

# HOW HAS COVID-19 IMPACTED PEOPLE WITH RARE DISEASES?

November 2020



**30 MILLION**  
people are living with a rare disease  
in Europe and 300 million worldwide



**NO CURE**  
for the vast majority of diseases and  
few treatments available

**The COVID-19 pandemic has exacerbated the many challenges  
that people living with a rare disease face.**

During the first wave of COVID-19 in Europe, access to the care and treatment that patients rely on was disrupted, and the stress and anxiety of daily life heightened. The pandemic has also changed the relationship of people living with a rare disease with the healthcare system, opening doors to more digital health options.

## RARE BAROMETER COVID-19 EUROPEAN SURVEY RESULTS

A large scale quantitative survey conducted by Rare Barometer about the impact of COVID-19 on the life and care of people living with a rare disease or their carers.

**18 April** 2020  **11 May** 2020

**6945**  
RESPONDENTS FROM  
ACROSS EUROPE

**23**  
LANGUAGES

**1250**  
DISEASE TYPES

**36**  
COUNTRIES

COVID-19 caused a **severe disruption to care** for people living with a rare disease

### Diagnostic tests

**6 in 10\*** did not have access to diagnostics such as blood tests and medical imaging



### Medical therapies

**6 in 10\*** were unable to receive therapies such as infusions and chemotherapies



### Surgery and transplants

**6 in 10\*** saw their intervention cancelled or postponed

### Rehabilitation therapies

**8 in 10\*** had interventions such as physiotherapy postponed or cancelled



**83%** of rare disease patients' care was disrupted



### Medical appointments

**7 in 10\*** had appointments cancelled or postponed



### Psychiatry follow-up

**6 in 10\*** had their sessions interrupted

\*of those who experienced a disruption to care.

“Cancellation of essential consultations, closure of the hospital for non-COVID patients and due to that, the non-continuation of the analysis essential to its treatment and control.”  
Rare disease patient

Hospital care for rare disease patients was **particularly stressful and difficult to access**



**47%\***

did not go to the hospital because they were scared of catching COVID-19

**34%\***

were told not to go to the hospital if their health problem was not COVID-19

**25%\***

reported that the hospital or unit that normally provides care for their rare disease was closed

Testimonies from patients and carers also reported additional support and help from healthcare professionals.

\*for those treated in hospitals.

**E-medicine** took over from face-to-face where possible

**50%** of the respondents participated in online consultations. They found this type of consultation useful, in particular:

**98%**

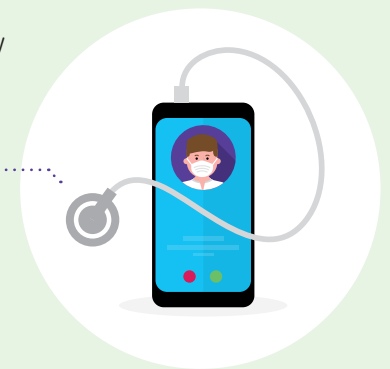
found prescription via emails useful

**90%**

found online education tools designed to help manage the rare disease themselves useful

**90%**

found online consultation or any other form of telemedicine useful



“The doctors, with whom I had appointments, called me and clarified the current health situation with me on the phone and then sent me the prescription to save me the waiting time in the consulting room. I thought that was very good.”  
Rare disease patient

A worrying period of **uncertainty and fear**

**Being well informed:**

**6 in 10** reported difficulties in accessing the information they needed on COVID-19

**Access to treatments:**

**21%** were unable to access treatments



**Patients' health:**

**6 in 10** found the interruptions to care detrimental to their health or the health of the person they care for. **3 in 10** perceive that these interruptions to care could even **probably (21%) or definitely (9%) be life-threatening**

**Mental health:**

**2/3** suffered from depression and/or a feeling of not being able to overcome their problems since the beginning of the pandemic

“The first weeks of COVID I had fears. Suddenly there was no longer much help or contact. Some operations that should have been done have been postponed. I'm really waiting for that. I'm in a lot of pain right now. In addition, I have the feeling that I am on my own.”  
**Rare disease patient**

**Family, friends and neighbours** were very supportive during the crisis



**64%**

needed their family, friends and neighbours' support during the pandemic. Among them, **3/4** told us that they still benefited from the help of their close relations despite the COVID-19 crisis

**80%**

the pandemic strengthened their family unit

“As I am in total confinement, I was able to appreciate the availability of my friends and neighbours to help me and do some shopping, as well as that of my general practitioner and the staff of the pharmacy where I get my supplies.”  
**Rare disease patient**

**THANK YOU** to all people living with a rare disease who participated in the survey and discussion groups, and to Rare Barometer partners!