and Parkinson's disease](#)

- [**The Pulmonary Hypertension Association**](#) has allocated a special place on their website for patients to discover how to maintain their health, tips for daily living during the pandemic, COVID-19 updates and ways to connect with PHA. The Pulmonary Hypertension Association's (PHA's) health and wellness series, *PHA Connects: COVID-19 and Your Health*, aims to educate and support the pulmonary hypertension community during the COVID-19 pandemic. *PHA Connects* provides patient education, live interviews and online events that matter to your health and wellness today.

Source:

[Covid-19 and Pulmonary Hypertension](#)

[PHA Connects: COVID-19 and Your Health](#)

- [**The American Diabetes Association**](#) has addressed the most common questions people with diabetes should know being in the risky group (both on their website and through live Q&A sessions). This information is based on current knowledge of COVID-19 and is updated as additional scientific evidence is released. Moreover, they allow people to connect with the community and share thoughts and experiences, they have provided resources for people to know their legal rights as well as understand their risk of getting sick.

Source:

[Covid-19 Hub](#)

- [Breastcancer.org](https://www.breastcancer.org)

Some breast cancer treatments – including chemotherapy, targeted therapies, immunotherapy, and radiation – can weaken the immune system and possibly cause lung problems. People who have weakened immune systems or lung problems have a much higher risk of complications if they become infected with this virus. This is why the organization has provided answers to important questions that patients with breast cancer should know if they are receiving treatment during the COVID-19 pandemic.

Source:

[Coronavirus \(COVID-19\): What People With Breast Cancer Need to Know](#)



Conclusion

This pandemic brought patient communities together. They have been looking out for each other. They have been sharing advice. They have been supporting each other at a time when many of them have felt society considers them to be “dispensable.”

While so much of the world currently feels out of control, there have been many benefits that were previously considered “away from the norm”. People with disabilities are finally allowed to work remotely as their employers have quickly adapted to using digital tools. Telemedicine and disease self-management have become increasingly important. Doctor’s appointments are happening online or through the phone and thus allowing those living far away or disabled to be in touch with their treating physician more often.

Healthy people finally stepped into the shoes of patients with chronic conditions and saw what it means to self-isolate, take extra measures to avoid infections and stay at home. The virus somehow inspired a sense of community spirit, from singing to support healthcare workers to a rise in volunteering with many individuals picking up prescriptions, doing food shopping for those in need and offering to virtually speak to people isolating from the disease.

Undoubtedly, one of the biggest positive sides of this Covid-19 pandemic is the fact that now people can learn about and see first-hand the amazing things that are being done in the name of science and medicine and how clinical research brings new hope through clinical trials, combined know-how and innovation in technology.

About Us

Bringing Clinical Trials Closer to Patients

FindMeCure is a TA-agnostic platform allowing patients and caregivers to volunteer for clinical trials and engage with sites. This allows sponsors to provide excellent support to volunteers for their clinical trial while boosting patient recruitment. So far 620,000 patients have searched for clinical trials through the FindMeCure infrastructure.

FindMeCure Foundation is a not-for-profit organisation devoted to improving the understanding of patient organizations, support groups and their members worldwide about clinical research. Its aim is to support patients to be up-to-date with the ongoing research studies and help them to be fully prepared and knowledgeable about the drug development process. One of its main focuses is to foster patient engagement in research and to sustain patients' key role in the drug development process.

TrialHub provides real-time Intelligence on country feasibility and patient recruitment:

- over 335 000 clinical trials analysed for competition, enrollment, and country capacity
- database of more than 1 million investigators in 70 countries
- country-specific patient pathway mapping
- direct-to-patient channels assessment

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