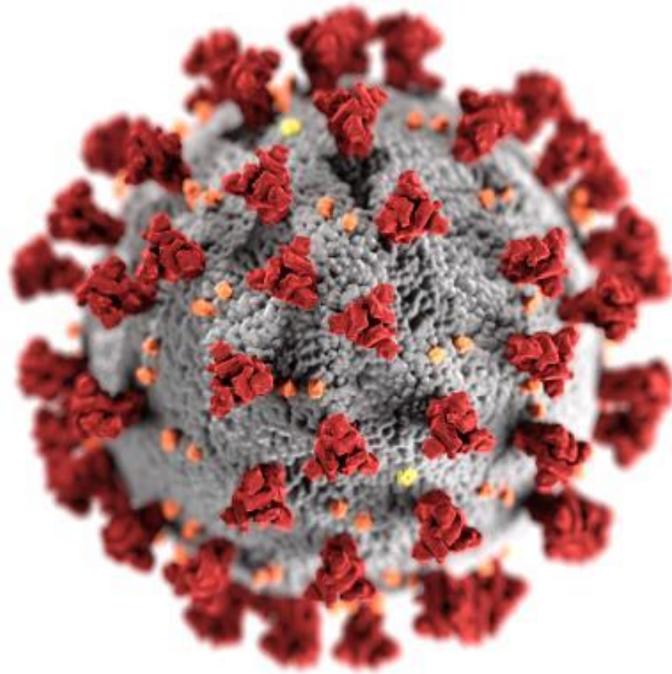


COVID-19 Impact on North Carolina Rare Disease Patients

North Carolina Rare Disease Advisory Council

February 2021



Introduction

There are more than 7,000 identified rare diseases with the number growing every year. Most rare diseases are genetic and are extremely difficult to properly diagnose. It is estimated that 25 to 30 million Americans (almost 1 in 10) have a rare disease. Many of these rare diseases are serious or life-threatening and it is estimated that half affect children who significantly benefit from early diagnosis and treatment. Unfortunately, only about 5% of rare diseases have FDA approved treatments.

For the millions of people living with a rare disease, the novel coronavirus disease COVID-19 presents challenges for their health and wellbeing. Many rare disease patients are experiencing a disruption in their access to health care and clinical trials, a weakening of their social services networks and everyday life and work conditions, and increased mental stress and anxiety. COVID-19 has had a major impact on the management of chronic conditions. Many of these would be considered common, such as diabetes, high blood pressure, heart failure and asthma. For those with rare diseases, this impact is many ways amplified with the challenges of in-person access to health care facilities, at times limited ability to manage care in virtual, and redeployment of resources from the outpatient to inpatient settings. As the pandemic continues it will be important to focus on management of the entire spectrum of conditions.

The two FDA Emergency Use Authorization approved COVID-19 vaccines developed by Pfizer-BioNtech and Moderna are not currently approved for children. Some children with rare diseases already have weakened immune systems and many children and adults with rare diseases receive immunosuppressant drugs. Where both vaccines are concerned, the sole FDA warning for immunocompromised patients, including those undergoing immunosuppressant therapy, is the potential for diminished response to the vaccine. The CDC notes that immunocompromised patients may receive the vaccines so long as they have no contraindications to vaccination, but that they should be counseled about the unknown safety profiles of the vaccines in immunocompromised populations.

Patients with respiratory diseases are highly susceptible to getting very sick if they are infected with the COVID-19 coronavirus. Many North Carolina rare lung disease patients who have dealt with their respiratory disease for years are taking extreme steps to social distance because they understand a COVID-19 infection could be fatal. Dr. Michael Knowles, Michael E. Hatcher Distinguished Professor of Medicine at the University of North Carolina Hospital, treats patients with cystic fibrosis (CF) and primary ciliary dyskinesia (PCD) lung disease. According to Dr. Knowles, these patients with high-risk medical conditions, including rare lung disease patients, have now been moved from COVID-19 vaccination Group 1c to Group 4 under the present Centers for Disease Control and Prevention and North Carolina Department of Health and Human Services guidelines.

This report synthesizes available information on the impact of COVID-19 on rare disease patients. Where possible, the report cites examples of the impact of COVID-19 on North Carolina rare disease patients and caregivers.

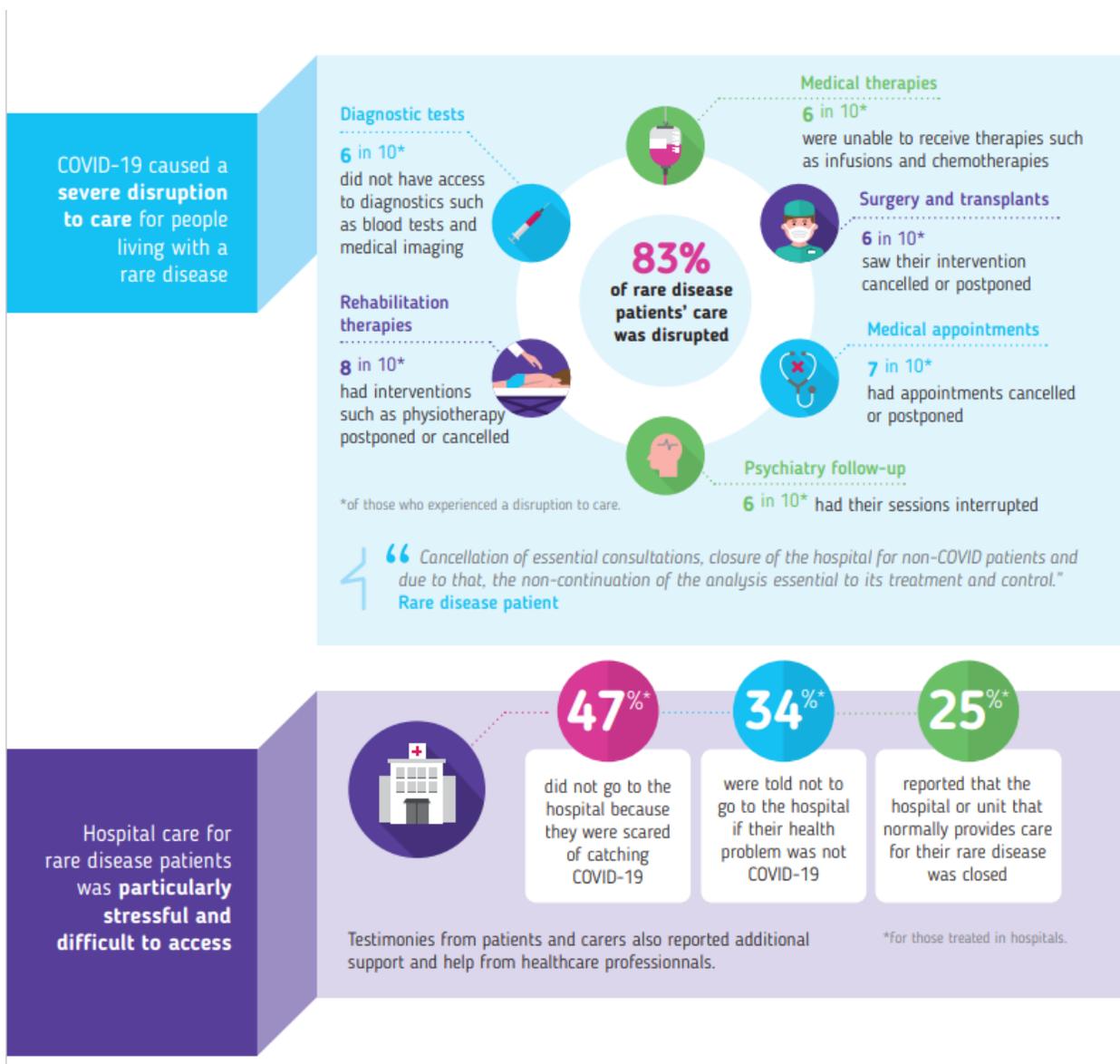
Rare Disease Organizations Response to COVID-19

Several rare disease organizations are studying the impact of COVID-19 on rare disease patients and their caregivers. EURORDIS-Rare Disease Europe conducted a survey of 6,945 rare disease patients and caregivers in 36 countries on the impact of the COVID-19 pandemic.¹ Carried out between 18 April and 11 May 2020, the survey recorded the significant impact that the first wave of the COVID-19 pandemic was having on the treatment, care, and living conditions of people living with a rare disease or caring for rare disease patients across Europe. Some of the challenges reported are listed below and in the following infographic.

- 83% of European rare disease patients surveyed experienced some sort of disruption of their care due to the COVID-19 crisis.
 - 64% of respondents said that they were concerned this would be detrimental to their health or the health of the person they care for.
 - 3 in 10 respondents reported that this would probably (2 in 10) or definitely (1 in 10) be life-threatening.
- Among those who reported a disruption of care:
 - 6 in 10 were unable to access diagnostic tests. As rare diseases are often highly debilitating and life threatening, the wait for diagnostic tests or for medical interventions can result in a severe deterioration of symptoms.
 - 6 in 10 were unable to receive therapies such as chemotherapies or infusions.
 - 6 in 10 saw their surgery or transplant postponed or cancelled.

¹ EURORDIS-Rare Disease Europe, People living with a rare disease were severely impacted during first COVID-19 wave. Nov 12, 2020.

http://download2.eurordis.org/rbv/covid19survey/PressRelease_COVID19surveyresults_Final2.pdf



Source: EURORDIS-Rare Disease Europe, People living with a rare disease were severely impacted during first COVID-19 wave. Nov 12, 2020.

The National Institutes of Health-supported Rare Diseases Clinical Research Network (RDCRN) is conducting an online survey to find out how the COVID-19 pandemic is impacting individuals with rare diseases, their families and their caregivers.² The research survey, developed and led by the RDCRN Data Management and Coordinating Center at Cincinnati Children’s Hospital Medical Center, is one of the first efforts nationwide to quantify the impact of a health crisis on the rare disease community. It is seeking responses from at least 5,000 people with a rare disease or caring for someone who has a rare disease. 104 North Carolinians responded to the survey. The results of the research survey are expected in 2021.

² <https://www.rarediseasesnetwork.org/covidstudy>

The National Organization for Rare Disorders (NORD) is the leading independent advocacy organization for Americans affected by a rare disease. On August 4, 2020, NORD published its COVID-19 Community Follow-Up Survey Report.³ NORD's latest poll was conducted the week of June 17, 2020. A total of 833 individuals responded from 48 states. The NORD survey found that COVID-19 is causing widespread impacts for people with rare diseases, including:

- 79% have experienced canceled medical appointments. Of those, half have had a medical appointment canceled by their provider.
- 32% have had challenges accessing medical care and treatment;
- 14% have had difficulties accessing medical supplies and devices, 68% of whom have had challenges accessing personal protective equipment (PPE). Prior to COVID-19, 46% of participants required PPE to help manage infection risks related to their rare disease.
- 14% have experienced issues accessing medication for their rare disease, 12% of whom can no longer afford it;
- 37% of households have been impacted by a loss of income;
- 27% of households have experienced job loss;
- 62% are concerned with medication supply shortages;
- 9% of people who have lost jobs have also lost health insurance; and
- 6% are in households with someone who has been diagnosed with or has been suspected to have COVID-19.

NORD has also established two COVID-19 Emergency Relief Programs⁴ for patients with rare diseases. The NORD COVID-19 Critical Relief Program provides eligible individuals with financial assistance for non-medical, essential expenses such as, but not limited to, the following:

- Unexpected utility expenses
- Communication expenses (e.g., phone, cell phone, internet)
- Emergency repairs to car, furnace, home or major appliances
- Assistance with travel and/or lodging logistics and expenses
- Rent or mortgage payment assistance
- Support for adaptive learning during school closures

The NORD COVID-19 Rare Disease Premium and Medical Assistance Program provides financial assistance for certain out-of-pocket costs associated with patient's health insurance premiums, such as:

- Medical visits and telehealth consults
- Laboratory and diagnostic testing
- Physical and/or occupational therapy and/or other physician prescribed therapy
- Durable medical equipment
- Medical supplies (tube feeding supplies, dressing kits, personal protective equipment)

³ National Organization for Rare Disorders. COVID-19 Community Follow-Up Survey Report. August 4, 2020. https://rarediseases.org/wp-content/uploads/2020/09/NRD-2061-RareInsights-CV19-Report-2_FNL-1.pdf

⁴ NORD's COVID-19 Relief Program. <https://rarediseases.org/covid-19-emergency-programs/>

The EveryLife Foundation for Rare Diseases is a 501(c)(3) nonprofit, nonpartisan organization dedicated to empowering the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments and cures. The EveryLife Foundation has created a COVID-19 Action Center⁵ website to help rare disease patients stay informed, stay connected and stay engaged. In October 2020, the EveryLife Foundation, in partnership with the Community Congress COVID-19 Response Working Group conducted a survey to better understand the rare disease community's perceptions and information needs about a vaccine for COVID-19 once one is approved.⁶ The results of the survey are not yet publicly available.

Global Genes is a global non-profit advocacy organization for individuals and families fighting rare and genetic diseases. Global Genes' mission is to eliminate the challenges of rare disease through public and physician education, building community through social media and supporting research initiatives to find treatments and cures for rare diseases. Global Genes has created a Coronavirus (COVID-19) Resources⁷ website to help rare disease patients and caregivers find information as easily as possible.

Impact of COVID-19 on Rare Disease Patients

On April 8, 2020, EURORDIS–Rare Diseases Europe published an open letter to policymakers⁸ that explained many of the impacts of COVID-19 on rare disease patients and caregivers. On August 4, 2020, NORD published its COVID-19 Community Follow-Up Survey Report.⁹ Some of the key findings of these two surveys are reported verbatim below.

Access to Health Care

The surge of patients seeking medical attention due to COVID-19 is stretching the capacity of healthcare systems in terms of human resources, medical equipment (personal protective equipment and devices such as respiratory aid equipment) and hospital beds. This is causing a number of challenges for people living with a rare disease. The nature of certain rare diseases, as well as hospital visitor restrictions, have prevented patients from receiving the best care possible during the pandemic.

People living with a rare disease are seeing their regular access to medical advice restricted and their continuity of care disrupted. This includes routine treatment administration that occurs in the hospital/clinic setting, (e.g., blood transfusions). Certain medical and surgical procedures labelled as 'elective' or 'non-essential' are being cancelled or postponed, and in some instances, other hospital units, such as transplant centers, are having to shut down to leave room for patients infected by COVID-19. As rare diseases can be highly debilitating and life-threatening, waiting for medical intervention can

⁵ EveryLife Foundation COVID-19 Action Center. <https://everylifefoundation.org/covid19/>

⁶ EveryLife Foundation. U.S. Rare Disease COVID Vaccine Study. Oct 21, 2020. <https://everylifefoundation.org/the-everylife-foundation-in-partnership-with-the-community-congress-covid-19-response-working-group-conducts-a-u-s-rare-disease-covid-vaccine-survey/>

⁷ Global Genes. Coronavirus (COVID-19) Resources. <https://globalgenes.org/coronavirus-covid-19-resources/>

⁸ EURORDIS open letter to policy makers: Recommendations to protect people living with a rare disease during the COVID-19 pandemic. April 8, 2020. <https://www.eurordis.org/covid19openletter>

⁹ National Organization for Rare Disorders. COVID-19 Community Follow-Up Survey Report. August 4, 2020. https://rarediseases.org/wp-content/uploads/2020/09/NRD-2061-RareInsights-CV19-Report-2_FNL-1.pdf

result in a severe deterioration of symptoms in addition to adding future strains on healthcare systems due to possible complications.

Several years ago, Patricia Sullivan of Hillsborough, NC was diagnosed with the pituitary disorder acromegaly caused by a benign brain tumor on her pituitary gland. Patricia had neurosurgery to remove the tumor at UNC Hospital in April 2019. She now takes an oral medication to get her insulin-like growth factor (IGF-1) back within normal range and keep it there.

Prior to the COVID-19 pandemic, Patricia was seeing her endocrinologist and having her lab work performed on a regular basis. Now during COVID, Patricia says she is not receiving the same level of routine health care. Her one-year anniversary MRI was postponed by UNC Hospital. Because Patricia was not comfortable going to the hospital the MRI was not performed until September 2020. She has used the phone and email to stay in contact with her endocrinologist and has had one telehealth consultation with her ENT surgeon. Patricia has only had her lab work done once when she went to see her cardiologist in the Fall, 2020.

Patricia thought she would be in the high-risk pool for the COVID-19 vaccine when the CDC first announced its guidelines. She is disappointed that the current vaccination guidelines are not including high-risk rare disease patients such as herself. Patricia now believes she will not get vaccinated until the Summer, 2021 along with the rest of Group 4.

When ill with COVID-19 themselves, people living with a rare disease may face barriers in receiving health care in the hospital setting as there are no protocols set in place for their care. People living with a rare disease also affected by COVID-19 might be hospitalized in medical centers that are not their usual center of expertise and where no link to their permanent medical practitioner is established. This is due, in part, to the limited knowledge and scattered expertise on rare diseases.

People living with a rare disease may be in fear of visiting hospitals because of the risk of catching COVID-19 or because they may not receive the appropriate level of care due to their underlying condition, and consequently may put themselves at higher risk by staying at home. According to the NORD survey, 28% of respondents have canceled their own medical appointments. Some were so worried that they did not go to the emergency room when necessary. Among the 15% of respondents who needed to seek emergency room care related to their rare disease, nearly one-third (or 4% of all survey respondents) did not do so out of fear of contracting the virus.

Unfortunately, COVID has led to many families delaying interventions such as cardiac procedures because of COVID with ultimate concern that care is being hindered. One such case is a child with severe Congenital Heart Disease with Eisenmenger's and needed a catheterization prior to surgery. She got COVID and we were quite worried that she would have a severe outcome with her Eisenmenger's. She ultimately did do well but had a significant delay in a life changing surgery.

Dr. Ann Reed, Chair, Department of Pediatrics, Duke University Medical Center

In the first 1 to 2 months of the COVID-19 pandemic, UNC Hospitals closed in-person outpatient clinics and switched to video visits. This impacted access for some families. The situation has significantly improved but some rare disease patients are still nervous about coming to the clinics. I can assure you that the clinic environment is very safe.

Dr. Stephanie Davis, Chair, Department of Pediatrics, UNC Children's Hospital

People living with a rare disease are not sufficiently considered among the target vulnerable populations for diagnostic testing for COVID-19, in the same way that health professionals, the elderly, people with diabetes and people with cancer are. Similarly, testing practices that leave out children as they are considered low-risk or asymptomatic can also be problematic. Since 70% of genetic rare diseases are present in children, there is a vast number of children living with a rare disease who may constitute a high-risk population in the face of COVID-19.

Screening and Diagnosis of Rare Diseases

Screening techniques such as medical imaging and laboratory tests can lead to the diagnosis of a rare disease. Not performing them in a timely fashion can be detrimental to the health of those who are yet undiagnosed or those who are affected by a degenerative disease as they are put at risk of severe progression of their disease if it is overseen. Appointments for medical imaging and for other screening tests are being postponed or cancelled due to the lack of medical personnel or the need to use the laboratory facilities for the testing of COVID-19 samples.

The Duke University Undiagnosed Disease Network (UDN) clinical site is part of a network of medical centers across the United States that is focused on solving the “diagnostic odyssey” for rare disease patients. Participants from North Carolina and elsewhere receive a comprehensive evaluation that may include laboratory testing, imaging and diagnostic procedures, along with examination by experts from many different subspecialties to provide a holistic understanding of each patient’s symptoms. In the early months of the COVID-19 pandemic, the Duke UDN was closed for patient visits. According to Dr. Vandana Shashi, principal investigator for the UDN at Duke University, new patient applications remain down. Some patients are afraid to travel and some patients think the UDN is still closed. In response, the Duke UDN has significantly expanded its telehealth services in an effort to stay connected with its rare disease patients and patient evaluations have resumed, with necessary procedures and sample collection being arranged through brief visits to Duke.

Social Services and Support

Holistic care covers the 360° spectrum of the health, social and everyday needs of people living with a rare disease and their families. The implementation of confinement measures and quarantines to avoid the spread of COVID-19 can have a serious impact in the provision of holistic care for people living with a rare disease. Months of social distancing and lockdown measures have compounded the feelings of isolation experienced by many in the rare disease community—which stem from the nature of having a medical condition held by few, and where patients and caregivers frequently encounter knowledge gaps about their disease and its progression.

The delivery of essential care services for people living with a rare disease such as at-home support or personal assistance is being disrupted, due to lack of available personnel and personal protective equipment (PPE) for both service providers and the patient. According to the NORD survey, nearly half (46%) of respondents needed PPE prior to COVID to help manage infection risks related to their rare disease, and almost 1 in 5 (18%) required PPE constantly. As a consequence, people with rare diseases and disability, who need intensive support to live independently, are facing long waiting hours for their basic and personal hygiene needs to be attended to.

A number of resource centers that offer rehabilitation therapy, physiotherapy, respite care and day care are having to close completely or reduce their offer of services. They do not have the necessary PPE or sufficient staff to provide them in the home setting. The sustainability of these essential resource centers is being impacted by the measures imposed due to COVID-19.

Confinement and social distancing measures can have a severe psychological impact on people living with a rare disease who already have a sense of isolation. Under normal circumstances, being affected

by a rare disease impacts mental health (in a 2017 survey¹⁰ 37% of the respondents declared that they often felt unhappy and depressed, compared to 11% of the general population), and the crisis can exacerbate this impact. Mental health visits and admissions especially for children has increased during the COVID-19 pandemic.

Everyday Life and Work Conditions

People living with a rare disease often face difficulties balancing work life and organization of care. In addition, they often experience lack of understanding from employers or school, which leads to a lack of adaptation of these settings. These issues are multiplied during challenging times such as the COVID-19 crisis.

Adding to the emotional stress is financial concern. According to the NORD survey, many rare disease patients said that they will need to make a choice between personal health and economic stability. Among households represented in the survey, 37% had been impacted by a loss of income and 27% had experienced job loss already.

The closure of specialized child care facilities and schools means that families of people living with a rare disease are unable to work and obliged to take full time responsibilities of care for their children or adult relatives.

People living with a rare disease are not systematically reported under the 'at risk population' to COVID-19, meaning that employers do not necessarily offer special accommodations for them, such as flexible working arrangements or working remotely. This is also true for caregivers who, as a consequence, put the people affected by the rare disease at risk or are obliged to take time off work.

Lack of adaptation in working practices and lack of Personal Protective Equipment also affect people living with a rare disease who work in essential services and have to attend the workplace, at risk of infection.

People living with a rare disease are particularly vulnerable to negative economic consequences (lay-offs and reduction in income) ensuing from the crisis' impact on the labor market.

Research and Clinical Trials on Rare Diseases

Only about 5% of the 7,000 known rare diseases have effective treatments and there is a great need to continue fostering research and innovation for rare diseases. The COVID-19 pandemic poses a threat to the continuation of vital research and clinical trials. In recognition of these challenges, the U.S. Food and Drug Administration (FDA) issued Guidance on the Conduct of Clinical Trials of Medical Products During the COVID-19 Public Health Emergency.¹¹

The rare disease drug development process is already complex and fraught with numerous challenges, and the COVID-19 pandemic has heightened the need to adapt innovations and strategic considerations

¹⁰ EURORDIS-Rare Disease Europe. Juggling Care and Daily Life: A Rare Barometer Survey. May 2017. http://download2.eurordis.org.s3.amazonaws.com/rbv/2017_05_09_Social%20survey%20leaflet%20final.pdf

¹¹ FDA Guidance on Conduct of Clinical Trials of Medical Products during COVID-19 Public Health Emergency, Updated December 4, 2020. [FDA Guidance on Conduct of Clinical Trials of Medical Products during COVID-19 Public Health Emergency | FDA](https://www.fda.gov/oc/2020/12/04/fda-guidance-on-conduct-of-clinical-trials-of-medical-products-during-covid-19-public-health-emergency)

to accelerate development and ensure commercial success. A number of sponsors have put some of their rare disease drug development programs on hold.¹² According to a Tufts Center for the Study of Drug Development (CSDD) Impact Report,¹³ rare disease/orphan drugs accounted for 31% of the clinical trial pipeline pre-COVID.

Research is focusing on repurposing certain rare disease drugs to help fight the most severely affected COVID-19 patients. Some of these products such as Hydroxychloroquine and Azithromycin are widely used in the rare disease community. People living with a rare disease may face difficulties in accessing their medicines as a number of countries are facing supply difficulties.

The ability to conduct clinical trials has been significantly impacted by the COVID-19 pandemic. Many clinical trials have been halted or delayed and the enrollment of new participants is being postponed. Without important data on the safety and effectiveness of treatments from clinical trials, the arrival of new treatments in the marketplace will ultimately be delayed. In addition, patients fighting serious and life-threatening diseases may not be able to access investigational products because of suspended clinical trials, even though those investigational treatments may be their best hope for health improvement in the absence of other approved drugs.¹⁴

Clinical trials are being cancelled on the basis of the safety of patients who are unable or not willing to travel to the clinical sites, or because healthcare professionals are re-assigned to other tasks. However, for some rare diseases, cancelling a clinical trial is more detrimental than being exposed to the virus in terms of life-expectancy.

In the case of clinical trials that were already at an advanced stage, developers may be struggling to put in place measures to protect the patients that were already enrolled and to preserve as much as possible the information that had been collected so far.

The crisis may require the use of decentralized or hybrid trials using digital tools or apps but this practice is not widely used. For already planned or ongoing clinical trials, introducing these types of designs requires significant amendments of the trial protocols and a revision of the endpoints to be used to conclude on the trial.

Increased Use of Telehealth

One bright spot for rare disease patients is the increased use and availability of telehealth. For many rare diseases, there are only a handful of specialists nationwide, or even worldwide, who have expertise in that condition. As a result, rare disease patients often are forced to travel long distances for medical appointments or treatments. However, during the COVID-19 pandemic many doctors and hospital have encouraged their patients not to travel and to get their care virtually. Initially, visits to medical facilities dropped in the first half of 2020, but then slowly improved with more telehealth options and better COVID-19 case numbers.

¹² Syneos Health. Accelerate Rare Disease Drug Development in Light of COVID-19 and Other Challenges. April 14, 2020. <https://www.syneoshealth.com/insights-hub/accelerate-rare-disease-drug-development-light-covid-19-and-other-challenges>

¹³ Tufts CSDD Impact Report July/August 2019, Vol. 21 No. 4. <https://csdd.tufts.edu/impact-reports/>

¹⁴ National Organization for Rare Disorders. The Impact of COVID 19 on Rare Disease Clinical Trials. June 2020. https://rarediseases.org/wp-content/uploads/2020/06/NRD-2043-CV19_RareEDU_Impact-on-Clinical-Trials_v1.pdf

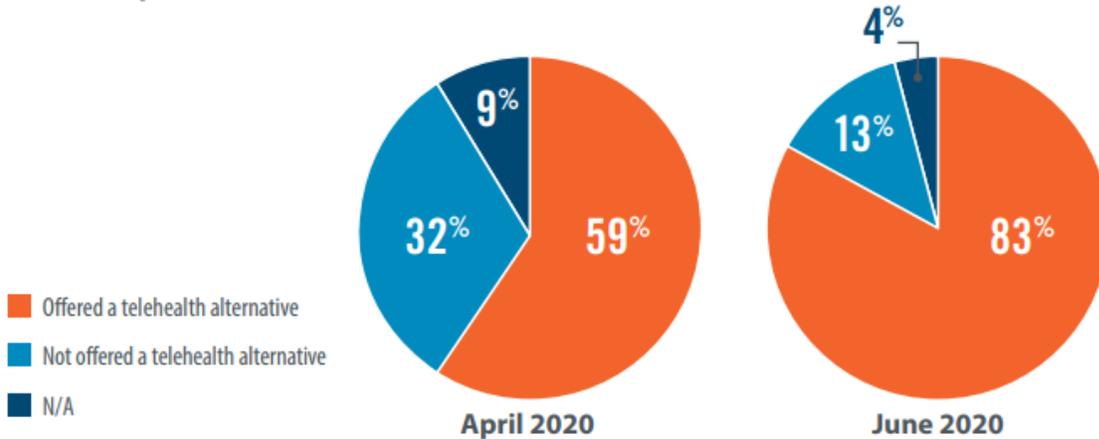
Our most complex patients have been disproportionately affected by COVID. Families early in the pandemic, not wanting in person visits, resulted in a rapid transition to multidisciplinary telehealth visits to allow continued care and limiting exposure.

Dr. Ann Reed, Chair, Department of Pediatrics, Duke University Medical Center

Many North Carolina rare disease patients do not have good access to the Internet. For those individuals, North Carolina's lack of a broadband infrastructure in rural communities can make accessing telehealth services rather challenging; internet connection can be a bit unreliable. Governor Cooper recently announced new funding to expand internet access to rural communities.¹⁵ Some rare disease patients were able to use their cell phone for telehealth visits. Non-English-speaking patients required interpretive services which were in demand.

The NORD survey¹⁶ found that out of over 800 rare disease patients and caregivers, more than 83% had been offered a telehealth visit during the COVID-19 pandemic by their health provider and, of those who were offered a visit, 88% accepted. Out of all patients who reported having had a telehealth visit, 92% described it as a positive experience, and 70% of respondents would like the option of telehealth for future medical appointments.

Figure 1.3
For people with rare diseases, access to telemedicine has increased since the start of the COVID-19 pandemic.



Source: National Organization for Rare Disorders. COVID-19 Community Follow-Up Survey Report. August 4, 2020.

¹⁵ Governor Cooper Announces \$30 million to Expand Internet Access in Rural Areas. December 17, 2020. <https://governor.nc.gov/news/governor-cooper-announces-30-million-expand-internet-access-rural-areas>

¹⁶ National Organization for Rare Disorders. COVID-19 Community Follow-Up Survey Report. August 4, 2020. https://rarediseases.org/wp-content/uploads/2020/09/NRD-2061-RareInsights-CV19-Report-2_FNL-1.pdf

Another NORD publication titled *Ensuring Access to Telehealth for Rare Diseases*¹⁷ discusses how federal and state governments have expanded access to telehealth for rare disease patients.

“In response to the pandemic, starting in early March, the federal government took important steps to temporarily expand coverage for telehealth services. This included removing barriers that had previously prohibited Medicare patients from utilizing telehealth services from the safety of their homes and allowing telehealth services only for those patients in designated rural areas. Additionally, a blanket waiver was issued permitting all physicians participating in federal health care programs (Medicare, Medicaid, TRICARE and Veterans Affairs programs) to receive payment for telemedicine services in states where they did not hold a license. Two weeks later, the US Department of Health and Human Services (HHS) Secretary Alex Azar reached out to all Governors recommending that they allow health professionals licensed or certified elsewhere in the US to practice in their states. In response to these actions by the federal government, combined with advocacy from patient groups including NORD, most states modified their state licensure requirements to allow out-of-state health care providers in good standing to practice medicine, including telehealth, across state lines. Many private insurers have also temporarily expanded access to telehealth services and often reduced patient cost-sharing associated with these services to help keep patients healthy and safe at home.”

North Carolina Governor Roy Cooper in his Executive Order 116 dated March 10, 2020 temporarily waived North Carolina licensure requirements for health care and behavioral health care personnel who are licensed in another state, territory, or the District of Columbia to provide health care services within the Emergency Area. The North Carolina Medical Board issued an order allowing anyone with a Limited Emergency License (namely, out-of-state clinicians who have obtained temporary licensure to assist in North Carolina) to have a ‘wind down’ period of 30 days after the current state of emergency is lifted before his or her license to practice medicine in North Carolina expires.

¹⁷ National Organization for Rare Disorders, *Ensuring Access to Telehealth for Rare Diseases*, October 2020. <https://rarediseases.org/wp-content/uploads/2020/10/NRD-2098-RareInsights-Telehealth-Report.pdf>