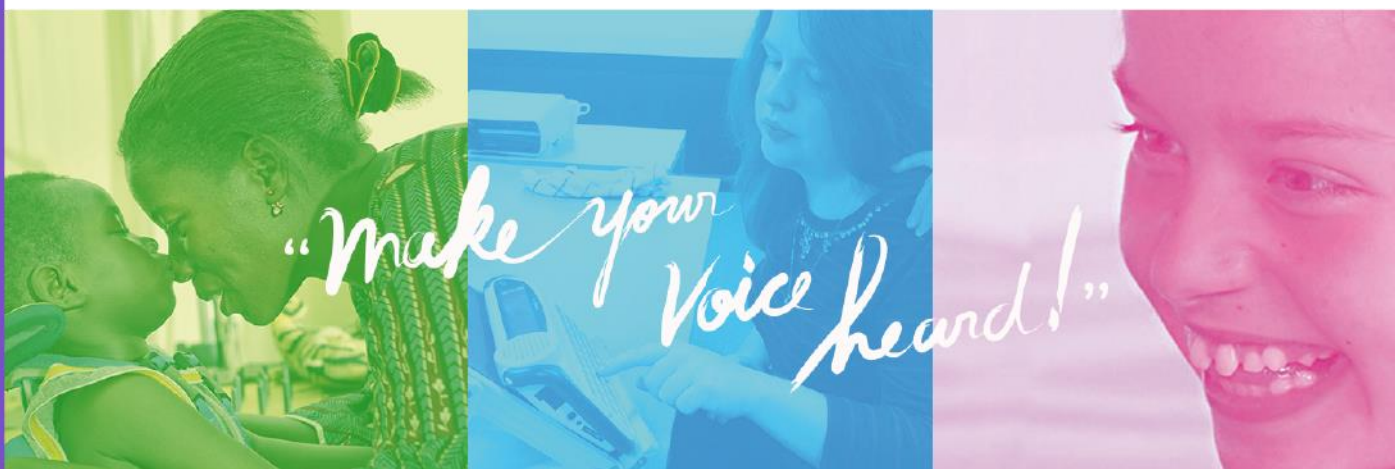




Rare disease patients' experience of COVID-19

April 2020



www.eurordis.org/voices

COVID-19 SURVEY QUESTIONNAIRE

Objectives

- Evaluate the impact of COVID-19 on rare disease patients' medical care, social care and well-being.
- Identify measures and facilities that are helping rare disease patients to cope with the pandemic
- Identify aspects that may have a negative impact on rare disease patients care and well-being
- Identify potential long-term consequences of the pandemic

Goals

- Flag "red signals" during the pandemic to be able to draw messages based on these feedbacks
- Suggest immediate efficient solutions to avoid detrimental consequences on rare disease patients
- Feed our advocacy work with case studies/testimonials
- Prepare our long-term advocacy messages for a potential new wave or another pandemic in the future

Analysis

Rare Barometer Voices framework will enable to filter and cross the results according to the following criteria:

- Comparison between countries
- Comparison with the general public
- Data by disease/group of diseases
- Patient/carers
- Age
- Gender
- Etc.

Translation and reach

Rare disease patients can answer from any country of the world.

The survey is translated in the following languages :

Bulgarian	Greek	Russian
Croatian	Hungarian	Slovak
Czech	Italian	Slovenian
Danish	Latvian	Spanish
Dutch	Lithuanian	Swedish
English	Norwegian	
Finnish	Polish	
French	Portuguese	
German	Romanian	

Presentation page of the survey:

Are you affected by a rare disease or are caring for someone affected by a rare disease? Share your experience and tell us how the COVID-19 pandemic is affecting you by completing this survey.

The survey will only take around 15 minutes to answer.

This survey will help EURORDIS-Rare Diseases Europe, a non-profit and non-governmental alliance of 900+ patient organisations to understand your experience of the COVID-19 pandemic.

We will share the overall results of the survey with you and communicate them (without communicating your individual responses) to decision-makers. The goal is to voice the specific needs of rare disease patients' in relation to the COVID-19 pandemic and to propose practical solutions to ensure rare disease patients are taken into account when handling the pandemic.

Your contact details and any written records of your responses during the study will be kept in secure storage which only the research team can access.

If you have any questions while taking part in this survey, you can contact rare.barometer@eurordis.org, or call our office on +33 1 56 53 52 63.

Questionnaire

1. How would you like to answer this questionnaire? In your capacity as a ...

- patient
 - patient representative
 - Parent of a child living with a rare disease
 - Grandparent of a person living with a rare disease
 - Spouse of a person living with a rare disease
 - Uncle/aunt of a person living with a rare disease
 - Sibling of a child or adult living with a rare disease
 - Other, please specify
- } carers category

If you are both a patient and a caregiver (parent, spouse, etc.), please choose in which capacity you want to answer this questionnaire.

2. Are the following measures currently in place in your country/region/state in order to fight against the COVID-19 pandemic?

- Closure of educational facilities
 - Social distancing, which includes avoiding mass gatherings, and maintaining distance from others when possible
 - Lockdown measures
 - Exceptions regarding containment measures for people living with intellectual disabilities and their caregiver
- Yes
 - No
 - I don't know

3. What level of threat do you think the coronavirus poses to each of the following? (Comparison with IPSOS survey in 8 countries: <https://www.ipsos.com/ipsos-mori/en-uk/public-opinion-covid-19-coronavirus-pandemic>)

- You personally
 - [TO CARERS] The person with a rare disease that you care for
 - Your family
 - Your country
- Very high threat
 - High threat
 - Low threat
 - Very low threat

4. With regard to COVID-19 and in relation to the rare disease you or your family member is affected with, do you feel that you have access to all the information you need?

- Most of the time

- Some of the time
- Seldom
- Never

5. Are protective equipment such as face masks and plastic gloves...

- For you
 - [TO CARERS] For the person you care for
 - For your health professionals
 - For your social care professionals
-
- ... available and easily accessible
 - ... difficult to find, sometimes not available
 - ... impossible to find, not available
 - ... not needed
 - Not concerned

6. Since the beginning of the COVID-19 pandemic, have you or the person you care for experienced an interruption in the following aspects of the care provided by healthcare professionals for the rare disease

....

- Rehabilitation therapies (ergotherapy, speech, physical therapy, massage, etc.)
 - Medical therapies at home or at the hospital (infusions, chemotherapy, hormonal treatment, etc.)
 - Psychiatry follow-up
 - Surgery or transplant
 - Appointment with the GP/specialist who provides care for the rare disease
 - Diagnosis test (lab test such as blood tests, bacteriological test, urinalysis, medical imaging, cardiac and respiratory tests etc.)
-
- Yes, it was completely cancelled
 - Yes, it was postponed or delayed
 - No
 - Not concerned

[If yes to at least one of the above]

7. Would you say that interruptions related to the COVID-19 pandemic you are experiencing are...?

- Life threatening
 - Detrimental to your/her/his health
 - Detrimental to your her/his well-being
-
- Definitely
 - Probably
 - Probably not
 - Definitely not
 - I don't know

8. Since the COVID-19 pandemic started, has one of the medicines/ treatments needed for the rare disease been unavailable when you visited your pharmacy or hospital?

- Yes, temporarily
- Yes, you had to stop taking it or take an alternative
- No

[To those answering no to Q8]

9. And are you afraid that this might happen in the future if the pandemic continues?

- Yes, a lot
- Yes, a little
- No

10. Do you or the person you care for receive/s at least part of the care for the rare disease through a hospital?

- Yes
- No
- I don't know

[If yes to question 10]

11. Since the COVID-19 pandemic started, did you experience the following...?

- The hospital/unit that provides care for the rare disease is closed
- [TO CARERS] You did not go to the hospital because you are fearful the person you care for might catch COVID-19
- [TO PATIENTS] You did not go to the hospital because you are fearful of catching COVID-19
- The necessary material needed for the rare disease care was missing because it is now used for patients affected by COVID-19
- Being told not to go to the hospital if you or the person you care for affected by a rare disease becomes unwell for other reasons than COVID-19
 - Yes
 - No

12. [TO EVERYONE] Have you been tested for COVID-19? (potential comparison with You GOV survey)
[TO CARERS] Has the person you care for been tested for COVID-19?

- Yes, because of obvious exposure to the virus
- Yes, because you/she/he are/is considered at risk
- Yes, because you/she/he had/s first symptoms
- No but you don't consider it necessary
- No but you think you/she/him need/s to be

[To those answering yes to Q12]

13. Were the results of the test positive or negative?

- Positive
- Negative
- I am still waiting for the results
- I don't know

[To everyone]

14. Are/were you or the person you care for hospitalised because of COVID-19?

- Yes, in a normal ward for Covid-19 patients
- Yes, in intensive care without intubation
- Yes, in intensive care with intubation
- No

[To those answering yes to Q14]

15. Were your family members allowed to help with the admission and/or care in the hospital?

- Yes
- No but it would have been better if they had been
- No but it was not necessary anyway

[To those answering yes to Q14]

16. Please describe how the rare disease was taken into account in the admission procedure or hospitalisation because of COVID-19...

[open question]

17. Since the beginning of the COVID-19 pandemic and in relation to the rare disease, have you experienced the following ...

- Online consultations or any other form of telemedicine online or via phone
 - Prescription via email
 - Online education and training to help you manage the rare disease yourself
-
- Yes and this is new to me
 - Yes and it was already the case before the COVID-19 pandemic
 - Yes and this enables me to keep in touch with my social and/or health professionals
 - No

[To those who answered yes to Q17]

18. How would you qualify your experience with

- Online consultations or any other form of telemedicine online or via phone
 - Prescription via email
 - Online education and training to help you manage the rare disease yourself
-
- Very useful
 - Fairly useful
 - Not very useful
 - Not useful at all

If you have any specific experiences in relation to the care received for the rare disease since the pandemic started that you would like to share with us, please relate this experience in the sections below.

19. Please report here positive experiences you had in relation to the care received for the rare disease since the pandemic started. Please provide as much detail as possible.

[open box]

20. Please report here negative experiences you had in relation to the care received for the rare disease since the pandemic started. Please provide as much detail as possible.

[open box]

21. Do you need the following support and do you still have access to them since the COVID-19 pandemic started?

- Social worker support
 - Psychological support
 - Support for house chores and daily tasks
 - Home care (nurse, personal assistant for self-care etc.)
 - Day care (access to a day centre, occupational activities)
 - Institutional long-term care (living in a care facility)
 - Respite care or resource center
 - Adapted school
 - Family, friends or neighbours support
-
- Yes I need this support and I can still access to it
 - Yes I need this support but I receive less support since the pandemic started
 - Yes I need this support but it stopped completely since the pandemic started
 - I need this support but have not received it before or during the pandemic
 - No I don't need this support

[TO THOSE ANSWERING YES TO SPECIFIC ITEMS IN Q21]

22. For what reason has the following support decreased or stopped completely?

- Social worker support
 - Psychological support
 - Support for house chores and daily tasks
 - Home care (nurse, personal assistant for self-care etc.)
-
- Because of lack of personal protective equipment such as gloves and masks available for the person providing the support
 - Because of lack of personal protective equipment for yourself and your family
 - Because the person is ill and no one can replace her/him
 - Other
 - I don't know

23. What is your current occupation? (Eurostat)

- Employed
- Unemployed and able to work
- Unemployed and not able to work (long-term illness, disability)
- Leave of absence
- Retired
- Student
- Homemaker
- Self employed
- Other, specify

[TO EMPLOYED]

24. In order to adapt to the COVID-19 pandemic, does your employer allow the following... :

- More flexible working hours
- Reduction of number of working hours
- Possibility to work from home
- Paid carer leave

- Yes and this was already imposed by public authorities
- Yes and this was advised by public authorities
- Yes and this an initiative from my employers
- No

[TO EMPLOYED/SELF EMPLOYED]

25. Please choose the sentence that best describes your situation, since the COVID-19 pandemic started.

- I work from home
- I had to significantly reduce my number of working hours
- I had to stop working
- I continue to working normally
- Other, please specify

26. Since the COVID-19 pandemic started, how often... (Comparison ISSP study, 2011, translated, Juggling care 2017)

- Have you felt unhappy and/or depressed?
- Have you felt you could not overcome your problems?
- Have you felt isolated?
- Have you felt tensions between family members?
- Have you felt a strengthening of the family unit?

- Never
- Seldom
- Sometimes
- Often
- Very often
- Can't choose

27. Including yourself, how many people – including children – live regularly as members of your household?

- 1
- 2
- 3
- 4
- 5
- 6 or more

28. How many children are currently living in your household?

- 0
- 1
- 2
- 3
- 4
- 5
- 6 or more

29. Including yourself, how many people live with a rare disease in your household?

- 1
- 2
- 3
- 4
- 5

30. How old are you ?

- Under 15
- 15-17
- 18-24
- 25-34
- 35-49
- 50-64
- 65 or older

