

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%

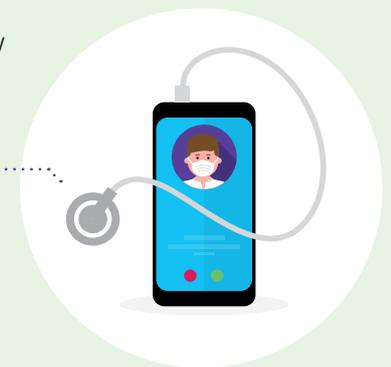
found prescription via emails useful

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

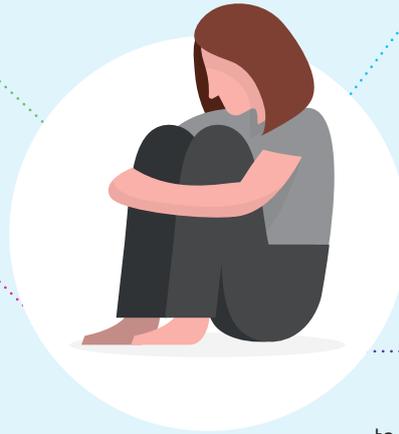
A worrying period of **uncertainty and fear**

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!



A EURORDIS INITIATIVE

EURORDIS-Rare Diseases Europe regularly surveys the rare disease community via its Rare Barometer programme to identify patients' perspectives and needs on a number of issues in order to be their voice within European and International initiatives and policy developments. Rare Barometer brings together over 10,000 patients, carers and family members to make the voice of the rare disease community stronger. For more information visit eurordis.org/voices.