

Access to Care for RD patients in Covid-19 times

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Focus of talk:

- **Impact of Covid-19** on the care of **RD** patients
- **Covid-19 vaccines** in context for people with RD

Putting the COVID-19 vaccines in context for people with rare diseases

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.



For people living with a rare disease, the perception of a health threat due to COVID-19 is **high or very high in 71% of cases**

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

**THERAPEUTIC
OPTIONS
FOR RD PATIENTS:
5%!**

**ONLY OPTION
PROPER CARE.....**

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



83%
of rare disease
patients' care
was disrupted

Rehabilitation therapies

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



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.

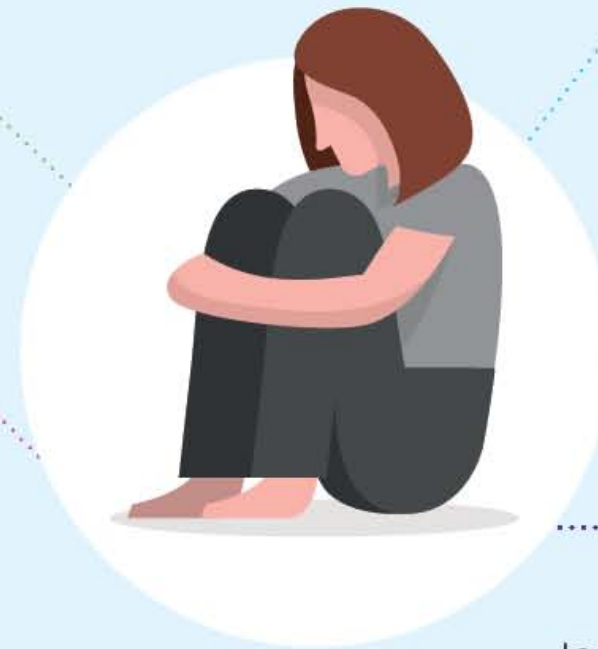
A worrying period of uncertainty and fear

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

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

Positive aspects of Covid-19 impact



E-medicine



Strengthening of ties with family, friends, neighbours

Prioritizing of RD patients and Carers in Covid-19 times...

- **TRIAGE**
- **BIASED DATA COLLECTION/STATISTICS**
- **“FORGOTTEN” IN CARE**
- **LACK OF PRIORITIZATION IN VACCINATION**



Vaccination of RD patients

- **Safe and effective vaccines (EMA assessment)**
- **Strong EU pharmacovigilance system**
- Member organisations engaging with their **European Reference Networks,**
- Discussions on-going **keeping patients as well informed as possible** (safety of vaccines in certain RDs etc)



Different RDs - similar challenges

~70% of RDs **pediatric onset**

Children excluded from vaccination

Vaccination of **CARERS** a **PRIORITY**



CALL FOR ACTION!

People living with a chronic and/or RD **AND THEIR CARERS** amongst the first beneficiaries of the vaccines following health care professionals and the elderly



Thank you !

