



Call to action for policy makers

How to protect people living with a rare disease as confinement measures are being lifted

10 June 2020, Paris - The COVID-19 pandemic has had an unprecedented impact on people and health systems. EURORDIS-Rare Diseases Europe already [brought to urgent attention](#) the needs of the 30 million people living with a rare disease in Europe as one of the most vulnerable populations during the crisis.

The EURORDIS COVID-19 [survey](#) shows that the pandemic heavily impacted the rare disease population. More than two months later, confinement measures are slowly being lifted in many countries. As the virus still circulates and as measures are constantly changing, it is crucial that COVID-19 post-confinement responses and policies in every country, region or locality prioritise the specific needs of vulnerable populations, including people living with a rare disease.

The risk for an exacerbation of pre-existing inequalities is very real and will translate into worse health outcomes for all, not just the most vulnerable. It is crucial to act now to limit collateral damage.

To this end, EURORDIS has consulted its member organisations, conducted a survey with **8,500 respondents** to measure the impact of the COVID-19 crisis on the care of people and now put together the below list of specific measures that need to be taken to protect people living with a rare disease during the post-confinement period.

We call on policy makers to advocate for and implement the below measures to protect members of the rare disease community:

- Close monitoring of the spread of the SARS-CoV-2 virus, while paying attention to the spread of the disease in high-risk populations including people living with a rare disease.
- When a vaccine or other prophylactic treatment becomes available, rare disease patients should have priority access, if their health condition allows for such vaccination.
- Schools, educational facilities and resource centres should be prioritised when relaxing confinement measures, as they are essential for both people living with a rare disease and their family and carers. Schools should be supported to ensure that they have the necessary flexibility to assess individual situations and adapt adequate measures for children with rare diseases.
- Guaranteed access to testing and PPE (personal protective equipment) for people who need it most, including prioritised serological testing for people living with a rare disease.
- Governments should actively take measures to protect the most vulnerable in the population, and not only leave measures to the discretion of service providers, employers, etc. Clear and realistic guidelines are needed that prioritise access to healthcare, social care, opening of schools and educational facilities and resource centres as confinement measures are being lifted.

Where possible, working from home should be encouraged, but with the understanding that some carers have children that need constant care. When the nature of a job does not allow for home working, adjustments to the workplace should be made to prevent people putting

themselves and their families at risk. These guidelines should be clearly communicated to the public.

- Clear guidelines on mobility (local, inter-regionally and internationally), while considering specific measures for people with increased needs.
- Continue providing online consultations when people are burdened to physically access healthcare facilities because of logistical/practical reasons or fear. Take the steps to integrate such telemedicine tools into routine care practice with the necessary clinical assurance and data protection safeguards.
- Lastly, we call upon all citizens to play their role in protecting the general population and the most vulnerable ones in particular by adhering to the guidelines and minimising the risk of infection.

Progress during the COVID-19 pandemic has been made possible by remarkable actions, efforts and dedication of all health/ social care professionals and all other citizens that continued to work in difficult and precarious situations. Remarkable solidarity has been expressed by families and the rare disease community at large. Policy makers at the EU, national and regional levels have played their role by swiftly implementing evidence-based policies. They must not drop the ball.

We must stand strong and build on this solidarity for the months to come.

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More detailed explanations of the measures listed above:

Planned care

When it comes to **planned care**, the EURORDIS Rare Barometer survey results clearly show that it has been disrupted in one way or another: **9 out of 10** people living with a rare disease have experienced interruptions of the care they receive for their rare disease either by not being able to meet with their regular healthcare professionals, or even worse, seeing some of the care they received being put on hold. At the same time, people could not access appropriate testing in relation to their disease (**6 in 10 people**) – this prevents people from receiving the treatment they need.

Many rare diseases have an impact on the immune system and cause immunodeficiency; a safe environment in which both patients themselves as well as healthcare staff are protected is crucial.

Measure to implement

- When a vaccine or other prophylactic treatment will become available, we call for rare disease patients to have priority access, if their health condition allows for vaccination. Priority access should also be given to professionals needed to keep health and care facilities safe and accessible for patients.

Social support

Next to healthcare, **social support** provided by social workers, psychologists, or support institutions, has been interrupted (decreased or completely stopped) for half of the respondents. Research shows that out of all rare diseases, 72% are genetic, and of those 70% of rare diseases start in childhood¹, therefore support services play a crucial role for families of people living with a rare disease. As schools

¹ <https://www.nature.com/articles/s41431-019-0508-0>

are opening it should be made sure that the needs of children with rare diseases are not disadvantaged or discriminated. As the measures that each child needs might differ depending on the implications of the disease, flexibility should be allowed for schools to assess individual situations.

- The necessary equipment and work conditions should be guaranteed to professionals in this sector so that they can restart their work.
- Support schools, educational facilities and resource centres should be prioritised when relaxing confinement measures, as they are essential for both people living with a rare disease and their family and carers.

The economy

Certain sectors of the **economy** and **services** are slowly opening again, but people belonging to any of the vulnerable groups, or their carers are at higher risk and should be treated appropriately in order to be able to participate actively in economic and social life. It should be noted that **3 in 10 carers** had to stop working or significantly reduce their number of working hours since the pandemic started.

- Governments should actively take measures to protect the most vulnerable in the population, and not only leave measures to the discretion of service providers, employers, etc. Those should be clearly communicated to the public. Where possible, working from home should be encouraged, but with the understanding that some carers have children that need constant care. At the same time, where the nature of a job does not allow for this, adjustments to the workplace should be made to prevent people putting themselves and their families at risk.
- People living with a rare disease should be prioritised when it comes to serological testing (**1 in 4** people living with a rare disease has not been tested for COVID-19 yet and consider that they should have been tested).
- Safe access to healthcare should be guaranteed by providing the necessary personal protective equipment (PPE) to healthcare professionals and support staff.

Travel

For the big group of rare diseases that cause physical disabilities, mobility issues are of crucial importance.

- With countries making increasingly more mobility options possible and allowing local, inter-regional and international travel, clear guidelines including for the more vulnerable should be provided, with sufficient access to PPE. Support and dedicated places in public transport should be made available for those who need it.

Telemedicine

There is also a positive angle to this crisis, and it will hopefully be possible to continue the work that has started in some areas. People living with a rare disease made increased use of **telemedicine** (mostly in the form of teleconsultations) which is essential to maintain the necessary care (**9 in 10** report that this experience was helpful). Some countries even making reimbursement possible when previously it was not foreseen. Flexibility has been shown when it comes to renewal of prescriptions which EURORDIS has called for in the past.

- We encourage policy-makers to see telemedicine and online consultations not only as a way to deal with a crisis, but to consider incorporating them as a component of routine care within their health systems with clear clinical governance standards, respecting patients' preferences and under adequate data protection safeguards.

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About EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 900 rare disease patient organisations from 70 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services.