Institute of Social Sciences and Humanities

Master Thesis in Policy Studies

MEDIA COVERAGE OF CYSTIC FIBROSIS ANR RARE DISEASES POLICY IN THE REPUBLIC OF NORTH MACEDONIA

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Disclarimer: All translations in this thesis are made by the Author.

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CF- Cystic fibrosis

RNM – Republic of North Macedonia

NM- North Macedonia

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Abstract

This research and study aim to explore the media coverage of CF in NM and how much it can impact public awareness about rare diseases. By using a mixed-methods approach that included the analysis of media articles, questionnaires and different news about public perception, and official perception, this research was done to understand and reveal the relationship between the media presence of CF and the understanding of CF in the general public.

By asking different patients and using the data online it was concluded that media coverage of CF is always limited, which leads to misconceptions. Furthermore, this research found a positive relation between media coverage and public awareness, by this understanding and support for these patients and other rare diseases increased.

The lack of awareness from other important groups such as ministries, policymakers, and the health fund is concerning, despite the general public being more aware, supportive and informed, the other part is always silent. With this study I also aim to reach more doors such as policymakers, authorities and governmental officials, to make sure that the life of people who fight against rare diseases gets easier and everyone receives what is needed to continue a more peaceful life.

In conclusion, this study highlights the need for more improved media presence and engagement, more accurate representation of CF and more supportive and aware communities. Future research can investigate further the topic of the long-term effects of media coverage especially on public opinions and the healthcare outcomes for patients with rare diseases.

Keywords: Media, Trikafta, Cystic fibrosis

Introduction

Background

Cystic fibrosis (CF) is a genetic condition that affects a protein in the body. People who have cystic fibrosis have a faulty protein that affects the body's cells, its tissues, and the glands that make mucus and sweat. Normal mucus is slippery and protects the airways, digestive tract, and other organs and tissues. Cystic fibrosis causes mucus to become thick and sticky. As mucus builds up, it can cause blockages, damage, or infections in affected organs. Cystic fibrosis used to cause death in childhood. Survival has improved because of medical discoveries and advances in newborn screening, medicines, nutrition, and lung transplants. Nearly 40,000 children and adults in the United States and more than 100,000 worldwide are now living with cystic fibrosis. Children born between 2018 and 2022 who have cystic fibrosis are expected to live an average of 56 years. On average, half of babies born in 2021 with cystic fibrosis are expected to reach the age of 65 or older. (NHLBI, 2023)

Rare diseases are characterized by a wide diversity of symptoms and signs that vary not only from disease to disease but also from patient to patient suffering from the same disease. Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offerings inadequate and research limited. Despite their great overall number, rare disease patients are the orphans of health systems, often denied diagnosis, treatment, and the benefits of research. Relatively common symptoms can hide underlying rare diseases leading to misdiagnosis and delaying treatment. Typically disabling, the quality of life of a person living with a rare disease is affected by the lack or loss of autonomy due to the chronic, progressive, degenerative, and frequently life-threatening aspects of the disease. The fact that there are often no existing effective cures adds to the high level of pain and suffering endured by patients and their families.

Trikafta is a medicine that works by improving the flow of chloride and water in patients with cystic fibrosis who have a certain genetic defect. Trikafta helps your breathing by improving your lung function. You may also notice that you do not get ill as often, or that it is easier to maintain a healthy weight. Trikafta on the other hand has been known as the magical medicine from the side of patients and the loved ones of people who suffer from CF.

Problem statement

Patients with cystic fibrosis fought on their own for several years, trying to make sure they reached better conditions and better medicaments. After a long time, protests were held, and different pressures were made, the authorities did not want to hear about anything related to it, so the media stepped in. With the media being on the side of patients, the word spread faster, and the need for Trikafta was urgent and people started noticing, that the only way to the finish line was for authorities to make sure that they give these patients what they wanted. Media coverage was successful in helping people who needed help, through different stories, being on news, interviews and even the journalists and media being supportive in protest. Despite traditional media, social media was all support, starting from influencers, different personas and just citizens sharing posts, liking and commenting. The most successful was the method of commenting on ministers and government official posts mentioning Trikafta and people with CF.

With this kind of campaign and strategy, the Trikafta started slowly reaching patients in North Macedonia, and the process is slow but, media coverage has helped the most to make sure that these people reached the one thing that they wanted, Trikafta.

Research objectives

The aim of this thesis and this research is to understand the power of media in serious situations nad how active activism gets people to the main goal, the fight with authorities, officials and the government in general in a corrupted and devilish country. The following research objectives are:

1. To examine how cystic fibrosis is portrayed in North Macedonian media;
2. To understand the difference in media coverage and policies between European countries and NM
3. To evaluate the level of public awareness and understanding of cystic fibrosis in North Macedonia as influenced by media coverage;
4. To explore the gaps in media representation regarding cystic fibrosis, including potential misconceptions, lack of information on treatment options, and patient experiences;
5. To assess whether media coverage has influenced public policy, funding, or support systems for patients with cystic fibrosis and other rare diseases in North Macedonia.

The listed objectives will be explained and are interconnected so they will be explained thoroughly through each step of the research and the study. The first objective will be covered in the first part “Literature review” where it will talk about the healthcare system, the media landscape and the connection between these two.

The second objective also will be covered in the first part which will be explained in detail, with numbers and percentages, and it will show how much difference there is between these countries and what exactly these differences are.

When it comes to the third objective, will be covered in many parts of the thesis, since everything and every appearance in the media has made an impact on people being more aware, asking more questions, doing research online and listening to the different experiences of the patients.

The fourth objective will be explained further in the discussion and the interpretation of the result, with answers from the participants in the questionnaire, it will be easily understood their thoughts and how much they could have manipulated whatever they wanted to say, add or remove.

The fifth objective will be answered further as well, with less information on that objective it will be seen how much the media can influence the political side of healthcare and how much it can help change a law, a policy or a rule.

Research questions and hypotheses

The research questions in this research were designed to answer every possible topic that it covers, such as CF, rare diseases, media coverage and Trikafta. The research questions are:

1. “What are the key components of the current rare disease policy in North Macedonia, and how effectively does it address the needs of individuals affected by rare diseases in terms of diagnosis, treatment access, and support services?”

2. “How does the range of media coverage of rare diseases in North Macedonia contribute to public awareness, understanding, and support for individuals affected by these conditions, and what factors influence the extent and nature of media attention on rare diseases?”

3. “How does the coverage and discourse surrounding rare diseases differ between legacy media and social media platforms, and what impact do these differing media channels have on public awareness, support networks, and advocacy efforts for individuals affected by rare diseases?”

4. “What are the current challenges and opportunities regarding the availability and accessibility of Trikafta, a breakthrough medication for cystic fibrosis, in North Macedonia, and how do factors such as healthcare infrastructure, regulatory processes, and affordability impact its distribution and uptake among individuals with cystic fibrosis in the country?”

5. “What are the lived experiences and perceptions of individuals with cystic fibrosis who have been prescribed Trikafta in North Macedonia, including their treatment journey, quality of life improvements, and challenges encountered in accessing and adhering to this medication?”

The objectives of this research include analysis, research on media coverage and public awareness about CF. Identifying gaps as well, based on these objectives the hypotheses are:

1. Media coverage in NM is visibly lower about CF and other rare diseases compared to other more common diseases and known diseases, and this leads to less and lower public awareness.

2. The presence of CF in media in NM raises the level of increase in public awareness and understanding of the disease in the public, despite being low.
3. The personal experience of patients leads to more positive public perception and empathy, which leads to more impact on individuals and their families.
4. Media attention leads to more positive influence on the supportive policies and healthcare funding for rare diseases in NM.

Significance of the study

Cystic fibrosis (CF) is a lifelong genetic disorder that has difficult challenges that make a person and their family’s life harder. CF is a rare disease, and most of the time it lacks visibility and attention compared to other more common diseases in NM and also around the world, which leads to gaps in the public’s perception and support. This study and research aim to analyze the media coverage of CF in NM, a topic that has been under-researched in the context of rare diseases in general.

The media plays a crucial role in shaping public opinion, perception and awareness of health issues. The successful representation of this disease can help the understanding of this issue, and reduce the misinformation and misconception about this disease and other rare diseases as well. This research intends to investigate how CF is portrayed in media in NM, and the goal of this research is to find out what the relationship of media with CF is, and how much effect the media coverage on these topics.

With this research, the contribution to the existing literature is higher, and addressing the specific context of NM, where rare diseases like CF do not receive the needed attention. The research done in this study can lead to more valuable insights for healthcare providers, help the government, and policymakers and a way for future awareness campaigns to save on the allocation of rare disease support.

By improving the media coverage in NM and public awareness of CF it benefits the patients and their families, but also it raises the understanding of this disease more broadly, which leads to a more informed community.

PART ONE: LITERATURE REVIEW

According to NORD (National Organization for Rare Diseases, 2020), the definition about cystic fibrosis says that it is a genetic disorder that often affects multiple organ systems of the body. Cystic fibrosis is characterized by abnormalities affecting certain glands (exocrine) of the body especially those that produce mucus. The symptoms of cystic fibrosis can vary greatly in number and severity from one individual to another. Common symptoms include breathing (respiratory) abnormalities including a persistent cough, shortness of breath and lung infections; obstruction of the pancreas, which prevents digestive enzymes from reaching the intestines to help break down food and may result in poor growth and poor nutrition; and obstruction of the intestines. Cystic fibrosis is slowly progressive and often causes chronic lung damage, which eventually results in life-threatening complications. Because of improved treatments and new treatment options, the outlook and overall quality of life of individuals with cystic fibrosis has improved and over 50 percent of individuals with the disorder are adults. Cystic fibrosis is caused by mutations to the cystic fibrosis transmembrane conductance regulator (CFTR) gene and is inherited as an autosomal recessive trait.

There are a few current treatments that have been developed for the better the recent years, which are: 1. Pharmacological treatments, which is Trikafta and for which will be talked thoroughly throughout the thesis and how it has changed the life of a patient struggling with this rare disease; 2. Antibiotic therapy, there are chronic bacteria that are treated with different antibiotics; 3. Airway clearance techniques, some techniques that are done by different breath and air exercises to help remove and take out the mucus in the lungs or airways; 4. Nutritional support, because there is pancreatic inefficiency it is needed to take enzymes with every meal to be able to keep the protein and the nutrition in the body.

There are many challenges in managing cystic fibrosis in everyday life:

1. Disease complexity and variability, despite there being many different drugs and treatments that help patients in everyday life, some patients struggle even when taking those drugs because this disease affects every person differently and can show different complexes along the journey;

2. Access to care, even though there is minimal payment for those with rare diseases or special needs in NM it is hard to be able to do everything properly since there are so many things a patient needs, such as vitamins, being able to travel to hospitals or even being able to eat well;

3. Psychological and social impact, being able to deal and fight with a lifelong disease has its challenges, trying to fit in a society, and trying to keep a job causes a lot of stress for the patients and their loved ones, and psychological guidance has a crucial role in the patient's life.

The newest magical drug which is Trikafta has a massive role and makes big changes in the life of someone with cystic fibrosis, the changes in the lives of patients have been drastic and very positive, the benefits of this magical drug and treatment are: improved CFTR function, enhanced lung function, fewer respiratory exacerbations, better nutritional status, enhanced quality of life. Besides these this drug has affected the psychology of the patients and the people around them positively, making them have hope and dreams for the future, having a job, creating a family and many other things that couldn't be dreamt before Trikafta.

There are many rare diseases that we do not even know about and naturally not many people know every rare disease and their challenges. The lack of awareness of many rare diseases is huge around the world and in our region as well. There are many challenges for those who have been and are struggling with those diseases, a few of them are: limited treatment options, despite living in a small or a big country there are always limited treatments that are "coming in very late" to make it easier for those in need, this creates stress and fear in patient's lives unfortunately. The high cost and accessibility of these treatments or any other condition is very hard and challenging, the parents or the patients themselves try their hardest to be able to reach something or a drug that means life for them by themselves with no help whatsoever, and this is one of the biggest challenges for those with rare diseases. Lack of awareness and expertise is another challenge, when you go to any other hospital or doctor you have to explain in detail what the rare disease is, or even at a job, school or any other event. People do not know much about any of the rare diseases, the awareness and information about rare diseases it is only known to those who struggle or those who are close to people with a particular disease. The daily struggle to manage everything in life and adding some 'must do' exercises to stay alive affects the social life and the psychology of one, all patients with CF struggle to do everything properly and have an active life.

Media coverage of the rare diseases rose after many scandals in the health system and the Ministry of Health. There are plenty of issues when it comes to that system in North Macedonia, including a lack of treatments, drugs, different tools and many other things, besides that the lack of budgeting when it comes to contemporary drugs and analyses is very much seen. There is a huge problem also with budgeting because of political crises and other situations where the only ones who lose from this are the patients and people who need help. The main issue for the politicians in our country is always different; the urgency of other issues has more importance than a citizen's life or death matters. The focus being there made people and citizens realize that there should be movement or some kind of action to get what they need and want. And just like that protests were held and our voices were heard just to be shut down in a few days. The lack of drugs is ongoing, an example of this is people with CF, a few patients got the Trikafta and the others are waiting for their turn patiently, because the state and the government do not have enough money to be able to afford the drugs for every single patient, and the stress waiting is always seen. Apart from this, a drug that has been produced and has been on the "Positive List" in NM, is not being produced and available to get, which is a worldwide problem, but of course more developed countries reacted immediately not making their citizens wait and struggle, and found a replacement almost immediately, whereas NM is not taking any action whatsoever and the institutions are blaming each other for not being able to even bring a replacement for enzymes that need to be taken with every meal from patients. There are a handful of problems just like these for every disease and rare disease in NM.

The budget in NM is supposed to be more each year and used properly for the needs of hospitals, patients, and doctors to make better conditions to be able to heal, treat and get better. Even though this might be seen, the way that money is spent is concerning. Each day we see types of news of people waiting, concerned, and disturbed. There are no movements from the government or an institution that is responsible for that. According to the Association for Emancipation, Solidarity and Equality of Women – ESE in an analysis done in 2016 comparing the conditions from 2012 until 2018, with a focus on 2016 concluded the data related to the coverage of people suffering from rare diseases with the Program for 2016 are compared with the same for 2015, progress can be noted in its implementation. That is, 94 more people were covered in 2016 than in 2015 (in 2015, 74 patients were treated, and in 2016, 168 patients were treated), and the program provided drugs for an additional 12 diagnoses (in 2015, drugs were provided for 24, and again in 2016 for 36 diagnoses of rare diseases) and 8 more generic drugs were procured (in 2015, 16 generic drugs were provided, and again in 2016 for 24 generics).

Media landscape and healthcare system

Media structure:

In North Macedonia the media structure is divided in two: traditional media (legacy media) and digital media. In traditional media, we have a range of private and public television channels, newspapers and radio stations. Whereas in digital media, we have blogs and many new platforms where current issues are more seen and faster reported, being seen by a wide range of citizens (Vangeli, A. 2018).

Coverage of health issues:

Covering health issues has been more ‘popular’ as mentioned earlier, the media focuses on more major topics, such as epidemics, a difference in major health policies or similar to that, the rare diseases policies or news are not as frequent as the major topics. In a few platforms or news reports, we can see a section, especially for health issues or anything related to health, but the majority does not report much on this topic. The challenges in reporting and covering this kind of topics are that there is a lack of sensitivity where sometimes journalists or reporters are not as careful as they should be and this might cause less interest in providing news and reporting on this topic (MIM, 2019).

Public engagement:

When it comes to public engagement we know that the use of social media is more and more frequent and almost everyone has a profile in any type of social media, by this something important is seen and shared very fast and reaches everyone. People have been able to learn more about rare diseases through social media and social media campaigns, getting help through different platforms as well (Markovikj, A. 2020).

Regulatory environment:

Media regulation in North Macedonia is done by laws, through institutions that are responsible for ensuring media freedom and responsibility, but with political and economic crises there have been struggles for the media to report with quality and this has impacted the media coverage in the country (Kovacevic, M 2019).

Healthcare system

Structure:

In North Macedonia, there are two types of healthcare: Public and private healthcare. In the public healthcare system the citizens are funded by the Government and here are included hospitals, clinics and clinic centers. The Health Insurance Fund (HIF) provides coverage for a lot of treatments and services but usually, important things are left out. There is also the private healthcare system which has been growing and providing services that are not in the public healthcare system and services (WHO, 2020).

Accessibility and quality:

There is a difference between urban and rural areas when it comes to the accessibility and the quality of the healthcare system, in urban areas the hospitals and simple clinics are more equipped and have more treatments compared to the ones in rural areas. There are efforts to improve the health system in every way possible even though the whole system has been failing for so many years now, to political crises, changing of ministers frequently, economic crises, you name it!

Healthcare challenges:

There are problems with funding as well as resources, and because of these things, the quality of the system is not as needed. Besides all of this, socioeconomic factors also affect the way that people are seen and treated in hospitals by doctors and the medical staff. The effectiveness of the healthcare system is also affected by the bureaucracies and the inefficiency in it.

Reforms and initiatives:

Reforms in the healthcare system are always attempted and every government and minister tries very hard to change it, but since the corruption trend arose in North Macedonia it has been very hard for them to manage and provide the needed conditions, materials, treatments, drugs and many other things. Overall, the Government and NGOs try their hardest to make public health campaigns related to vaccination, preventive care and health education (Vasilevski, S.2020).

Interactions between Media and Healthcare system

Information dissemination:

Media plays a crucial role in sharing information about health issues, preventive measures, and health campaigns. The effective communication of the media can support and improve health literacy. Also, during health crises such as epidemics and pandemics, the media serves as a crucial channel to inform citizens in real-time, it also serves as guidance for a better understanding of the situation a country or a region might be in (Petrova, M. 2022).

Advocacy and policy influence:

When it comes to influencing the policies media has a huge part in this by promoting reforms, highlighting issues and also raising public awareness by just reporting, giving screen time to these kinds of issues and stories influencing the informing of citizens in more detail (Petrova, M. 2022).

Challenges in coordination:

Another issue in media reporting might be misinformation, which can lead to misunderstanding and harm to hospitals or even patients. Reporting responsibly and sensitively is an important step in journalism in North Macedonia and everywhere around the world. The coordination between these two channels, media and the healthcare system, is important to maximize the impact of health information and services (Petrova, M. 2022).

Rare diseases across Europe

Rare disease policies across Europe are different from the Balkan countries and try to make more opportunities and dealing with a particular disease easier. There are many articles and studies done on rare diseases.

According to a study done in several countries in Europe about 18 different rare diseases, Health authorities, healthcare providers, patients and their organization representatives all agree that rare disease patients are denied this right and are all confronted with similar obstacles in attaining the highest possible standards of health including (1) lack of scientific knowledge of their disease, (2) lack of access to correct diagnosis, (3) delays in diagnosis, (4) lack of appropriate multidisciplinary healthcare, (5) lack of quality information and support at the time of diagnosis, (6) undue social consequences, (7) inequities and difficulties in access to treatment, rehabilitation and care, (8) dissatisfaction with and loss of confidence in medical and social services and (9) rejection by health professionals. (EURODIS, 2009, p: 20)

Access to care is made difficult for all groups in all situations. The following might be used to summarize the factors affecting care availability for people with rare diseases: gaps in scientific understanding, institutional obstacles, financial obstacles, and individual obstacles. When compared to more prevalent diseases, rare diseases have less incentive for publically funded research, which has delayed the development of basic scientific information necessary to determine the best course of treatment, whether it be medication therapy or other medical care. Most rare diseases have poorly understood causes and mechanisms, which can lead to misdiagnosis, underdiagnosis, or delays in diagnosis, complicating therapy. (EURODIS, 2009, p: 21)

The results of the questionnaire and the research done by EURODIS in many countries in Europe CF were included as well, here are some results that came after the research:

A later diagnosis in women than in men is surprising since the life expectancy of women is shorter than that of men among patients with CF. Patients with CF, especially those who experience symptoms later in life, are not taken seriously and are told that their symptoms are imaginary. Apart from those who are diagnosed during the neonatal period, many CF patients are not diagnosed until lung function is significantly altered; meaning a portion of the lung is already destroyed. Even after a CF diagnosis has been made, some related complications, such as diabetes, are not considered, despite their well-established associations. Before the possibility of neonatal screening, a delay in diagnosis often resulted in the birth of additional children with the disease. Today, the opposite is true: previously born siblings with CF are diagnosed as a result of the neonatal diagnosis of their newborn brother or sister. Patients vividly remember the announcement of the diagnosis as an unpleasant memory, especially when it occurs in a corridor in haste. The diagnosis of CF must be announced calmly, several times to assure that the reality of the diagnosis is understood. It should be accompanied by psychological support and additional written information on the disease so that patients can have materials to refer to in a day and age when a lot of unreliable information is available on the Internet. (EURODIS, 2009, p: 126)

Access to Medical and Social Services

Participants of the survey

Responses from 539 families of CF patients from seven countries were analyzed in the survey. An equal number of female and male patients were represented (51% and 49%, respectively). The mean age of patients was 18 years (mean age at diagnosis: 4 years) (EURODIS, 2009, p: 126).

Need for medical services

According to the Eurodissurvey, overall, patients with CF needed more than 11 different kinds of medical services related to their disease (more than the average nine medical services for the 16 rare diseases surveyed). In addition to consultations mentioned in Figure 5, consultations of ophthalmology, genetics, immunology, internal medicine, endocrinology, emergency services and hepato-pancreato medicine consultations were also sought by a range of 13% to 19% of patients. The most frequently needed explorations were biological testing (86%), microbiology (78%), radiology (75%), functional testing (69%), ultrasound (54%), specialized imagery (41%) and ECG (29%). As for other care services, physiotherapy (63%), injections (45%) and nursing care (32%) were the most frequently used, followed by dental care, glasses and surgery (by a range of 12% to 28% of patients). Hospitalization occurred in 62% of patients for an average total duration of 29 days (EURODIS, 2009, p: 127).

Access to medical services

The study of Eurodis back in 2009 showed that the lack of access to medical services in 7% of situations overall for CF patients Psychotherapy (22%), nutrition (17%) and gastroenterology (14%) consultations were the most frequently impossible to access for CF patients. A lack of referral was the most frequent cause of impossible access to psychotherapy (52%), gastroenterology (48%), functional testing (43%) and pulmonary medicine (29%) services. Unavailability of the service was reported as the main barrier to access for microbiology (62%), physiotherapy (50%) and nutrition (55%) services and was a significant barrier for psychotherapy (42%). Personal cost was a hurdle to access for pulmonary medicine (14%) consultations. Waiting time for obtaining an appointment was considered a significant hurdle for access to pulmonary medicine (21%) consultations. Barriers to access related to the distance from the medical structure were mainly excessive distance for physiotherapy (46%), pulmonary medicine (29%), functional testing (29%), microbiology testing (23%), psychotherapy (21%) and nutrition (20%), and cost of the journey for pulmonary medicine (36%) and physiotherapy (32%). The inability to find anyone to go with was an additional barrier to access for physiotherapy services (25%) (EURODIS, 2009, p: 127).

Access to medical services was difficult in 9% of situations Patients experienced difficult access to gastroenterology (16%), physiotherapy (16%) and psychotherapy (16%) services. The number of appointments for physiotherapy services was considered insufficient in 22% of situations. Personal cost was considered excessive for psychotherapy (32%) and gastroenterology (25%). The assistance of a professional for the journey to a medical structure was very infrequently reported overall (2%). Satisfaction with medical services Overall, 94% of patients considered that medical services responded fully or partially to their expectations. The level of satisfaction varied slightly according to the kind of medical service, from 97% for microbiology to 87% for psychotherapy (EURODIS, 2009, p: 127).

Social assistance

Amongst the 26% of families needing social assistance 6% failed to meet with a social worker and 32% met one with difficulty. As compared to medical services, access to social assistance was more difficult, and the level of satisfaction with this assistance was lower (EURODIS, 2009, p: 128).

Rejection

Patients with CF experienced rejection by health professionals as frequently (19%) as respondents overall for the 16 surveyed rare diseases (18%). The reluctance of health professionals to treat patients due to the complexity of their disease was the main cause of rejection (81%) but communication difficulties were reported by 13% of patients. The frequency and cause of rejection varied according to the patient's country of origin (EURODIS, 2009, p: 128).

Consequences of the disease

As a consequence of the disease, 10% of patients had to move house. Amongst these, families most frequently moved to a more adapted house (45%), but also to be nearer to disease specialists (43%) or to be closer to a relative (26%). As a consequence of their disease, a member of the family had to reduce or stop their professional activity to take care of a relative in 48% of situations. In 15% of situations, the patient had to stop work as a result of the disease (EURODIS, 2009, p:129).

And here were the expectations of patients and their loved ones that were interviewed:

Expectations regarding Centers of Expertise differed somewhat for respondents affected by CF as compared to the overall opinion of survey participants. Respondents affected by CF considered the following functions provided by a Centre of Expertise as the four most essential:

- Coordinating the sharing of medical information on the patient between all professionals who care for him/her in the specialized center

- Facilitating the follow-up of patients at different stages of their life by easing the passage from pediatric care to adult care, or from adult care to geriatric care

- Communicating with other specialized centers and professional networks to harmonize treatments and research at the national and European levels

- Coordinating the sharing of medical information between professionals of the specialized center and local professionals, to facilitate the continuity of the patient’s follow-up. As a disease diagnosed during the early childhood years, it is not surprising that facilitating the difficult transition from pediatric to adult medical care is considered so important. Survey participants concerned with CF considered ‘offering patients the option of grouping consultations or tests on the same day in the specialized center and organizing the appointments’ as the fifth most essential function provided by a Centre of Expertise, reflecting the multidisciplinary needs of young patients. CF respondents more frequently expressed the importance of the following statement regarding the implementation of Centers of Expertise: ‘Rather than concentrating all the expertise and competencies in a single, national center, sharing them between several centers would be preferable because it is more accessible to patients.’ (EURODIS, 2009, p: 129)

The results of the study were:

The large number of medical needs goes hand in hand with the complexity of the disease. As the life expectancy of CF patients has increased, new medical needs, such as the management of diabetes, or assistance with family planning, have emerged. Frequent hospitalizations for CF are usually due to the need for antibiotic treatment. When possible, delivery of such treatment at home is preferred, as patients can remain close to family and overall costs can be reduced. In many countries in Europe, access to medical care has greatly improved with the establishment of specialized centers of care for CF. However, long wait times to obtain a consultation remain a barrier to access. Patients are often refused physiotherapy services when physiotherapists find that their sessions are too demanding. Although psychological services are often offered in specialized centers of care, patients are required to pay for their psychological services outside the center if they are not satisfied with the particular psychologist on staff. In these cases, CF patients often forego psychological services. Social services for CF patients are inadequate. The number of available social workers is insufficient and they lack the expertise about CF to properly address patients' needs. Many CF patients hesitate to seek social services as they assume that they are reserved for the most severe cases of illness or financial need. It is only once they find themselves in more extreme situations that they seek assistance. To avoid this unnecessary deterioration in patients' lives, social assistance should be offered systematically and should be as available as medical services in specialized centers. Sometimes, CF patients feel as though their healthcare providers are only interested in their lungs (EURODIS, 2009, p: 130).

Comparison of media

Through all the media that have talked about this issue and phenomenon, the traditional media was present in every step, even though most of these media are promoted and funded by the government and all of them support a particular political party or an official. Despite being in the position or with those in opposition, they always chose to be by the side of the patients and different NGOs.

The most work and stories covered in Macedonian channels were Sitel, Telma and 24. mk, which in every case used the most critical tone and did the most about these patients. Putting pressure on institutions and other Media as well to talk more about this issue. NTV was also present and made much news about this, these kinds of stories were given mostly during the news hours because in this way it was always easier to target a larger audience, this audience covers middle-aged people and older ones, but these channels posted many things on social media as well. Despite the channels, the journalists working on the channels helped the story and shared those stories in their profiles, commenting on it and reaching many likes and shares.

The quietest channel in North Macedonia was and is Kanal 5, they were the last one in the list of helping these people. They used to share stories about more general diseases such as diabetes or the story where the director of a particle clinic with a nurse stole medicine for people with cancer and sold them, but rarely about CF. The last medium that we can talk about is Alfa, they used to share these kinds of stories only when they could make those in position seem bad back in the day since they are rooting only for VMRO-DPMNE, and in their eyes, other parties are not doing enough, with this chance they only took some shots when LSDM and DUI needed a hit.

On social media and other portals, these kinds of stories were shared the most and reached even a bigger audience, patients sharing their stories were always posted immediately on bigger channels and those got many likes, shares and comments even from other places around the region.

When it comes to Albanian channels, the only television talking about this was TV21, they did their most by being present on protests, interviews, news and many other platforms helping the patients. They were even joining protests to make sure the voices of these people were heard and not neglected. Alsat and other channels on the other hand were barely making any news and posts about these particular issues, focusing more on the political stuff and not losing any ratings on being one of the most “trusted” media channels in North Macedonia. The Albanian portals were active as well, helping with the boost and making sure that every single story was posted and translated so everyone could understand and be able to learn a story. Any other social media person or any celebrity on the Albanian side was quiet.

Overall traditional media and social media helped the most to reach Trikafta, if this had not been the case, people with CF would have had it much harder and reaching today would have taken much longer time. The ACF was always grateful for the support that they got through these tough fights and they will always be.

The struggle is still going on with other people trying to reach Trikafta and with better conditions on the way, but will these people reach those “luxuries” is still a big question mark. Ministers changing and other issues surfacing the trails of rare diseases and their policies are slowly but surely being forgotten.

The news in the news can be divided into some parts, such as:

Critical tone in the mediums and on the news titles

The following are examples and analyses of media reports of cases related to patients with CF that use a critical tone regarding news related to patients with CF:

> "Factor.mk: "LAST YEAR HE WAS AT PENDAROVSKI WITH AN OXYGEN BOTTLE TO PRAY FOR A CURE: Ilievski and the rest of the cystic fibrosis patients are still waiting for the cure"
>
> The lungs of 45-year-old Blagojce Iliveski from Bitola barely allow him to take a breath. The rare disease, cystic fibrosis, has almost completely eroded these organs, but the multisystem disease that Ilievski has been fighting for 10 years, apart from destroying his respiratory system, also leaves serious consequences for the digestive system, digestive organs and glands with internal secretion.
>
> In a conversation with Factor, one of the most seriously ill patients from cystic fibrosis, told what his everyday life looks like. He spoke slowly to reduce his fatigue. There are many challenges, says Ilievski, and the biggest one is to take a breath.
>
> A little more than nine years ago, that is, in August 2013, I faced the terrible reality for the first time. I had a cold, I went to the doctor, I had to receive infusions, but the doctor suspected exactly this disease, which is why she sent me to the so-called sweat test. Then I had other examinations at MANU and I was indeed diagnosed with cystic fibrosis. It was a bolt from the blue for me. Professor Stojka Naceva Fushtic, now the current director of the Clinic for Children's Diseases, began to monitor my state of health, as well as the rest of the 140 or so patients in Macedonia. I started immediately with therapy consisting of inhalations, and mandatory multivitamins, and as for the enzymes needed for digesting food, which are called creons, I have to take even 30 of them during the day. The diet must be high-calorie and extremely high-quality. This means that during the day I have to have four meals and a snack in between, Ilievski points out.

He says that until two years ago, his health condition was somehow under control, but far from what he needs most for a quality life, which is modular therapy, which, in addition to prolonging their lives, also does a lot to patients suffering from cystic fibrosis better quality.

I had to be hospitalized about two years ago. In conditions when the coronavirus pandemic had a strong intensity in Macedonia, I was placed in the Institute for Lung Diseases in Children - Kozle. There were excellent conditions for us cystic fibrosis patients. There were eight completely isolated rooms and there was a great medical team, the nutrition that plays a huge role in our lives was at the highest level. After 14 days spent there, my condition improved significantly. Unfortunately, I can no longer imagine everyday life without oxygen support. My saturation with constant oxygen, is up to 93, and without oxygen, it drops to 65. The capacity of the lungs, that is, what the spirometry shows me is from 25 to 28. Fatigue is an essential part. My heart rate exceeds 140 just to climb a flight of stairs. And now my health has deteriorated even more after the last hospitalization at the Pulmonology Clinic, says Ilievski, who explained in detail in our conversation the condition in which he was placed.

From October 28 to November 10, I was in the Pulmonology Clinic in Skopje. I am sicker now than before I was hospitalized. There are only two rooms dedicated to cystic fibrosis patients who are in dire condition. They are not isolated from the rest of the rooms, although the disease itself requires, unfortunately, that we be put under a glass bell because even the slightest infection of our damaged lungs can be fatal. Not to mention the food. There it was as if we were on survival, muffin and yogurt. Indeed, after that stay, my health is even more impaired. For us, adult cystic fibrosis patients in Macedonia, there is no hospital where we can be hospitalized. The Children's Clinic only accepts patients up to the age of 18, and Kozle is no longer available to us, says the patient from Bitola.

The only salvation for him, as he says, is either lung transplantation or modular therapy.

There is no other solution. We also begged President Pendarovski for the medicine. There were four of us. I had to have the oxygen bottle with me. We talked for maybe more than

40 minutes. He promised to do everything. But now, how much time has passed, there is nothing from the medicine. Only in Macedonia and Kosovo, it is not there. It is already available to patients everywhere, both in Europe and in the world and the neighborhood, and they don't pay for it. That therapy is too expensive. It costs about 220,000 euros per year. But their governments, their states took care. With us, what can I say, it's as if we are invisible. They neither hear nor see. Transplantation, on the other hand, is also a very expensive operation. I was advised to do it either in Zagreb or Vienna. It costs about 300,000 euros. Where did so much money come from, says Ilievski.

Otherwise, the modular drugs that act directly on the causative agent and prevent the consequences of the disease are "kalideco" and "caftrio". In Macedonia, only "kalideco" is available, and only for three patients who were in the most serious condition. Ilievski hopes that now that his condition has worsened, perhaps the health authorities will finally start some negotiations for the purchase of the medicine that means life to him. And not only for him but also for all 140 cystic fibrosis patients, the largest percentage of whom are children.

Telma: “Sali makes calculations as cystic fibrosis patients prepare for another protest”

While patients are begging for medicine - the Ministry of Health is calculating. There is nothing in sight from the purchase of a new modern therapy that should improve the quality of life of patients with cystic fibrosis, and the line ministry is passing the ball to public health institutions that have not allocated funds from the budget for this category of patients.

The drug Trikafta for one patient costs 300,000 euros per year, and in the country about 65 patients need it, claims Sali.

The revolt of patients with cystic fibrosis did not subside, so after protesting in front of the Ministry of Health, they announced a new protest in front of the Government on February 4th.

Last year, the Association for Cystic Fibrosis with 10 thousand signatures tried to ask the health department to provide them with the drug, but even after all this time, they are still waiting for the answer. In neighboring countries, the drug is already on the positive list and easily available for patients with cystic fibrosis.

Makfax: “When a patient dies, the authorities will see the urgency of the need for a quick cure, say cystic fibrosis patients”

The president of the Association for people suffering from Cystic Fibrosis, Fiki Gaspar, tells "Makfax" that the health condition of the patients is bad enough and that waiting and prolongation should not be allowed for the procurement of the drug "Trikafta". Gaspar sent her a public message: "We must not allow a patient to die," after which he added that three patients are in critical condition and every day means a lot to them.

"One patient had three interventions by ambulance during the previous week, we are doing all the pressures everything in order not to lose that human life, but if we wait for the change of certain laws, which Minister Sally announced, it is not at all accordingly and we don't have time to allow certain processes to drag on", says the representative of people suffering from cystic fibrosis in a statement to "Makfax".

When asked if there will be a next protest, the representative of the Association says that for now there is no such announcement, but if one of the patients who are in critical condition dies, there will be a big revolt from the parents and other patients.

Gaspar, as a representative of cystic fibrosis patients for "Makfax", points out that they are constantly putting pressure on, but they have no information when the medicine will be procured by the Ministry. It is decided that they do not have time to wait and that for every patient it is a luxury.

"We are quite satisfied with how the protest went, there were many people and more than expected despite the weather and considering the other events that happened that day in the country, but we still do not have any official response from the institutions. On Friday, we had a meeting with the minister, and they gave us some steps that they think should be completed, such as changing certain laws, changing certain regulations, as well as establishing contact with the company that would procure that medicine. "Yesterday, as a result of the meeting we had with the management and supervisory board, it was announced that we will wait until Friday for an official response regarding our protest," he adds for "Makfax".

The first person in the Association believes that progress has been achieved in the negotiations with the authorities, which has not been seen in the last three years. At the same time, he points out: "There will be another protest if the minister does not stick to his word that things will move dynamically and by the end of the year there will be medicines for 30 patients, and for the remaining, they will be delivered in the year."

The Ministry of Health had a meeting with the Ministry of Finance to find a way to procure the expensive drug directly from the manufacturer. They pointed out that negotiations are already underway. But for the procurement to be realized - three laws must be changed. This means that the Government should prepare the amendments and submit them to the Parliament, where the MPs will have to express their opinion through voting.

On Saturday, a protest was held chanting "We want medicine, not a commodity" and "'Trikafta' for all". The patients and their families held a protest in front of the government and demanded that the government hurry up with the decisions and provide medicine for all the sick.

Factor.mk: “IS THE MINISTRY OF HEALTH CREATING A QUEUE FOR THERAPY OR A QUEUE FOR DYING? Trikafta is only for patients with moderate and severe lung function”

On July 4, the Guidelines for the Practice of Evidence-Based Medicine for the Treatment of Cystic Fibrosis Patients were adopted and published in the Official Gazette.

This instruction prescribes the treatment of cystic fibrosis, and the indications for setting up the therapy with the most modern modular therapy Trikafta are listed.

-Patients with diagnosed cystic fibrosis, confirmed by determining two disease-causing CFRT mutations (https://cftr2.org/List of current CFTR2 variant) of which at least one is FS08del (c.1521_1523delCTT).

- Our age criteria are 12 years and older, and as an exception (with the Decision of an expert council that gives a conciliar opinion valid for 12 months, due to more severe clinical expression of the disease and frequent exacerbations) it can be given from a younger age from 6 years and up.

- When determining priorities, the expert council takes into account lung function (FEV1=40-70pp moderate and FEV1<40pp severe lung function (ERS reference); the frequency of exacerbations, lung CT changes, nutritional status, adherence to the recommendations of regular monitoring and treatment of the disease (compliance) and lifestyle.

Although almost everyone is silent regarding the guidelines that have already been adopted, Natascha Novakovska, a parent of a child with cystic fibrosis, is extremely outraged in a conversation with Factor, saying that this is not medicine based on evidence, but based on available finances and subjectivism.

- After several months of "intense work" as declared by the Ministry of Health, on 04.07.2023, the Guidelines for the practice of evidence-based medicine for the treatment of patients with cystic fibrosis were published and adopted in the official gazette. There was and still is no announcement about this in the public or any notification for the patients. Played again in the cruelest way possible! According to this guideline, I quote "our" that is, theirs, or to express myself more eloquently, the criteria of the Ministry of Health include patients with moderate and severe lung function, which every patient eligible for therapy will reach in the absence of the drug! So I ask publicly, who will bear the responsibility that my child is suitable and can receive the therapy, which is, FIRST OF ALL, preventive and prevents the progression of the disease, and does not meet "OUR" criteria? Who will be responsible when, in the absence of therapy, the disease progresses? What is this subjectivism completely contrary to my expectations? In which line will we wait for therapy? In what order? Time for therapy or time to die? I'm asking publicly! This is a completely wrong approach compared to what is accepted in Europe and many neighboring countries, Novakovska points out.

At the same time, she addressed a series of questions to the Ministry of Health, primarily based on what were made, as she says, "OUR" criteria.

- What will be used to finance the procurement of the medicine? - Have the negotiations with the procurement company started (the law has been changed and there are no legal obstacles)? Or will it be a one-time purchase with intervention import again? - Is this a measure of success and why did the Ministry of Health not boast publicly? Or is it for public condemnation? Or is that the strength? (let's know why we are running out of strength and patience).

-Does this instruction have a legal opinion (it interests me in terms of subjectivism and a discriminatory approach in my opinion) or should I seek a lawyer?

Finally, modern therapy has a much broader meaning than TRICAFTA. It's just one segment, one modulator. Other modulators are given from 0+ ie. from birth with proven very positive effects. Width is achieved by negotiation and price by quantity (at least that's what I was taught). And finally, none of the "writers" of this guide is personally affected and does not "burn" under his feet. Both with and without the manual, their salary is guaranteed. It is "hot" under our soles, that we have been living this harsh reality for years. "Fry enough for a lawsuit and the "bolt" from here," Novakovska stressed indignantly.

By the way, the most up-to-date therapy "trikafta" was procured by interventional import immediately after the death of Blagojce Ilievski, the most seriously ill patient from this rare disease. For three years, he waited for the state to buy the drug, for him, but also other patients with cystic fibrosis. After several months, the drug was provided to only eight, and then to four more patients.

After the last protest at the beginning of May, representatives from the Cystic Fibrosis Association were called to a meeting with managers from the Ministry of Finance, after which they received a new promise, which is that the drug will soon be procured for another 18 patients who are in moderate and severe condition. There are about 130 patients with cystic fibrosis in Macedonia.

Novamakedonija: “Bureaucratic procedures are an obstacle for additional patients to receive "Trikafta"

Bureaucratic procedures were an obstacle for other patients with cystic fibrosis to receive the drug "Trikafta", in addition to the 12 who are already receiving it. This was announced at today's meeting of the Minister of Health, Fatmir Mexhiti, with patients with this rare disease and their parents. There is no exact date when new patients will start receiving the modulatory therapy, and the problem of the shortage of the drug "Creon", which these people take daily with food, will be addressed.

The president of the Cystic Fibrosis Association, Fiki Gaspar, said that the meeting discussed their request to have modular therapy for all patients.

- The Government itself mentioned that one hundred million denars have been made available and that it is about an additional 55 patients with cystic fibrosis to start receiving "Trikafta". Today we were told that the finances have been approved and transferred, but, according to the negotiations with the company from which it will be procured, they cannot say a number, because they hope that there will be a larger number of patients. There was also talk about the shortage of the drug "Creon", which patients use daily in their diet. The drug is in short supply and very often has to be bought from other places, or borrowed from patients who have stock. We were promised that this problem will be considered, and we hope it will be solved - said Gaspar after the meeting at the Ministry of Health.

He informed that they did not receive an exact date when the new number of patients would start receiving "Trikafta".

- Our great hope is that the modulatory therapy will be procured by the middle of December, but we were told not to be tied to dates, that according to all, unfortunately, bureaucratic procedures, a date may be picked up a little later. The minister listened to patients who have been waiting for a long time; we 12 have the therapy until the end of the year. It was mentioned to us that there should be no stoppage - explained Gaspar.

As he pointed out, it was also discussed their complaint that there was a protocol where patients from 12 years old and above would receive the modulatory therapy, which was not the practice in other states that already use it and already have, as it was pointed out, many positive effects of itself.

- We asked the commission to reconsider its decision if it can make a suitable change, like other states. We were told by the Ministry that the program is made by experts. We have to continue to negotiate about that - underlined Gaspar.

When asked by a journalist whether there will be new protests, he answered that it is necessary to talk with the membership, but he hopes that things can be sorted out without a protest.

- Although we have had protests in the past, which, in my opinion, contributed to a positive effect - added Gaspar.

He informed that at the Children's Clinic, the conditions for patients with cystic fibrosis are excellent, and they, as an association, helped to equip the clinic with donors.

- The problem remains for adult patients; Pulmonology does not have a large enough capacity when more than two or three patients deteriorate at the same time, Gaspar said.

The spokeswoman of the Ministry of Health, Berna Sherifovska, about the announced new center for people with this rare disease, said that the funds have been provided through a donation and it is expected that in a short period, the procedures for equipping will begin, for the complete reconstruction of the facility in "Kozle".

- It will be a truly modern facility, built according to European standards. The patients will be in one place, where they will be treated by doctors - specialists, exactly experts in this disease, which we are all aware of, the kind of life they go through and the problems they face - added Sherifovska.

She informed that on Thursday they received a letter from the Fund, where funds were approved for the purchase of the modulatory therapy.

- We as a Ministry have acted to the end, now it is up to the Public Procurement Bureau to prepare the module and therefore when it is ready, we will immediately announce the tender and everything will proceed according to the procedure - said Sherifovska, clarifying that it is a different module type, required for this type of public procurement.

Important news related to Trikafta and other medicaments

The following examples are news related to Trikafta and other medicaments that are needed in the country:

Sitel: “Legal changes will find a way to provide cheaper medicine for cystic fibrosis patients”

In anticipation of the protest of Cystic Fibrosis patients in front of the Government on Saturday, the Prime Minister announced that the health institutions are making efforts to provide the medicine they are looking for. Kovacevski stated that if necessary, they will also prepare legal amendments so that the therapy can be purchased directly from the sole manufacturer, and not through suppliers. The Prime Minister emphasized that the medicine is very expensive. The purchases will be within the budgets of Children's and Pulmonology, but he did not say whether there will be enough for all 60 patients, for which approximately 20 million euros are needed annually.

- It is also necessary to check whether the therapy is suitable for all patients, if necessary, legal changes will be made and the drug should be purchased directly from the manufacturer, and not through merchants who add a margin to the highest price and receive an extremely high price, said Prime Minister Dimitar Kovachevski.

The Cystic Fibrosis Association is adamant that all patients should receive modern therapy and that it should be permanent. They will withdraw from the protest only if they receive in writing that the authorities have contacted the manufacturer and a guarantee that they will receive the medicine.

- We must have an official confirmation that we will receive the medicine, only in that case we can postpone or not hold the protest, said Fiki Gaspar from the Association for Cystic Fibrosis.

The protest of Cystic Fibrosis patients and their relatives, friends and citizens who support them will be held on Saturday at noon exactly in front of the Government.

TV21.mk: “Cystic fibrosis patients protest "This approach makes us feel cursed to live in RNM"

"We don't want the institutions to see us as just a number that protests against them or has something personal against them. We are in a situation where we just want to save our loved ones!”

Patients with cystic fibrosis again protested in front of the government today, with an appeal to the state to provide them with the necessary medicine, so that they can live normally. Although yesterday the Minister of Health, Bekim Sali, said that they will start the procedure for the procurement of the drug, these patients demand that the promises be written on paper.

The drug that is being sought is a drug that significantly increases the quality of life of people with cystic fibrosis, said actor Elmir Seyfulai, urging that it be provided to all patients.

"Of course, the psychological and emotional revolt is reaching its peak. The despair is very great and I am sure that some of us have often felt cursed for being born in a country that has this approach to our lives. Yesterday there was a small point of light at the end of the tunnel, but we decided to come here today to deliver a message to those we have chosen to sit in the chairs in this building behind us - that despite the initial efforts we will not stop looking for the cure until he gets the last patient," says Elmir Sejfullai.

> There are about 130 patients diagnosed with fibrosis in the country, but currently, only eight of them, who are in a more serious state of health, will receive the necessary therapy. The relevant minister, Sally assures that they are making efforts to procure the medicine for 30 more patients by the end of the year.
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> Telma: “Trikafta arrived at the Children's Clinic, eight patients will start therapy these days”
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> The medicine "Trikafta" for cystic fibrosis has arrived at the University Clinic for Children's Diseases, the Minister of Health Fatmir Medjeti announced today. In cooperation with other institutions, as he clarified, the most pressing issue of this category of patients has been resolved.
>
> "We expect this therapy to significantly improve the quality of life of patients with cystic fibrosis," emphasized the minister.
>
> The director of the Clinic for Children's Diseases, Stojka Fushtic, said that the medicine arrived this morning and they are already accepting patients who need to start therapy.
>
> "We receive six patients at the Clinic, and two will be referred to the Pulmonology Clinic. Of the eight patients, two are in a truly critical condition. Seven patients are over 18 years old, and one patient is a child. We got a slightly lower price than expected, than the one publicly announced. We requested to Health Fund, additionally within the same budget, to include four more patients. It is about annual therapy, once a month we will give them tablet therapy", she clarified.

Interviews

The last news that is gathered for this part of the study is the interviews done with patients and their loved ones related to Trikafta and the experience with CF:

> Telma: “CODE: Confession of Pain and Race for Longer Life - Cystic Fibrosis and State Neglect”

For several months now, cystic fibrosis patients have been alarmed that there is an effective new drug for them, Trikafta, and that the state is not supplying Trikafta.

Blagojce Ilievski, from Bitola, paid for the slow reaction and state negligence with his life, he died last week.

In KOD tonight, the confession of several patients who live with the pain of cystic fibrosis and with the hope that the state will stand on their side.

Sitel: “Patients with cystic fibrosis with a new call to the Government to provide Trikafta to everyone”

There is still no specific date when the rest of the cystic fibrosis patients will receive Trikafta. Together with the other 100 comrades, 17-year-old Andrej Isaeski is eagerly waiting for the medicine.

- We must be able to socialize, to walk without inhalers, without drugs and not to depend on some drugs and venous therapies, and that is why it is one of the most necessary drugs, says Andrej.

The high school student says that when his condition worsened and his lung capacity decreased, not only he but everyone around him felt it.

- I cough much more, I am less active and I get very tired, says Andrej.

Due to this condition, Andrej spent 15 days in a hospital bed at least 3 times a year. He is now in the 3rd year of high school, and the disease was diagnosed at the age of 6 months. He goes through his education so far with many difficulties.

- And it is a little more difficult to endure those 15 days, there is not much climbing, we are limited with climbing, they don't let us go to the store so we don't catch any bacteria, God forbid, and we have to lie in a room within four walls for those 15 days, he says Andrei Isaeski.

Andrej's greatest wish is that all patients with cystic fibrosis get Trikafta so that they can see what it's like to live normally and that he can continue to university without problems and contribute to society.

- As soon as the cure comes for everyone, it means a lot to us to see what it's like to live with a full stomach, says high school student Andrej.

But how long they will wait for this, there is no concrete answer from the authorities. The reports of the Commission at the Ministry of Health, which patients will have priority for the drug according to the worsened condition, are not ready either.

- The preparation of the Commission's reports is in the final stage.

A representative from the Cystic Fibrosis Association will attend the next meeting to be held next week, the Ministry of Health replied.

After a cystic fibrosis patient died 4 months ago, 12 people have received Trikafta and all of them have seen a significant improvement in their condition. During the last protest at the beginning of May, they received a promise from financiers that the government would provide money for another 18 patients, and another 130 are waiting for the medicine, including Andrej, as well as other children with cystic fibrosis.

TV24: “24 analysis – Will the medicine for cystic fibrosis patients be procured in time?”

Unfortunately, the death of Ilievski, who did not receive the Trikafta medicine, woke up the institutions, but the question is whether they will stay awake and whether we need such examples to see that the system is rigged.

Pepo Levi from the Association of Chronic Myeloid Leukemia Patients, Vesna Stojmirova Alexovska from the Alliance for Rare Diseases, Fiki Gaspar from the Cystic Fibrosis Association and Slobodan Katushevski, parent of a child with cystic fibrosis.

Sitel: “Trikafta stuck in the triangle Government-health-finance – 30 patients with cystic fibrosis are still waiting for a cure”

The promise of supplying the drug Trikafta to cystic fibrosis patients remained just a promise. At their last meeting at the Ministry of Finance, a month and a half ago, they were told that they were waiting for an answer from the Government regarding the treatment of 30 patients. The Ministries of Health and Finance missed the deadlines, and the promise remained unfulfilled. While the procedure for the procurement of the drug Trikafta is stuck in institutional labyrinths, patients are fighting for their lives.

They spend their days hoping that their health condition will not suddenly deteriorate and that they will be able to get the medicine. They ask the authorities to act faster and not allow another tragic fate like that of Blagojce, who died at the age of 45 while waiting for the medicine.

One of the authorities from whom an answer is requested for the procurement of the medicine, the Minister of Finance Besimi, was surprised by this question.

In the Parliament, the MPs agreed to exempt patients with cystic fibrosis and their families from paying tolls and road fees. This decision was also welcomed by the Association for Cystic Fibrosis, which remains in the position of three-way for all.

TV24: “Patients with cystic fibrosis will have to wait some more time to be exempted from co-payments for treatment”

The MPs will again be tested for the health of the most vulnerable categories of citizens, this time for people with disabilities, which according to the current classification also includes patients with cystic fibrosis.

Although a few years ago they were managed as patients with rare diseases through a program of the Ministry of Health, they were then transferred to the category of persons with disabilities, who are entitled to exemption from participation only until the age of 26.

Member of Parliament and Dr. Nenad Kocić from SDSM says that the Parliament is now proposing amendments to the current law on health insurance, which provides for exemption from participation for all patients with disabilities, which practically includes patients with cystic fibrosis. Kocic says that yesterday they were put in session and he expects them to be voted on soon.

- They were covered through a program by the Ministry of Health along with other diseases, which exempted them from participation, but seven years ago the Ministry of Health removed them from the list of rare diseases and I don't know why they are included in the list of persons with disabilities. Now, when they receive the exemption, it says persons with disabilities, which is not logical, why they have been put in that group? The mistake was made seven years ago. I believe that by solving the participation of people with disabilities, people with cystic fibrosis will also enter. - says Nenad Kocic, deputy of SDSM.

Yesterday, VMRO-DPMNE's proposal for exemption from participation after the age of 26 for people with Cystic Fibrosis was not voted on. The party recognized politics in this move by the government.

"We were looking for a legal solution specifically for people with cystic fibrosis because they are dealing with 50 to 60 people and that means nothing for the state. We have been looking for a legal solution specifically for patients with cystic fibrosis and now if they submit a new identical law, their intention may be not to adopt our proposal, they will submit a similar one, but we will certainly support it for the benefit of patients, because there should not be a policy when it's about this issue." - says Petar Risteski MP of VMRO-DPMNE.

Meanwhile, patients with cystic fibrosis who have reached the age of 26 have to pay for all medicines out of their pocket. Every month they have to buy a large number of vitamins, antibiotics and enzymes to control the disease, which costs them hundreds of euros per month.

"We are hoping that they will grant us an exemption from participation because the disease is multi-complex and the law is a bit strange because here I am 26 years old and I did not recover as well as other patients who did not recover, on the contrary as we get older the condition worsens and the costs are increasing, which represents a greater burden." - says Aleksandar Stamboliski, a patient with cystic fibrosis.

Estimates say that if a hundred people with cystic fibrosis were to be exempted from the maximum amount of 100 euros of participation per year, it would cost 120,000 euros per year. Patients with cystic fibrosis in the country are mostly young people and children. Apart from the exemption from participation in the institutional labyrinths, the procurement of the drug trikafta, which means life for these patients, also got stuck.

Government: "Mexhiti: Trikafta arrived at the children's clinic, and we fulfilled the promise"

The Minister of Health, Dr. Fatmir Mexhiti, held a press conference today in the Government of the Republic of North Macedonia on the occasion of the arrival of the drug Trikafta for patients with cystic fibrosis.

In the following, we convey to you his address in its entirety:

"I remember a few months ago the crisis that was created due to bureaucratic procedures that created panic among patients with cystic fibrosis, their revolt was justified, of their families, and loved ones. The revolt of the public was also justified, and we as the Government had to change something. As the Minister of Health, and above all as a long-term doctor, my patients and their health were always in the first place.

And I've always advocated that all the needs in terms of drugs, diagnostics, in terms of aids, something that is a daily need of patients be addressed as quickly as possible, immediately! Bureaucratic obstacles cannot and should not be the reason for the health of citizens.

The drug Trikafta is already at the University Clinic for Children's Diseases. With 100 million denars, therapy was procured for the following months. In addition, 854 million

> denars are planned for the drug, for 2024 and 2025, so in the next two years, patients with cystic fibrosis will be provided with therapy.
>
> Patients with cystic fibrosis are gradually included in therapy, according to the Protocol and precise evaluation criteria, decision is made to receive therapy. The list of patients was made by the Expert Commission, after medical examinations of all patients with cystic fibrosis, according to scoring.
>
> The drug Trikafta is a safe drug, approved by the European Medicines Agency. What is very important is that the effect of the therapy is fast, significant and sustainable. In Europe, the drug is standard therapy for the treatment of patients with cystic fibrosis.
>
> Dear,
>
> As a minister, I am open and transparent with patients to hear what their real needs are and what the way to solve them is. "The solutions that we bring are not imposed, but have a real effect," said Mexhiti.

These three types of categories used by the mediums are a good example and are important because these types of reports from the mediums give the greatest contribution to influence exerting pressure on the public and authorities and also on the institutions to take solid measures and actions.

PART TWO: METHODOLOGY

The research design of this thesis is mixed methods, where I used qualitative and quantitative methods to reach my results and have a better understanding of the issue and the current policies in North Macedonia. The questionnaire consisted of open-ended questions and questions with comments for the participants to get a better understanding of the current issues and the new drug Trikafta. The material collected was also from news websites, research done by other associations and other diseases. The approach of this thesis is descriptive because to research this topic and to be able to get deeper into this topic it is needed a more in-depth analysis of the current situation.

Within this study there was original research conducted with people who struggle with CF and/or their loved ones, such as parents, siblings and people who are caring for these patients, this research was done to see the power of media in important cases, how much media covers difficult cases, how much impact it has on rules, policies and laws. This was also done to reveal the struggle of people with rare diseases in North Macedonia, and how much they have to fight every day to live another day. In this study a mixed method was used, with qualitative and quantitative research because the questionnaire was done online it was easier to reach a broader target with people from different cities in NM, also second research was used to have a clearer version of everything that has been going on in the country, especially related to rare diseases.

The main questions will be asked in a mixed methodological approach, where these questions will have to do more of expression of feeling, interpreting those and will be explained in detail. The targeted audiences are patients and their loved ones; the questionnaire was shared online, more specifically in the group on Viber of the Association of Cystic Fibrosis in North Macedonia. The answers will be collected with a questionnaire that will include questions for both parents and people who struggle with this disease. This type of method will be used because it will be easier to reach a wider audience and easier access to those who cannot be met in person. For this research 50 people will be interviewed or questioned, all over North Macedonia to get to know more about everyone’s experience and those questions will be interpreted in detail and include everything that is needed. Also, the other questionnaire will include questions for those participants and patients who themselves alone struggle with it, to ask about the current situation and also for those who have accepted and started the treatment with Trikafta, how their experience is and whether they have seen any changes while taking it.

In these questionnaires of course it will be included the help of the media, how it has affected the whole campaign, how much was it effective and fast to be included in the media while asking for something very important for their children and for those who have this disease. Also, it will be included how their patience was tested, some of them struggling to do the exercises needed until Trikafta arrived in North Macedonia. In the questionnaire, it will be included the psychological fight also after losing a very important person while participating in the campaign and how it affected the aftermath including the patience and the “image” of politicians and officials. The results of these questionnaires will be analyzed and interpreted thoroughly, explaining every detail related to the topic and questions included in this thesis. The analysis of the questionnaire will be given to patients all over North Macedonia, which will affect the result because many patients outside of Skopje have it harder and harsher with the conditions and possibilities in their cities or villages.

The main question of this research is the media coverage of rare diseases in North Macedonia, there are other questions as well such as:

1. "What are the key components of the current rare disease policy in North Macedonia, and how effectively does it address the needs of individuals affected by rare diseases in terms of diagnosis, treatment access, and support services?"
2. "How does the range of media coverage of rare diseases in North Macedonia contribute to public awareness, understanding, and support for individuals affected by these conditions, and what factors influence the extent and nature of media attention on rare diseases?"
3. "How does the coverage and discourse surrounding rare diseases differ between legacy media and social media platforms, and what impact do these differing media channels have on public awareness, support networks, and advocacy efforts for individuals affected by rare diseases?"
4. "What are the current challenges and opportunities regarding the availability and accessibility of Trikafta, a breakthrough medication for cystic fibrosis, in North Macedonia, and how do factors such as healthcare infrastructure, regulatory processes,

and affordability impact its distribution and uptake among individuals with cystic fibrosis in the country?"

5. "What are the lived experiences and perceptions of individuals with cystic fibrosis who have been prescribed Trikafta in North Macedonia, including their treatment journey, quality of life improvements, and challenges encountered in accessing and adhering to this medication?"

Participants / Sample

The study's sample consists of 50 participants from all over North Macedonia. They were selected according to the disease and those who have and do not have access to Trikafta. The number of participants was selected according to the efficient number to be able to understand more in-depth about the issues surfacing.

Data collection

The data collection was conducted through an online questionnaire to be able to have participants from all of the cities in North Macedonia and via Microsoft Forms. Most of the participants live in Skopje but many issues occur for those outside of Skopje and every patient from all the cities needs to be able to express their problems. In this questionnaire, there were 20 parents and 30 patients, expressing their knowledge and their thoughts as to what is best for CF patients and how their life was affected by this disease.

Data analysis

The data was collected through the Association of Cystic Fibrosis group on Viber, where all the patients and parents are taking place, to discuss issues and talk about everything related to CF and their daily lives. The data collected from this survey is related to CF and its treatments, besides that it is also related to media coverage and the rare diseases policies and how effective everything is in North Macedonia.

Section / Theme	**Questions**
Demographics	4
Awareness and Access to Trikafta	4
Experience with Trikafta	2
Awareness and perception	3
Impact and effectiveness	3
Additional comments	1

Table 1. Questionnaire: Breakdown and questions

Ethical considerations

Before participating in the questionnaire all the participants were informed about the process, even though the questionnaire was going to be anonymous, and it was explained why I needed this data and how it would be conducted and analyzed and the purpose of it. Everyone participated voluntarily knowing and being aware of everything.

Limitations

The only limits on this questionnaire and response it is that not everyone has answered the open-ended questions and sometimes the questions were confusing for the participants, most likely because of the language barrier, since the questionnaire was in English.

PART THREE: ANALYSIS OF THE RESULTS AND DISCUSSION

Media coverage analysis

The scope of the analysis is to see how much media coverage has impacted the understanding of rare diseases and the importance of the drug named Trikafta. Through this questionnaire and this analysis, it is seen how much the media shapes the thoughts and knowledge of citizens about rare diseases and CF.

Data summary

Many of the participants on the question “Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?”, 48% of the participants or 24 participants voted for “Yes, greatly”, 46% or 23 participants voted for “Yes, somewhat”, 2% or 1 participant voted for “No, not really” and 4% or 2 participants voted for “Not at all”. In this questionnaire, it is seen that many participants also have mixed feelings and thoughts related to the news about CF and Trikafta in any type of media.

Key findings

Through the crises and before media didn’t report much about the issues of rare diseases, this kind of news is seen occasionally and in short-term periods and they differ in every type of media. The coverage in media was generally positive and in support of patients and there was so much criticism of the government, politicians and those who didn’t do the job as they should to make the lives of patients easier. Included in the media coverage are social media, traditional media and every other type, the most successful and helpful to the campaign and the needs of patients were social media and television, more specifically news. Before this issue, the citizens were not enough informed about any of these kinds of diseases especially CF, after the reporting continuously changed, the views and the general knowledge related to this.

Comparative analysis

Despite having issues in general in the Health System and the hospitals, the rights of minorities were never fulfilled and there were always issues. These all took a more serious turn when one of the patients with CF passed away and everyone reacted in supporting patients and reacting negatively to the politicians, the politicians in fear of the public image were taking more "serious" steps further. The news reporting was much more different from social media, in television particular patients were taking place and telling more about their stories but generally, it was about the current issues in the country, but when it came to social media it was easier to interact and share more widely and in detail about personal issues and making sure everyone understands with less medical terms.

Thematic analysis

There were times when other crises were talked about in the media mostly, whereas, in a country like North Macedonia, there were no "off days" in crises, through that period the media were not reporting and the only activity was through social media trying to gain attention all over again. The patients were doing everything trying to do everything to be able to include every patient in the treatments, trying to change laws and policies about how the system is working even though there are huge gaps still in the system. Generally, the issue was covered by all media and even though the media are divided in supporting different things, politicians, political views and issues, everyone was working together to criticize and hold accountable those in power and those who were in the wrong.

Comparison

The HAEi RPA Natasha Angjeleska was announced as the next president of the National Rare Disease Alliance, receiving the sincere support of most Member Organizations. Natasha addressed the event, which was greatly covered by media, by saying that strength is not in numbers but in character and integrity, elaborating that over the years, she has learned that regardless of whether you are one, part of a group, or part of the majority, you are worth as much as your character and actions. She added that, although rare disease patients are always asked about numbers, numbers don't matter; what matters is that each patient is a valuable individual. Natasha also added that she had met great people throughout her ordeal with her child's diagnosis and mentioned that doctors and nurses felt like an umbrella to her, come rain or shine. She, however, stressed that the greatest people she had met in her life, who felt like her second family, were rare disease patients and their families. (HAEi, 2024)

Besides the traditional media, social media has a big influence on the knowledge of people related to rare diseases and cystic fibrosis in general. People become more eager to get to know and support people who need it. Many other people with another rare disease might even relate to the struggles that are ongoing in North Macedonia as the result of poor management from the Government, Ministry of Health and other institutions.

Other successful campaigns done on social media are usually from those who are more “IN” in the healthcare system, as an example we have the well-known company Roche for the whole month of February, which is known as the Rare Disease Month, which has posted for many rare diseases. A few examples are:

> "The state must ensure timely, regular and efficient access to therapy and treatment for all patients. Treatment is a right, not a privilege." - Dusica Nofitoska - Association of Young Lawyers
>
> "Our countrie’s leaders must address health disparities and ensure that all people have equal access to the best individualized medical care – regardless of background, lifestyle or type of cancer." - Milan Miskovic - Vice President and Program Manager at Hepar Center-Bitola and ELPA Director
>
> "Together, we can build a healthcare system that leaves no one behind in the battle against cancer. Together, we can make a difference!”
>
> #MacedoniaAgainstCancer #WorldCancerDay #DemandACancerPlan - Lidija Petsova, President of HEMA-ONKO, Association dedicated to cancer patients and their caregivers
>
> "The need for a better quality of life through better health is not just a hope, but a goal that we will achieve." -Vesna Aleksovska, president of Life with Challenges

"Regardless of the challenges we face, the focus of our society must be the health of children, it is the only option for the future of a community." - Maria Vuk - SANO - Association for better health, education and social care

Many celebrities take part in raising awareness by sharing posts and reaching a bigger audience through their following which can lead to louder voices and easier reach to those who need to take part in making a change for these people and this country.

Bozhidar Bozhnivski on his Facebook profile posted:

"The Ministry of Grubi gave 160,000 euros for royalties last year alone"

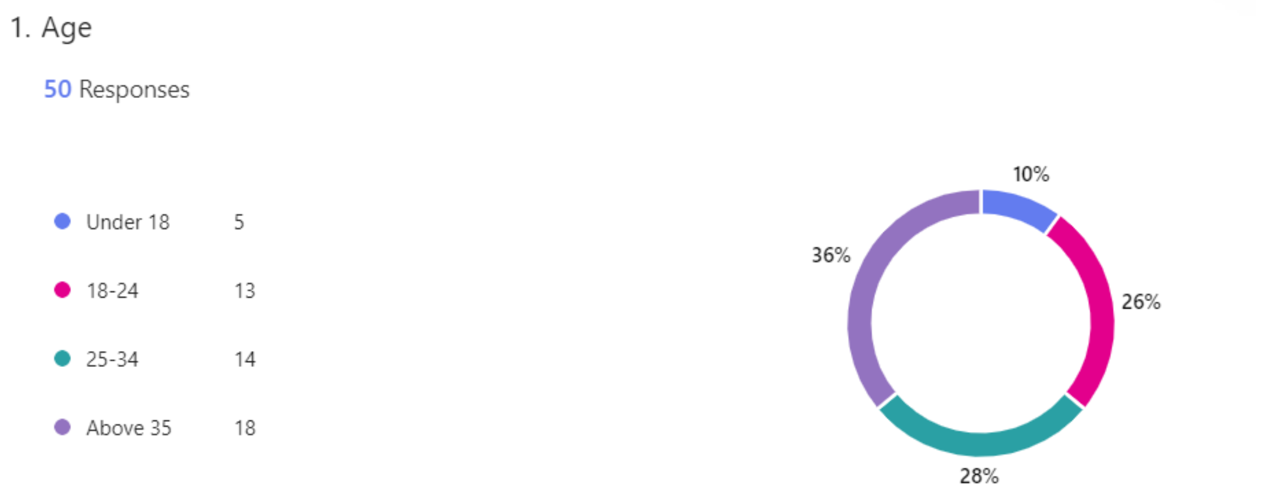
The Ministry of Grubi has over 1200 employees - as many as the next three ministries combined. Various thieves who are rude and party poltroons have eaten our future, people are dying without medicine while we feed them, there are no ambulances, and children are being treated by text messages while we pay the government's fees to support it while it destroys us.

There will hardly be any responsibility now, but the day will come for the rude. And you can give a list of the despots of the government a few years ago.

Discussion

Interpretation of results:

Here is the demographic structure of the respondents:



1. Age

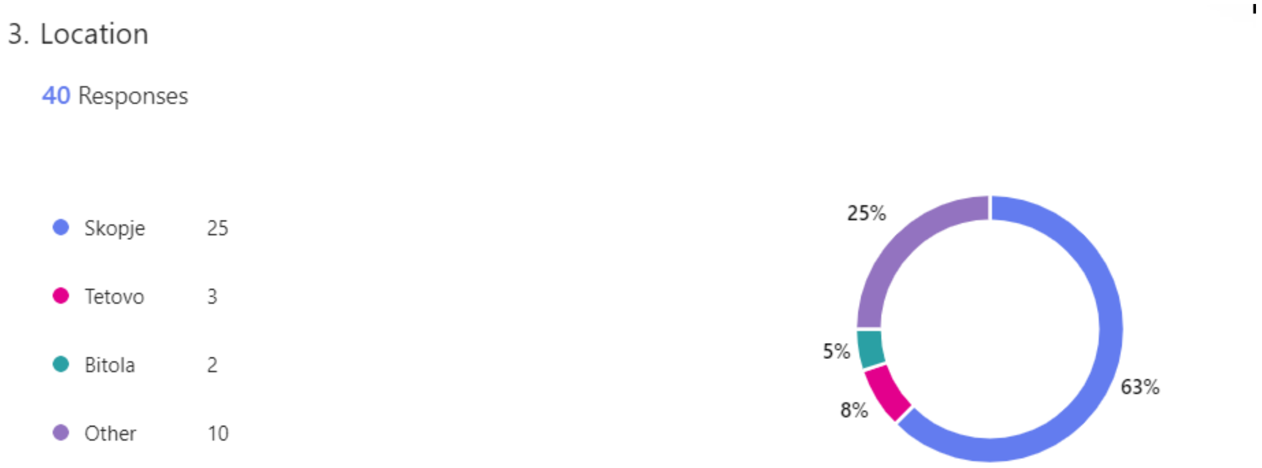
50 Responses

●	Under 18	5
●	18-24	13
●	25-34	14
●	Above 35	18

2. Gender

50 Responses

●	Female	30
●	Male	20



3. Location

40 Responses

● Skopje	25
● Tetovo	3
● Bitola	2
● Other	10

4. Role

49 Responses

● Patient	29
● Parent (Caregiver)	20

The first question on the questionnaire given both to patients and/or their parents or caregivers was the age, out of 50 participants 10% or 5 people were under 18, out of 5 participants that were under 18 were 2 patients, 2 parents or caregivers and 1 of them didn’t pick any role.

13 participants or 26% of the participants were 18 to 24 years old. All of the 13 participants are patients of this age.

Participants that are from 25 to 34 years old were around 28% or 14 of them. Out of 14, 12 of them were patients and 2 were parents or caregivers.

And the most participants were above 35, more specifically 18 participants or 36%. Out of 18 participants, 17 were parents or caregivers and 1 of them was a patient.

On the second question, we had the question of gender, where out of 50 participants 30 were female, or 60% and 20 male or 40%.

Out of 30 females, 1 of them didn't choose a role, 14 were patients and 15 were parents or caregivers.

Out of 20 males, 15 of them were patients and 5 of them were parents or caregivers.

On the question about their location, since this questionnaire and study want to include every city around North Macedonia and get to know all about the conditions and the awareness around North Macedonia, there are plenty of different places.

25 participants or 63% of them are from Skopje, out of 25, 14 were patients and 10 parents, and 1 of them didn't choose a role. 3 participants were from Tetovo, 2 of them were patients and 1 of them was a parent or caregiver. From Bitola, there were 2 participants, 1 patient and 1 parent or caregiver.

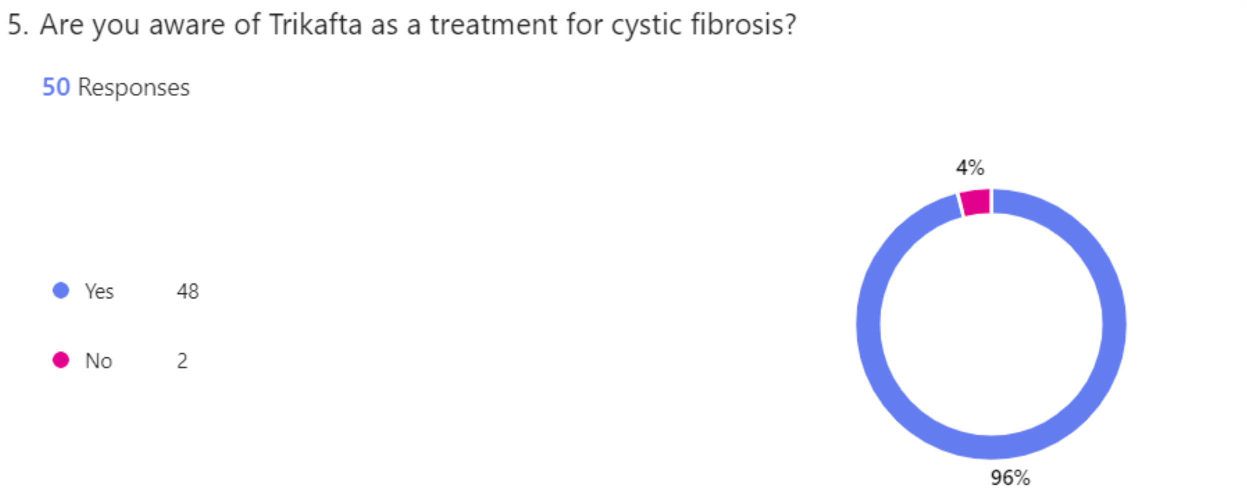
In the option of "Other" they had the opportunity to choose or write the city that they are from which 10 participants did and those cities are: Kumanovo with 2 parents or caregivers and 1 patient, Prilep with 1 patient and 1 parent, Ohrid with 1 parent, Kocani with 1 patient, Debar with 1 patient, and Struga with one patient.

10 participants did not write about where they come from or where they live.

On the 4th question we have the question of what role they have, which 49 participants answered and 1 of them didn't choose anything. 29 participants were patients or 59% and 20 participants were parents or caregivers or 41%.

Cystic Fibrosis and Trikafta

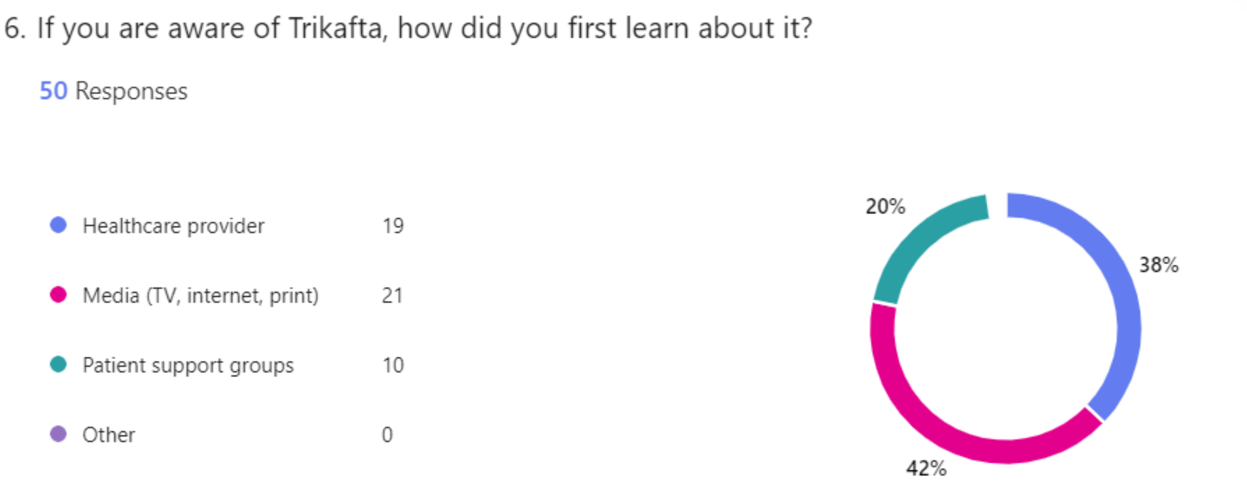
A. Awareness and Access to Trikafta:



5. Are you aware of Trikafta as a treatment for cystic fibrosis?

50 Responses

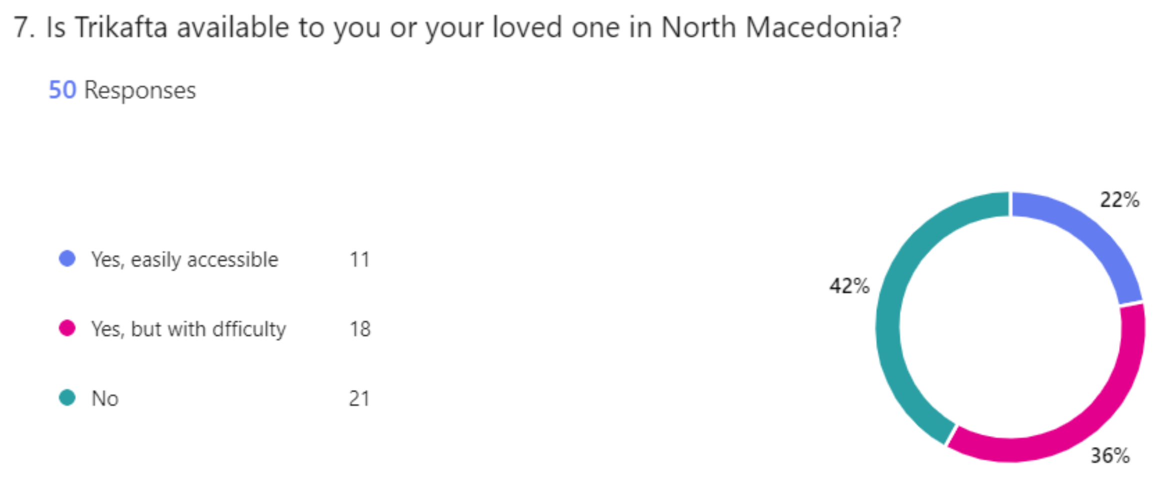
●	Yes	48
●	No	2



6. If you are aware of Trikafta, how did you first learn about it?

50 Responses

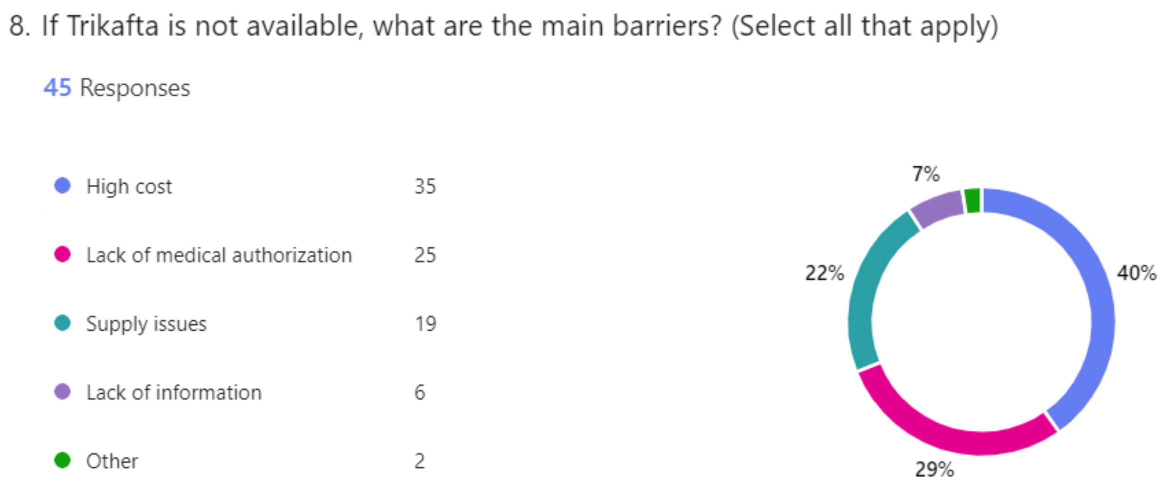
●	Healthcare provider	19
●	Media (TV, internet, print)	21
●	Patient support groups	10
●	Other	0



7. Is Trikafta available to you or your loved one in North Macedonia?

50 Responses

● Yes, easily accessible	11
● Yes, but with dfficulty	18
● No	21



8. If Trikafta is not available, what are the main barriers? (Select all that apply)

45 Responses

● High cost	35
● Lack of medical authorization	25
● Supply issues	19
● Lack of information	6
● Other	2

After the section of the participants telling us about themselves, the next section is about the awareness of Trikafta in North Macedonia.

On the 5th question out of 50 participants were aware of Trikafta as a treatment for CF. 18 of the answers with "Yes" was parents and 29 patients. As a "No" answers were answered by 2 parents. And one of the "Yes" didn't pick a role.

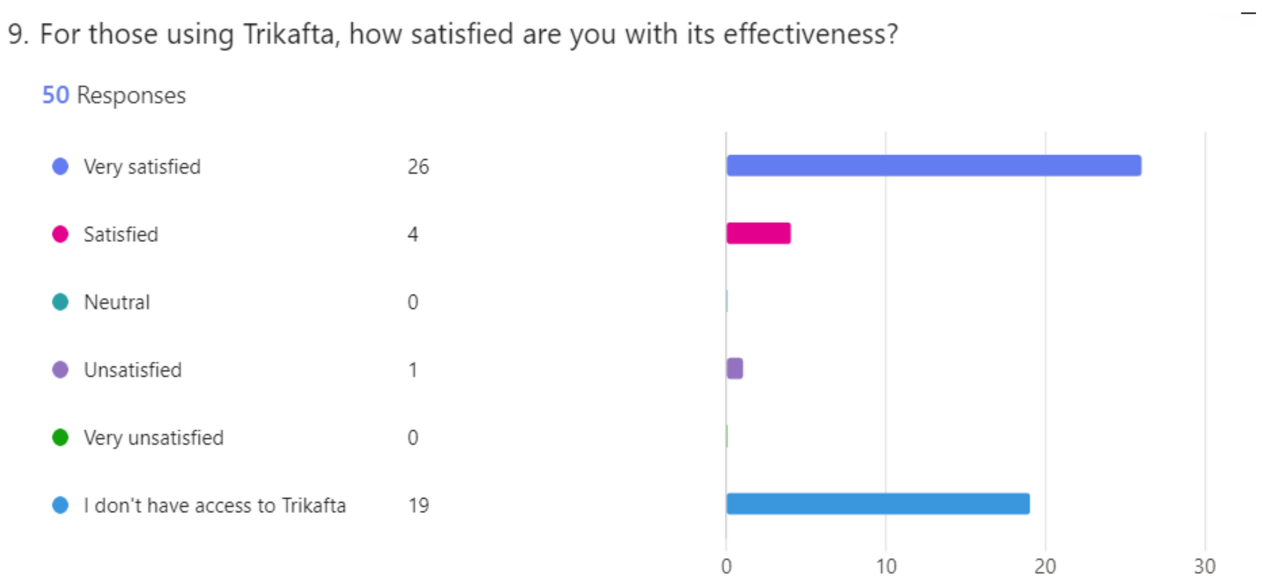
On the 6th question when asked where they got to know about Trikafta as a drug out of 50 participants, 19 participants or 38% said that they were informed by a healthcare provider, 21 participants or 42% said that they were aware after this was more posted on Media which includes TV, print and even social media. And the other 10 participants, 20%, said that they knew from patient support groups.

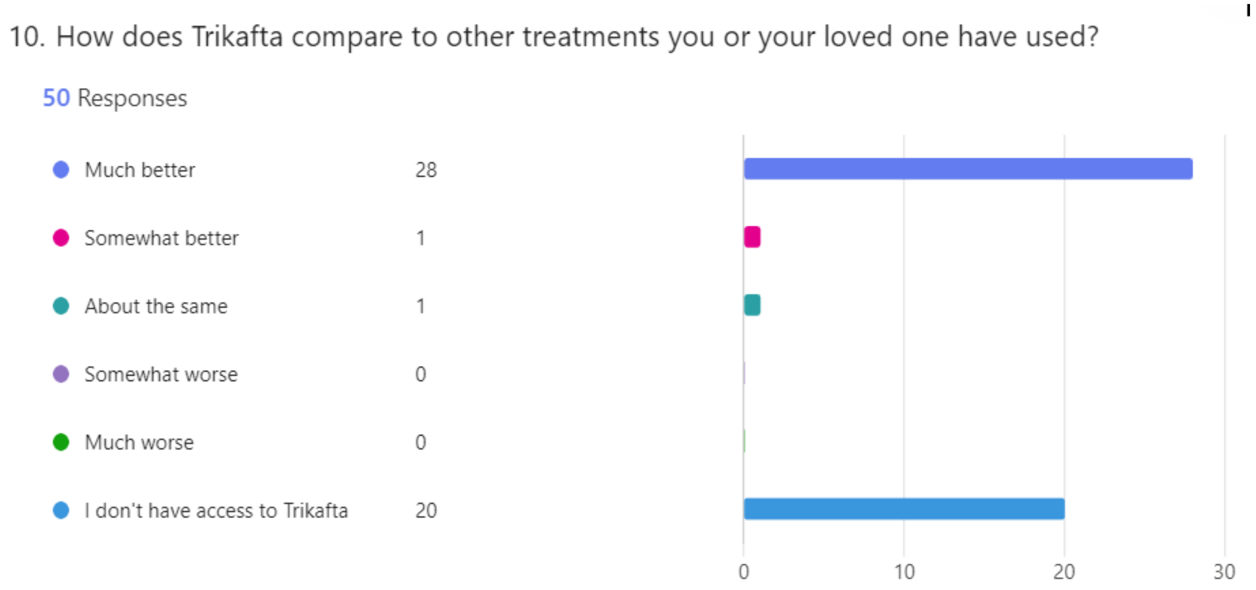
Trikafta is not available for many in North Macedonia and in the 7th, question it was asked if Trikafta was available for patients or if it is available for their loved ones. Out of 50 responses, 11 participants or 22% said that it was available and that it was easily accessible. 18 participants or 36% said that it was available but with difficulty. And 21 participants or 42% said that they didn’t have access to Trikafta.

On the 8th question, they were able to choose more than just a question and why they think that Trikafta is not available in the country for everyone. On this question, 5 participants didn’t choose anything. On the first option on the answer as “High cost”, there were 35 participants or 40%. 25 other participants or 29% thought that the reason behind not having Trikafta was the “Lack of medical authorization”. 19 other participants or 22% thought that the issue was on the “Supply issues”. 6 other participants or 7% also thought that the issue was “Lack of information”. And 2 other participants answered “Other”, which one of them specified as “Bad organization of health in the country”.

As it was expected, the information about the medicine was obtained from the medium most often by the patients and their relatives. Once again this speaks about the importance and influence of the mediums. These results show that almost 80% of the respondents had difficulty or did not manage to get this medicine at all.

B. Experience with Trikafta:





The 9th question was directed to those who use Trikafta and how satisfied are they with the start of taking the new drug. Also, those who didn't have access to Trikafta had the right to choose that they didn't have access to Trikafta. In this question, many people who do not take Trikafta also chose the "satisfied" or "very satisfied" because of the experiences of those who take it as patients everyone shared their experiences and they were able to see and monitor how Trikafta worked on everyone.

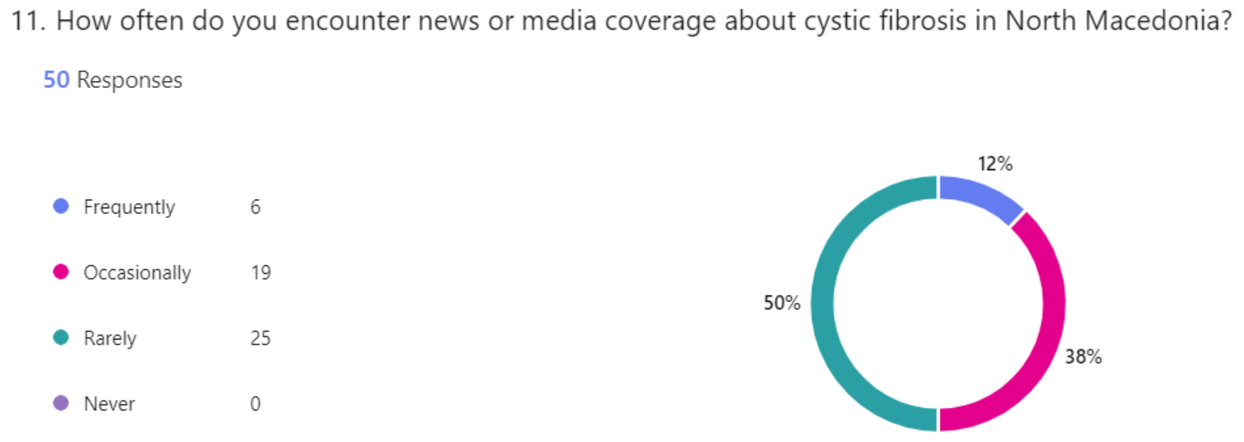
Out of 50 participants, 26 said that they were “very satisfied” with Trikafta, 4 said that they were “Satisfied”, 1 said that they were not satisfied and 19 other participants mentioned and said that they do not have access to Trikafta.

The 10th question was about the difference between Trikafta and other treatments that a patient with CF has experience with. There were 50 responses and 28 of them said that Trikafta is doing a better job than any other treatment, 1 said that it is somewhat better and another one said that it is about the same. 20 participants that they didn’t have access to Trikafta so they wouldn’t know the difference.

As seen from these results, most of the patients using Trikafta are more than happy with their lives now, even though they haven’t been taking it for so long but it has an immediate reaction. When it comes to comparison with other medicaments the results show that it has a better effect on the lives of people with CF.

Media Coverage of Cystic Fibrosis

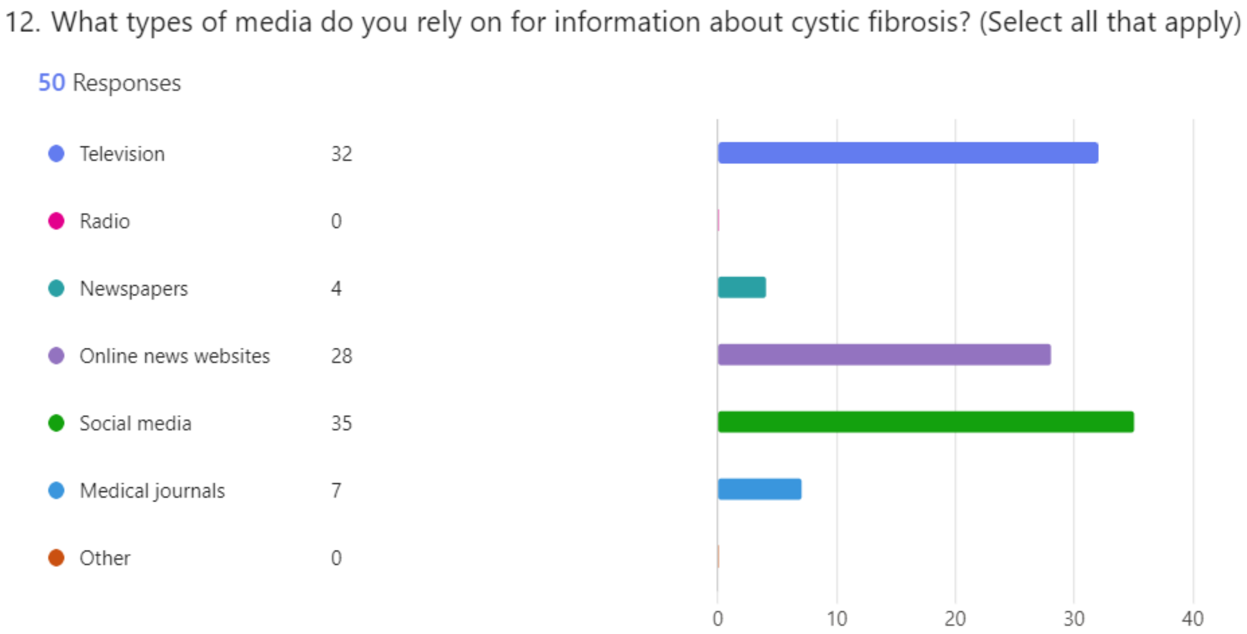
A. Awareness and Perception:



11. How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

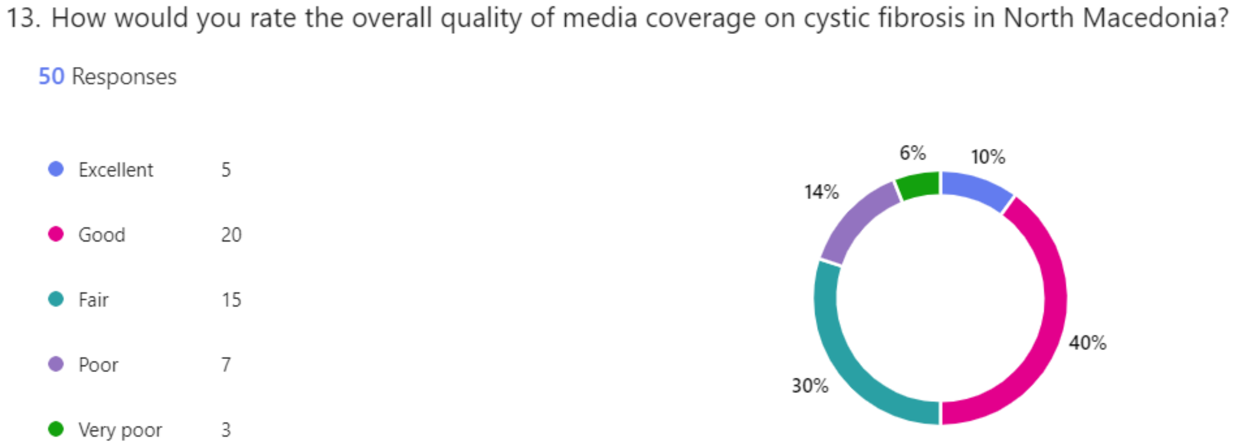
50 Responses

●	Frequently	6
●	Occasionally	19
●	Rarely	25
●	Never	0


12. What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

50 Responses

● Television	32
● Radio	0
● Newspapers	4
● Online news websites	28
● Social media	35
● Medical journals	7
● Other	0


13. How would you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

50 Responses

● Excellent	5
● Good	20
● Fair	15
● Poor	7
● Very poor	3

The other part of the questionnaire was about the media coverage in North Macedonia. The question was about how many times or how often people encounter news about CF in different media, out of 50 responses, 6 responses or 12% said that they frequently encounter it, whereas 19 or 38% said that they occasionally encounter it and the most chosen answer was rarely with 25 responses or 50% of the participants.

On the 12th question, the participants were asked about the types of media that they rely on for information related to the news about CF or rare diseases in general, and they had the opportunity to choose more than one answer.

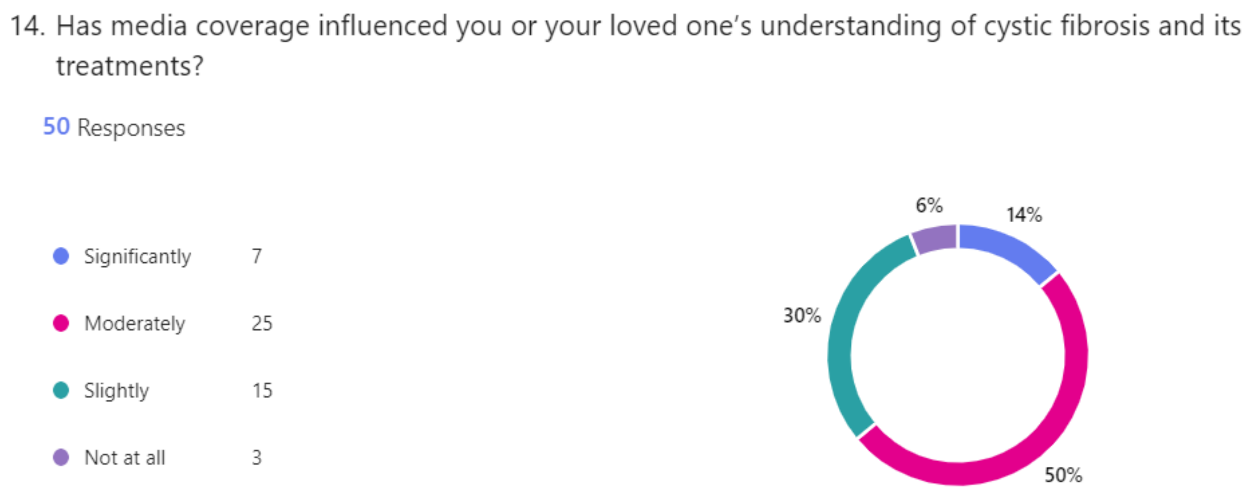
All 50 participants chose an answer, there were 32 responses about Television, 0 responses on Radio, 4 responses about Newspapers, there were also 28 responses on Online news websites, more responses on Social media, and 7 on Medical journals. Most responses were about Social media, Online news websites and Television, from here it is understood that usually campaigns were successful and patients on TV asking about their rights made more people aware and made patients more seen.

The 13th question was about the quality of media coverage in North Macedonia, especially about cystic fibrosis, and all 50 participants answered this question.

5 out of 50 participants or 10% thought that the media coverage about CF in NM was Excellent. 20 participants out of 50 or 40% thought that it was Good, 15 participants out of 50 or 30% thought that it was Fair, 7 participants out of 50 or 14% rated it as Poor, and 3 participants out of 50 or 6% thought that it was Very poor. The answers to this question were mixed but the majority thought that the media somewhat made good coverage related to this disease.

Most of the participants think that the media coverage and the presence of media have a huge impact on getting this drug and informing people about this issue. Also, these results show that traditional media and social media are used the most to reach a broader audience and have more attention; overall the thoughts of the patients were that the media coverage was good.

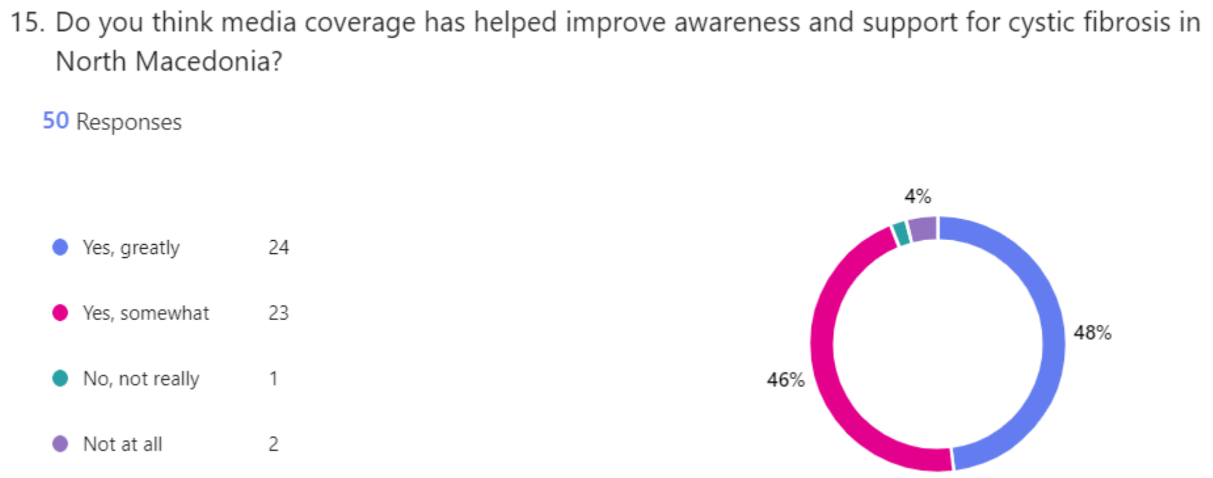
B. Impact and Effectiveness:



14. Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

50 Responses

● Significantly	7
● Moderately	25
● Slightly	15
● Not at all	3



15. Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

50 Responses

● Yes, greatly	24
● Yes, somewhat	23
● No, not really	1
● Not at all	2

The 14th question was about how media coverage has influenced or shaped the understanding of CF to patients or their loved ones. Out of 50 responses, 7 participants or 14% said that it has influenced Significantly, 25 or 50% of respondents said that it has influenced the understanding of CF Moderately, out of 50 participants 15 of them or 30% responded with Slightly ad 3 of them or 6% said that it hasn't influenced their understanding at all.

The 15th question was about media coverage and how much it has influenced or helped improve the awareness and support of CF in NM in general. All participants responded, and the majority of 47 participants said that the media has had a powerful take in pushing the authorities to move further which is 94% of the participants.

The results also show that media has had the power to shape thoughts and perceptions about CF in the families of patients and other citizens in general. Most of the patients think that the media has improved awareness about this medicament and this disease.

Two other questions were open-ended and not every participant added to those any comments but those who did kept it short. One of the questions was "What additional information or improvements would you like to see in media coverage of cystic fibrosis?" the general responses were about improving the health system and adding all those who are not taking Trikafta to the list of taking it and to improve the "Positive list" of medications.

The other question was "Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?" the responses in general were criticizing the Government and that it should be more on the public topic of rare diseases and that there should be more campaigns especially to have funds and to make sure that patients have it easier in fighting this disease.

Implications

Theoretical implication: The results of the questionnaire and the research done in general about this topic support all the theories related to this issue in North Macedonia. Despite many changes throughout the years, the small changes barely seem not to define a good healthcare system according to participants in the questionnaire and the criticism in media and social media. It always was and is the politics that is a barrier to making the lives of citizens and patients easier, hardly changed policies, laws waiting in officials' offices and voices not being heard. Despite the need for bigger changes and steps taken to improve the healthcare system, educational programs and many other issues in North Macedonia, all that has been done is people coming into power and racing who will steal more and jobs easier and cheaper just to say that the job has been done.

Also knowing that many media channels especially on TV have been supporting different politicians it has been seen that now many support citizens despite being harsh towards those who these media channels support. The voice of the people has been heard only through more aggressive and louder noises.

Through the research and questionnaire, we have also seen the importance of the media covering these kinds of stories and giving more space to those who have to make a point and to news that are not only politics, investments and different ‘crazy’ business and position-opposition fights in the political sphere. The influence of media and social media is and was used to educate people on this topic and other topics, despite being aware in general that these issues have always been there pointing at them through media made it easier to take action faster and more harshly. At the end of the day, after a few patients were on the list to take the medicaments and drugs, others are still waiting and with this pace, they will be waiting for a very very long time, because there are and they will be always more important topics, such as EU, the request of Bulgarians, The French Porposal, who stole more money from citizens, what two different parts of the political sphere has done more, who has done more about different systems in the country. Where nothing has changed and everyone has been and is thinking of how to be in power because being in power is more important than helping people, making better changes in the country, and giving the citizens something that will make life easier.

Clinical implications: The voice of the patients has always been heard by doctors and medical staff, in difference from officials, the medical staff has always done its best for patients to make sure they feel at home and loved, with very few doctors in the country the life of patients with CF has been very good, knowing that one person cannot cover 150+ patients. Other than that patients with CF have been struggling for part only for them for years, where they have been staying with babies and different people who were sick from other diseases, even though they are not supposed to mix with other people. This was a result of incapable people and Ministries who didn’t make sure to make a place for these people and do something for this, the problem was always the budget, even though these kinds of ministries have always had money for expensive sofas and cars, but not a single penny for hospitals (Trpkovski, 2022).

Policy implications: The lack of policy changes in the healthcare of North Macedonia is visible, and the process to take action was never seen or at least it was always postponed. No matter how much people and activists tried it was always a slow process, but after a topic goes more in public and the pressure rises every politician and every institution responsible “takes” action. Even though most of the time it is stuck in the labyrinth of different areas in these places. There were and are different fund actions and campaigns organized by different NGOs and citizens who help in different organizations, such as concerts, and exhibitions and with the presence in media this was seen even more, but changes in policies were and are barely made.

Media impact

As mentioned before the media had a huge role in the awareness of this disease in public, especially for Trikafta and how important it was for patients with CF. Besides the CF there are people with many other diseases in North Macedonia who fight every day for better medicaments and or better conditions, and this presence in media made by particular organizations and patients made citizens and the public more interested in researching the struggles and posts were made in different social media platforms about everything. This topic rose fast but was covered with other bigger problems in North Macedonia, such as the pandemic, economic crisis and elections.

Through all this process we saw the power of social and traditional media and how much it influences different policies and how the steps are taken. The more representation patients got, the more those in power tried to make something for their image, not because they cared, but because everyone was fighting about who ordered and made agreements for Trikafta, which in this case was seen as the intention of these people, trusted doctors in different clinics, becoming ministers and then fighting over a place in power represent the comedy and the circus performed in North Macedonia, playing with peoples life.

The role of media in the patient’s advocacy has been unbelievable, because no matter what they stood on the side of patients, facing different powerful people voted by those citizens who struggle. After so many covered stories different associations and different organizations were even more seen and taken seriously.

Besides the positive side of the media impact in this journey, there was space for misinformation and misleading mostly in social media, but traditional media sometimes has struggled to cover fully or at least present our story, because it was mostly other stories told such as who visited NM this week and other political stuff, and the story of those who need more representation was given in the end.

Being on the media benefited these people through more donations and investments in the clinics where these people stay for 14 days or more. One of the successful investments is NLB bank with many donations and helpful medical appliances.

Translation:

Under the motto "A world full of kindness is a world full of opportunities", today NLB Bank organized an event where it officially presented five non-governmental organizations and institutions with donations in the total value of 150,000 euros (30,000 euros for each). The winners were selected by the employees of the Bank through an internal survey, recognized as organizations and institutions that bring positive changes and are a strong support in the local community.

The recipients of the donations are: the Association for Cystic Fibrosis, the University Clinic for Gynecology and Obstetrics in Skopje, the National Network against Violence against Women and Domestic Violence, the Red Cross of the City of Skopje and the Association for Assistive Technology "Open the Windows".

Through the process of being in media, not many patients were included because there were many people not feel confident about being there and sharing their stories. Many patients were bullied as kids and now they hide their disease, which shows a lack of psychological support in this part. In hospitals, there are always psychologists but visibly they didn’t do a good job and the ministry or those who are responsible didn’t do a good job securing psychologists for these patients.

Limitations

In this thesis the targeted audience was patients who struggle with CF, 50 people were asked and answered through a questionnaire, 30 of the participants were patients and 20 were parents or caregivers, since the questionnaire was in English, it was limited to those who speak English. Despite there being more patients with this disease, not all of them are adults or teenagers and in general many patients or caregivers struggle to respond in a different language. This was a barrier to reaching a larger audience and having clearer results, especially adding everyone’s experience.

The data availability in North Macedonia was hard to reach, nothing exact was reached, and any type of data was just news or publications from institutions explaining the rare disease and not the policies or details about how everything in the field of healthcare works. In this case, digging deeper was unsuccessful.

The hardest thing for a patient is to explain their disease to another doctor, who has no clue what CF is, it is hard to know about every single disease, especially the rare ones, but it is not normal to be a doctor and not know what someone is talking about, this is a result of the lack of education among doctors, the lack is because no one take a step to learn more, and everyone tries to do less in working hours, despite that even the ministry of health or the government doesn’t move a finger to make sure everyone is knowledgable about a particular disease and hold training, educational conferences or anything of that type.

Conclusion

In conclusion, this research set out to explore the media coverage of CF in NM and the rare diseases, and especially how much impact it had on public awareness. This was done by analyzing media presence and representation of this disease, how much and how it shaped the opinion of the public; the research aimed to uncover the relationship between media exposure and the public's thoughts on CF.

The research questions for this study were:

1. "What are the key components of the current rare disease policy in North Macedonia, and how effectively does it address the needs of individuals affected by rare diseases in terms of diagnosis, treatment access, and support services?"

2. "How does the range of media coverage of rare diseases in North Macedonia contribute to public awareness, understanding, and support for individuals affected by these conditions, and what factors influence the extent and nature of media attention on rare diseases?"

3. "How does the coverage and discourse surrounding rare diseases differ between legacy media and social media platforms, and what impact do these differing media channels have on public awareness, support networks, and advocacy efforts for individuals affected by rare diseases?"

4. "What are the current challenges and opportunities regarding the availability and accessibility of Trikafta, a breakthrough medication for cystic fibrosis, in North Macedonia, and how do factors such as healthcare infrastructure, regulatory processes, and affordability impact its distribution and uptake among individuals with cystic fibrosis in the country?"

5. "What are the lived experiences and perceptions of individuals with cystic fibrosis who have been prescribed Trikafta in North Macedonia, including their treatment journey, quality of life improvements, and challenges encountered in accessing and adhering to this medication?"

By the end of this study, it is concluded that it is really hard to find material or the current policies related to rare diseases, even though every government tries to make more money and raise funds related to rare diseases and medicine in general yearly. Besides that, treatment access has been improving very slowly, many patients with rare diseases or more common diseases find it very hard to reach particular medicaments.

After the questionnaire it was clear that media coverage plays a huge role in shaping thoughts, its contribution to public awareness, and the understanding of people who have never heard of a particular disease or anything new, besides the public, the impact was huge also in the process of getting Trikafta for patients with CF, through media patients got the chance to express the importance of this medicament in their lives.

The difference between legacy media and social media was not much visible, the news made a huge impact on patient’s lives, and legacy media being present on social media made the difference smaller to notice. Besides being on the news, interviews, and sharing stories everywhere, social media personas and the general public had the chance to put more pressure on authorities and officials who were responsible for taking any action related to this issue.

The current challenges in NM related to Trikafta or other medications related to CF are still ongoing and very hard, Trikafta is not available for all patients, and with the change of the government, the fear of losing this medication is huge. Besides Trikafta, other medicaments are removed from pharmacies and the replacement for this kind of medicament has been stuck in the labyrinth of Health Fund.

The experiences of people with CF in NM have been challenging, hard and full of hardships. Patients with CF see a better future in other countries that are more developed, in the need for better conditions, treatments and life quality. Patients who suffer from CF also struggle to find a stable job, they have it hard after reaching the age of 26 because the country doesn’t allow them to pay less on different occasions just like they have to opportunity to pay less before reaching 26 years old. In general, these people have been struggling for everything in their lifetime, and with this pace and slow steps, it seems like they will be struggling even more and for much longer.

As mentioned the results showed that the media coverage often was limited and it sometimes led to misinformation and misconceptions. However, the study showed that the increased media attention raised the level of public awareness, revealing that effective media representation can lead to more understanding and support citizens and the public of those with rare diseases.

These results and insights lead to more implications for healthcare providers, organizations and policymakers. Through this information and studies, stakeholders can help to build more supportive and informed individuals and communities for people with rare diseases and their loved ones.

While this research provides a very valuable contribution to how media can influence rare diseases, public awareness and other organizations, it is seen that there are limitations, such as being able to reach a broader public, or other patients who fight different rare diseases or even every patient with CF. Future research can have a deeper study and explore the impact of media coverage on media strategies public opinions and different attitudes which led to awareness and support for rare diseases.

In conclusion, being able to improve the media coverage and presence of CF and other rare diseases, promoting different campaigns, and reducing misinformation and misleading, is crucial for a better life for patients. This study highlights the crucial role of media in shaping public perception and the need for a continuous effort to make sure that rare diseases get the attention that it needs.

Reccomendations

1. Negotiate with healthcare authorities and pharmaceutical companies to make sure that there are more choices available and an affordable price;
2. Develop an educational campaign for healthcare works, to get to know more about Trikafta, its side effects and the diseases in general;

References

Antik, D. (2016), *КОЛКУ ЛИЦАТА КОИ ЖИВЕАТ СО РЕТКИ БОЛЕСТИ ЧУВСТВУВААТ БЕНЕФИТ ОД СПРОВЕДУВАЊЕТО НА ПРОГРАМАТА ЗА ЛЕКУВАЊЕ НА РЕТКИ БОЛЕСТИ И КОЛКУ ДРЖАВАТА ГИ ИСПОЛНУВА СВОИТЕ ОБВРСКИ КОН ОВИЕ ЛИЦА*?, Available at: https://esem.mk/pdf/Publikacii/2018/%D0%90%D0%BD%D0%B0%D0%BB%D0%B8%D0%B7%D0%B0%20%D0%A0%D0%B5%D1%82%D0%BA%D0%B8%20%D0%B1%D0%BE%D0%BB%D0%B5%D1%81%D1%82%D0%B8%202.pdf [Accessed 28 July 2024]

Buhovski. A. (2022), *СО КИСЛОРОДНА БОЦА ЛАНИ БЕШЕ КАЈ ПЕНДАРОВСКИ ДА МОЛИ ЗА ЛЕК: И Илиевски и останатите болни од цистична фиброза уште го чекаат лекот*, Faktor.mk, https://faktor.mk/so-kislorodna-boca-lani-beshe-kaj-pendarovski-da-moli-za-lek-i-ilievski-i-ostanatite-bolni-od-cistichna-fibroza-ushte-go-chekaat-lekot [Accessed 30 August 2024]

Buhovski. A. (2023), *МИНИСТЕРСТВОТО ЗА ЗДРАВСТВО ПРАВИ РЕД ЗА ТЕРАПИЈА ИЛИ РЕД ЗА УМИРАЊЕ? Трикафта само за пациентите со средно тешка и тешка белодробна функција*, Faktor.mk, https://faktor.mk/ministerstvoto-za-zdravstvo-pravi-red-za-terapija-ili-red-za-umiranje-trikafta-samo-za-pacientite-so-sredno-teshka-i-teshka-belodrobna-funkcija [Accessed 30 August 2024]

Brif.mk (2024), *Анализа: Борбата на лицата со ретки болести и што сè е направено за нив досега?*, https://www.brif.mk/analiza-borbata-na-licata-so-retki-bolesti-i-shto-se-e-napraveno-za-niv-dosega/ [Accessed 31 August 2024]

Commission of the European Communities, *"Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the regions on Rare Disease: Europe's challenges"*, November, 2008, COM (2008) 679 final, Brussels, Пристапено во август, 2015: http://ec.europa.eu/health/ph_threats/non_com/docs/rare_com_en.pdf [Accessed 28 August 2024]

COMMISSION OF THE EUROPEAN COMMUNITIES (2008), *COMMUNICATION FROM THE COMMISSION TO THE EUROPEAN PARLIAMENT, THE COUNCIL, THE EUROPEAN ECONOMIC AND SOCIAL COMMITTEE AND THE COMMITTEE OF THE REGIONS on Rare Diseases: Europe's challenges*, http://www.europlanproject.eu/Resources/docs/ECCommunication_COM-2008-679final.pdf [Accessed 29 August 2024]

Dodevska, A. (2023), *24 анализа - Ќе се набави ли навреме лекот за болните од цистична фиброза*?, 24.mk, https://24.mk/details/24-analiza-kje-se-nabavi-li-navreme-lekot-za-bolnite-od-cistichna-fibroza [Accessed 31 August 2024]

DZR (2024), *Новите лекови за цистична фиброза не достапни за сите пациенти, Државен заво за ревизија*, https://dzr.mk/mk/240213-novite-lekovi-za-cistichna-fibroza-ne-dostapni-za-site-pacienti [Accessed 01 September 2024]

Dinev. A. (2023), *Пациентити со цистична фиброза со нов повик до Владата да им обезбеди трикафта на сите,* Sitel, https://sitel.com.mk/pacientiti-so-cistichna-fibroza-so-nov-povik-do-vladata-da-im-obezbedi-trikafta-na-site [Accessed 30 August 2024]

Dinev. A. (2023), *Со законски измени ќе се наоѓа начин да се обезбеди поевтин лек за болните од цистична фиброза*, Sitel, https://sitel.com.mk/so-zakonski-izmeni-kje-se-naogja-nachin-da-se-obezbedi-poevtin-lek-za-bolnite-od-cistichna-fibroza [Accessed 31 August 2024]

EURODIS. (2009), *The Voice of 12.000 Patients Experiences and Expectations o Rare Diesease Patients on Diagnosis and Care in Europe,* France [Accessed 28 August 2024]

Gjorgjioska, M. A. (2023), *North Macedonia social briefing: The Cystic Fibrosis Association protests against the Government urging for the procurement of a life-saving medicine*, China-CEE Institute, https://china-cee.eu/wp-content/uploads/2023/03/2023s02_North-Macedonia.pdf [Accessed 31 august 2024]

Gagovska, E. (2023), *Животот со цистична фиброза не мора да биде толку тежок*, Respublica.mk, https://respublica.edu.mk/blog/zdravstvo/zhivotot-so-cistichna-fibroza-ne-mora-da-bide-tolku-tezhok/ [Accessed 01 September 2024]

Iris (2022), *Health Systems in Action 2022 Edition North Macedonia*, Available at: https://iris.who.int/bitstream/handle/10665/362345/9789289059169-eng.pdf?sequence=1 [Accessed 28 July 2024]

Jakimova, J. (2023), *Сите бегаат од одговорност, лек за само неколку пациенти со цистична фиброза*, Slobodnaevropa, https://www.slobodnaevropa.mk.html [Accessed 01 September 2024]

Kajoli, S. (2023), *Пациентите со цистична фиброза на протест – „Овој пристап нѐ тера да се чувствуваме проколнато што живееме во РСМ*“, TV21.mk, https://mk.tv21.tv/patsientite-so-tsistichna-fibroza-na-protest-ovoj-pristap-n-tera-da-se-chuvstvuvame-prokolnato-shto-zhiveeme-vo-rsm/ [Accessed 31 August 2024]

KOD, (2023), *КОД: Исповед за болката и трка за подолг живот- цистична фиброза и државна негрижа*, Telma, https://telma.com.mk/2023/02/12/kod-ispoved-za-bolkata-i-trka-za-podolg-zhivot-cistichna-fibroza-i-drzhavna-negrizha/ [Accessed 31 August 2024]

Kovacevic, M. (2019). "Media Regulation and Political Influence in North Macedonia." Communications Law, 24(2), 112-128. [Accessed 22 May 2024]

Life with challenges (2019), *ANNUAL NARRATIVE REPORT Association of citizens for rare diseases LIFE WITH CHALLENGES*, https://challenges.mk/wp-content/uploads/2020/01/Narrative-report-2019-Life-with-challenges.pdf [Accessed 28 August 2024]

Ministry of Finance (2023), *ПРЕДЛОГ БУЏЕТ НА РЕПУБЛИКА СЕВЕРНА МАКЕДОНИЈА ЗА 2024 ГОДИНА*, Skopje, Available at: https://finance.gov.mk/wp-content/uploads/2023/11/za-Sobranie-Buxet-2024-so-obrazloz-1.pdf [Accessed 28 July 2024]

Ministry of Health (2023), *Стратешки план, Министерство за здравство за 2023-2025 година*, Skopje, Available at: https://zdravstvo.gov.mk/wp-content/uploads/2022/10/Strateshki-plan-na-ministerstvoto-za-period-2023-2025-matritsa-A.pdf [Accessed 28 July 2024]

Manasieva A.M. (2019), *Весна Алековска: Патот на лицата со ретки болести е како минско поле, никогаш не знаеш кога и на што ќе нагазиш*, https://www.fakulteti.mk/news/27022019/vesna-aleksovska-patot-na-licata-so-retki-bolesti-e-kako-minsko-pole-nikogash-ne-znaesh-koga-i-na-shto-kje-nagazish [Accessed 29 August 2024]

Ministry of health (2022), *ГОДИШЕН ПЛАН ЗА РАБОТА ЗА 2022 ГОДИНА НА МИНИСТЕРСТВО ЗА ЗДРАВСТВО*, https://zdravstvo.gov.mk/wp-content/uploads/2022/10/Godishen-plan-za-rabota-na-ministerstvoto-za-2022-godina.pdf [Accessed 31 August 2024]

Ministry of Health (2021), *ПРОГРАМА ЗА ЛЕКУВАЊЕ РЕТКИ БОЛЕСТИ ВО РЕПУБЛИКА СЕВЕРНА МАКЕДОНИЈА ЗА 2021 ГОДИНА*, https://zdravstvo.gov.mk/wp-content/uploads/2021/04/Programa-RETKI-BOLESTI-za-2021-god_.pdf [Accessed 31 August 2024]

Markovska. T. (2023), *Трикафта заглавена во триаголникот Влада-здравство-финансии – 30 пациенти со цистична фиброза сѐ уште чекаат лек*, Telma, https://telma.com.mk/2023/06/14/trikafta-zaglavena-vo-triagolnikot-vlada-zdravstvo-finansii-30-pacienti-so-cistichna-fibroza-se-ushte-chekaat-lek/ [Accessed 30 August 2024]

Ministry of Health (2018), *ПРВПАТ ВОСПОСТАВЕН ЕЛЕКТРОНСКИ РЕГИСТАР ЗА РЕТКИ БОЛЕСТИ*, https://zdravstvo.gov.mk/prvpat-vospostaven-elektronski-registar-za-retki-bolesti/ [Accessed 31 August 2023]

Macedonian Institute for Media. (2019). "*Health Journalism in North Macedonia: Challenges and Opportunities*." Retrieved from MIM website. [Accessed 29 April 2024]

Markovikj, A. (2020). *"Social Media's Role in Public Health Awareness: The Case of North Macedonia*." International Journal of Public Health, 65(1), 35-47. [Accessed 20 May 2024]

Novamakedonija (2023), *Бирократски процедури се пречка за дополнителни пациенти да добијат „трикафта"*, https://novamakedonija.com.mk/makedonija/birokratski-proceduri-se-prechka-za-dopolnitelni-pacienti-da-dobijat-trikafta/ [Accessed 30 August 2024]

NHLBI (2023), *What Is Cystic Fibrosis*?, NHLBI, https://www.nhlbi.nih.gov/health/cystic-fibrosis [Accessed 20 June 2024]

NORD (2020), *Cystic Fibrosis*, https://rarediseases.org/rare-diseases/cystic-fibrosis/ [Accessed 31 August 2024]

Nikoloska, E. (2023), *Тема на ТВ 24: Најава за нови протести поради "институционален молк " по апелите да се обезбеди лек за пациентите со цистична фиброза*, 24.mk, https://24.mk/details/tema-na-tv-24-najava-za-novi-protesti-poradi-institucionalen-molk-po-apelite-da-se-obezbedi-lek-za-pacientite-so-cistichna-fibroza [Accessed 01 September 2024]

Petrovska. S. (2023), *Сали прави калкулации додека пациентите со цистична фиброза се спремаат за нов протест*, Telma, https://telma.com.mk/2023/01/25/sali-pravi-kalkulacii-dodeka-pacientite-so-cistichna-fibroza-se-spremaat-za-nov-protest/ [Accessed 30 August 2024]

Petrova, M. (2022). "Misinformation and Health: The Media's Influence on Public Perception in North Macedonia." Health & Social Care in the Community, 30(1), 78-86. [Accessed 25 May 2024]

Stojkova. I. (2023), *Болните со цистична фиброза ќе чекаат уште време за ослободување од партиципација за лекување*, 24.mk, https://24.mk/details/bolnite-so-cistichna-fibroza-kje-chekaat-ushte-vreme-za-osloboduvanje-od-participacija-za-lekuvanje [Accessed 30 August 2024]

Stoller, K. J. (2018), *Chest, The Challenge of Rare Diseases*, Available at: https://www.sciencedirect.com/science/article/pii/S0012369218300643 [Accessed 27 July 2024]

Terziova, M. (2023), *Кога ќе ни почине пациент, тогаш надлежните ќе ја видат итноста на потребата од брз лек, велат болните од цистична фиброза*, Makfax.mk, https://makfax.com.mk/makedonija/%D0%BA%D0%BE%D0%B3%D0%B0-%D1%9C%D0%B5-%D0%BD%D0%B8-%D0%BF%D0%BE%D1%87% [Accessed 31 August 2024]

Trpkovski, G. (2022), *Владини возила: комфорот извесен, исплатливоста и не баш*, Prizma.mk, https://prizma.mk/vladini-vozila-komforot-izvesen-isplatlivosta-i-ne-bash/ [Accessed at 15 July 2024]

Telma, (2023), *„Трикафта" пристигна на детската Клиника, осум пациенти деновиве ќе почнат со терапија*, https://telma.com.mk/2023/03/09/trikafta-pristigna-na-detskata-klinika-osum-pacienti-denovive-kje-pochnat-so-terapija/ [Accessed 31 August 2024]

Vlada.mk (2023), *Меџити: Трикафта пристигна на детската клиника, ветувањето го исполнивме*, https://vlada.mk/node/35583 [Accessed 30 August 2024]

Vangeli, A. (2018). "The Media Landscape in North Macedonia: A Report on the State of Journalism and Media." Journal of Balkan Studies, 12(2), 45-67. [Accessed 15 July 2024]

Vasilevski, S. (2020). "Healthcare Reforms in North Macedonia: Progress and Obstacles." Balkan Medical Journal, 37(3), 146-153. [Accessed 29 May 2024]

World Health Organization**.** (2020). "Health System Review: North Macedonia." [Accessed 22 May 2024]

Appendix A: Rare diseases policy and media coverage of CF participant questionnaire

Demographics

Age:

- Under 18
- 18-24
- 25-34
- Above 35

Gender:

- Female
- Male

Location:

- Skopje
- Tetovo
- Bitola
- Other

Role:

- Patient
- Parent (Caregiver)

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

- Yes
- No

If you are aware of Trikafta, how did you first learn about it?

- Health provider

- Mdia (TV, internet, print)
- Patient support groups
- Other

Is Trikafta available to you or your loved one in North Macedonia?

- Yes, easily accessible
- Yes, but with difficulty
- No

If Trikafta is not available, whar are the main barriers? (Select all that apply)

- High cost
- Lack of medical authorization
- Supply issues
- Lack of information
- Other

B. Experience with Trikafta:

For those using Trikafta, how satisfied are you with its effectiveness?

- Very satisfied
- Satisfied
- Neutral
- Unsatisfied
- Very unsatisfied
- I don't have access to Trikafta

How does Trikafta compare to other treatments you or your loved one have used?

- Much better
- Somewhat better
- About the same
- Somewhat worse
- Much worse
- I don't have access to Trikafta

Media Coverage of Cystic Fibrosis

A. Awareness and Perception:

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

- Frequently
- Occasionally
- Rarely
- Never

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

- Television
- Radio
- Newspapers
- Online news websites
- Social media
- Medical journals
- Other

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

- Excellent
- Good
- Fair
- Poor
- Very poor

B. Impact and Effectiveness:

Has media coverage influenced your or your loved one's understanding of cystic fibrosis and its treatments?

- Significantly
- Moderately
- Slightly
- Not at all

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

- Yes, greatly
- Yes, somewhat
- No, not really
- Not at all

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

Appendix B: Rare diseases policy and media coverage of CF participant responses

Respondent 1

Demographics:

Age: Above 35

Gender: Female

City: Skopje

Role: Parent (Caregiver)

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Health provider

Is Trikafta available to you or your loved one in North Macedonia?

Yes, but with difficulty

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost; Supply issues; Lack of medical authorization

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisifed

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. Awareness and Perception:

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television; Online news websites

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Fair

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one’s understanding of cystic fibrosis and its treatments?

Slightly

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

To have more awareness and attention on rare diseases and CF especially.

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

We need more rules and laws that will make the patient’s life easier.

Respondent 2

Demographics:

Age: 25-34

Gender: Female

City: Bitola

Role: Patient

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Media (TV, internet, print)

Is Trikafta available to you or your loved one in North Macedonia?

Yes, easily accessible

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television; Online news websites; Social media;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Good

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one’s understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 3

Demographics:

Age: Above 35

Gender: Male

City: Tetovo

Role: Parent (Caregiver)

Cystic Fibrosis and Trikafta

A. Awareness and Access to Trikafta:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Healthcare provider

Is Trikafta available to you or your loved one in North Macedonia?

No

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost; Other (The governemtn supply only patients above 12 years old;

B. Experience with Trikafta:

For those using Trikafta, how satisfied are you with its effectiveness?

I don’t have access to Trikafta

How does Trikafta compare to other treatments you or your loved one have used?

I don’t have access to Trikafta

Media Coverage of Cystic Fibrosis

C. Awareness and Perception:

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television; Online news websites; Social media;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Good

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

To be more persistent about important questions and to have continuity in reporting.

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

I suggest that media should do more to make government work on supplying all patients with Trikafta.

Respondent 4

Demographics:

Age: Above 35

Gender: Female

City: Skopje

Role: Parent (Caregiver)

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Media (TV, internet, print)

Is Trikafta available to you or your loved one in North Macedonia?

Yes, but with difficulty

If Trikafta is not available, what are the main barriers? (Select all that apply)

Lack of medical authorization;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Frequently

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Social media

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Good

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 5

Demographics:

Age: Above 35

Gender: Female

City: Skopje

Role: Parent (Caregiver)

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Healthcare provider

Is Trikafta available to you or your loved one in North Macedonia?

Yes, but with difficulty

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Occasionally

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Online news websites

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Poor

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one’s understanding of cystic fibrosis and its treatments?

Slightly

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, somewhat

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

Everything about the positive effects.

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 6

Demographics:

Age: 25-34

Gender: Female

City: Skopje

Role: Parent (Caregiver)

Cystic Fibrosis and Trikafta

A. Awareness and Access to Trikafta:

Are you aware of Trikafta as a treatment for cystic fibrosis?

No

If you are aware of Trikafta, how did you first learn about it?

Media (TV, internet, print)

Is Trikafta available to you or your loved one in North Macedonia?

No

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost;

B. Experience with Trikafta:

For those using Trikafta, how satisfied are you with its effectiveness?

I don’t have access to Trikafta

How does Trikafta compare to other treatments you or your loved one have used?

I don’t have access to Trikafta

Media Coverage of Cystic Fibrosis

C. Awareness and Perception:

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television; Social media; Medical journals;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Very poor

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Not at all

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, somewhat

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 7

Demographics:

Age: Above 35

Gender: Male

City: Prilep

Role: Parent (Caregiver)

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Patient support groups

Is Trikafta available to you or your loved one in North Macedonia?

Yes, easily accessible

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Frequently

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television; Online news websites;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Excellent

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 8

Demographics:

Age: 18-24

Gender: Male

City: Skopje

Role: Patient

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Media (TV, internet, print)

Is Trikafta available to you or your loved one in North Macedonia?

Yes, easily accessible

If Trikafta is not available, what are the main barriers? (Select all that apply)

Lack of medical authorization;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Frequently

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Social media;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Good

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, somewhat

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 9

Demographics:

Age: Under 18

Gender: Male

City: Struga

Role: Patient

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Media (TV, internet, print)

Is Trikafta available to you or your loved one in North Macedonia?

Yes, easily accessible

If Trikafta is not available, what are the main barriers? (Select all that apply)

Lack of medical authorization;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Occasionally

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Online news websites; Social media; Television;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Fair

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Slightly

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, somewhat

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 10

Demographics:

Age: 18-24

Gender: Female

City: Kocani

Role: Patient

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Media (TV, internet, print)

Is Trikafta available to you or your loved one in North Macedonia?

Yes, but with difficulty

If Trikafta is not available, what are the main barriers? (Select all that apply)

Other (Bad organization of health in the country);

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television; Online news websites; Social media;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Poor

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, somewhat

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

Number of patients included for the drug

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 11

Demographics:

Age: 18-24

Gender: Male

City: Tetovo

Role: Patient

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Healthcare providers

Is Trikafta available to you or your loved one in North Macedonia?

Yes, easily accessible

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost; Supply issues;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Occasionally

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Social media;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Fair

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, somewhat

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 12

Demographics:

Age: Above 35

Gender: Male

City: Other

Role: Parent (Caregiver)

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Media (TV, internet, print)

Is Trikafta available to you or your loved one in North Macedonia?

No

If Trikafta is not available, what are the main barriers? (Select all that apply)

Other (not specified)

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Very satiesifed

How does Trikafta compare to other treatments you or your loved one have used?

I don’t have access to Trikafta

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Social media;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Poor

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, somewhat

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

Trikafta for all.

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

Trikafta for all.

Respondent 13

Demographics:

Age: Above 35

Gender: Female

City: Other

Role: Parent (Caregiver)

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Healthcare provider

Is Trikafta available to you or your loved one in North Macedonia?

Yes, but with difficulty

If Trikafta is not available, what are the main barriers? (Select all that apply)

Supply issues;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Online news websites;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Poor

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one’s understanding of cystic fibrosis and its treatments?

Slightly

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

New information

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

To lower the age limit

Respondent 14

Demographics:

Age: Under 18

Gender: Female

City: Skopje

Role: Patient

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Patient support groups

Is Trikafta available to you or your loved one in North Macedonia?

Yes, but with difficulty

If Trikafta is not available, what are the main barriers? (Select all that apply)

/

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Social media; Television

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Fair

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, somewhat

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 15

Demographics:

Age: Above 35

Gender: Female

City: Other

Role: Patient

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Media (TV, internet, print)

Is Trikafta available to you or your loved one in North Macedonia?

Yes, easily accessible

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Very, satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Occasionally

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Social media; Television; Online news websites;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Good

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

News about Trikafta benefits studies

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 16

Demographics:

Age: Above 35

Gender: Female

City: Bitola

Role: Parent (Caregiver)

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Patient support groups

Is Trikafta available to you or your loved one in North Macedonia?

No

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

I don’t have access to Trikafta

How does Trikafta compare to other treatments you or your loved one have used?

I don’t have access to Trikafta

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Online news websites;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Poor

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Slightly

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 17

Demographics:

Age: Under 18

Gender: Female

City: Skopje

Role: Parent (Caregiver)

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Healthcare provider

Is Trikafta available to you or your loved one in North Macedonia?

Yes, but with difficulty

If Trikafta is not available, what are the main barriers? (Select all that apply)

/

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Frequently

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Good

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 18

Demographics:

Age: 25-34

Gender: Female

City: Kumanovo

Role: Patient

Cystic Fibrosis and Trikafta

A. Awareness and Access to Trikafta:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Patient support groups

Is Trikafta available to you or your loved one in North Macedonia?

Yes, easily accessible

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost; Lack of medical authorization; Supply issues; Lack of information;

B. Experience with Trikafta:

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. Awareness and Perception:

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Frequently

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Social media;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Excellent

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Significantly

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 19

Demographics:

Age: Above 35

Gender: Female

City: Skopje

Role: Parent (Caregiver)

Cystic Fibrosis and Trikafta

A. Awareness and Access to Trikafta:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Patient support groups

Is Trikafta available to you or your loved one in North Macedonia?

Yes, easily accessible

If Trikafta is not available, what are the main barriers? (Select all that apply)

Lack of medical authorization;

B. Experience with Trikafta:

For those using Trikafta, how satisfied are you with its effectiveness?

Satisfied

How does Trikafta compare to other treatments you or your loved one have used?

About the same

Media Coverage of Cystic Fibrosis

C. Awareness and Perception:

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Occasionally

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Good

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Slightly

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, somewhat

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

I want to hear more about general treatments where every gene will be included and will help the patients.

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 20

Demographics:

Age: Above 35

Gender: Female

City: Skopje

Role: Patient

Cystic Fibrosis and Trikafta

A. Awareness and Access to Trikafta:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Patient support groups

Is Trikafta available to you or your loved one in North Macedonia?

Yes, easily accessible

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost; Lack of medical authorization; Supply issues;

B. Experience with Trikafta:

For those using Trikafta, how satisfied are you with its effectiveness?

Satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Somewhat better

Media Coverage of Cystic Fibrosis

C. Awareness and Perception:

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Occasionally

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television; Newspaper; Online news websites; Social media; Medical journals;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Good

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

I want patients above 26 years old to have free treatments just like before 26

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 21

Demographics:

Age: Above 35

Gender: Female

City: Skopje

Role: Parent (Caregiver)

Cystic Fibrosis and Trikafta

A. Awareness and Access to Trikafta:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Patient support groups

Is Trikafta available to you or your loved one in North Macedonia?

Yes, but with difficulty

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost; Lack of medical authorization;

B. Experience with Trikafta:

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. Awareness and Perception:

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Occasionally

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television; Online news websites; Social emdia;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Poor

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

New protests

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

All patients to get Trikafta.

Respondent 22

Demographics:

Age: 25-34

Gender: Female

City: Skopje

Role: Patient

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Media (TV, internet, print)

Is Trikafta available to you or your loved one in North Macedonia?

Yes, but with difficulty

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost; Lack of medical authorization; Supply issues; Lack of information;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Social media;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Fair

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, somewhat

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 23

Demographics:

Age: Above 35

Gender: Male

City: Kumanovo

Role: Parent (Caregiver)

Cystic Fibrosis and Trikafta

A. Awareness and Access to Trikafta:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Healthcare provider

Is Trikafta available to you or your loved one in North Macedonia?

No

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost; Lack of medical authorization; Supply issues; Lack of information;

B. Experience with Trikafta

For those using Trikafta, how satisfied are you with its effectiveness?

I don’t have access to Trikafta

How does Trikafta compare to other treatments you or your loved one have used?

I don’t have access to Trikafta

Media Coverage of Cystic Fibrosis

C. Awareness and Perception:

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Social media; Medical journals;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Very poor

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one’s understanding of cystic fibrosis and its treatments?

Not at all

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

No, not really

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

Trikafta for all.

Respondent 24

Demographics:

Age: 25-34

Gender: Female

City: Prilep

Role: Patient

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Media (TV, internet, print)

Is Trikafta available to you or your loved one in North Macedonia?

Yes, but with difficulty

If Trikafta is not available, what are the main barriers? (Select all that apply)

/

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Online news websites; Social media; Medical journals;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Fair

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Significantly

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

Nutrition, lifestyle with CF.

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 25

Demographics:

Age: Above 35

Gender: Female

City: Skopje

Role: Parent (Caregiver)

Cystic Fibrosis and Trikafta

A. Awareness and Access to Trikafta:

Are you aware of Trikafta as a treatment for cystic fibrosis?

No

If you are aware of Trikafta, how did you first learn about it?

Healthcare provider

Is Trikafta available to you or your loved one in North Macedonia?

No

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost; Lack of medical authorization; Supply issues; Lack of information;

B. Experience with Trikafta:

For those using Trikafta, how satisfied are you with its effectiveness?

I don’t have access to Trikafta.

How does Trikafta compare to other treatments you or your loved one have used?

I don’t have access to Trikafta.

Media Coverage of Cystic Fibrosis

C. Awareness and Perception:

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Medical journals; Online news websites;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Very poor

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Slightly

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

Medical news about new drugs.

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

Higher and better treatment for people with CF.

Respondent 26

Demographics:

Age: Above 35

Gender: Male

City: Kumanovo

Role: Parent (Caregiver)

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Patient support groups

Is Trikafta available to you or your loved one in North Macedonia?

Yes, but with difficulty

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Social media;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Good

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, somewhat

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

The improvement of the general conditions and of the hospital, the food of the hospital to be better.

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

The supply Creon enzymes and vitamins is too low, we haven't taken Creon for 1 year. And also for vitamins that the state has never provided, which is necessary for CF.

Respondent 27

Demographics:

Age: 18-24

Gender: Female

City: Skopje

Role: Patient

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Healthcare provider

Is Trikafta available to you or your loved one in North Macedonia?

Yes, but with difficulty

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost; Supply issues; Lack of medical authorization;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Occasionally

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television; Online news websites; Newspaper; Social media; Medical journals;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Fair

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, somewhat

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

I think that there are many other needs for people with CF that need to be talked about and taken care of.

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

I think that not only CF ut also other rare diseases shoud be more seen in every field in everyday life.

Respondent 28

Demographics:

Age: 25-34

Gender: Female

City: Ohrid

Role: Parent (Caregiver)

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Patient support groups

Is Trikafta available to you or your loved one in North Macedonia?

Yes, but with difficulty

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Medical journals; Social media; Online news websites; Television;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Good

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Significantly

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

Interviewing patients more frequently.

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

Make an advertisement about the benefits of the medicine.

Respondent 29

Demographics:

Age: Above 35

Gender: Female

City: Skopje

Role: Parent (Caregiver)

Cystic Fibrosis and Trikafta

A. Awareness and Access to Trikafta:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Media (TV, internet, print)

Is Trikafta available to you or your loved one in North Macedonia?

Yes, but with difficulty

If Trikafta is not available, what are the main barriers? (Select all that apply)

/

B. Experience with Trikafta:

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. Awareness and Perception:

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Occasionally

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Social media;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Excellent

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Significantly

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

A system solution for everyone in the country.

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 30

Demographics:

Age: 25-34

Gender: Male

City: Debar

Role: Patient

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Media (TV, internet, print)

Is Trikafta available to you or your loved one in North Macedonia?

Yes, easily accessible

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Occasionally

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Excellent

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 31

Demographics:

Age: Under 18

Gender: Female

City: Skopje

Role: Patient

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Healthcare provider

Is Trikafta available to you or your loved one in North Macedonia?

Yes, easily accessible

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Unsatisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Online news websites;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Good

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Not at all

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 32

Demographics:

Age: Under 18

Gender: Female

City: Skopje

Role: Parent (Caregiver)

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Media (TV, internet, print)

Is Trikafta available to you or your loved one in North Macedonia?

Yes, but with difficulty

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost; Lack of medical authorization; Supply issues;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Occasionally

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Online news websites;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Fair

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

Continuity in informing about improvements and deficiencies related with CF.

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 33

Demographics:

Age: Above 35

Gender: Female

City: (Other)

Role: Parent (Caregiver)

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Media (TV, internet, print)

Is Trikafta available to you or your loved one in North Macedonia?

no

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost; Lack of medical authorization;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television; Social media;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Poor

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Not at all

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Not at all

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 34

Demographics:

Age: 18-24

Gender: Male

City: Skopje

Role: Patient

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Media (TV, internet, print)

Is Trikafta available to you or your loved one in North Macedonia?

No

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost; Supply issues;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

I don't have access to Trikafta

How does Trikafta compare to other treatments you or your loved one have used?

I don't have access to Trikafta

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Online news websites

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Fair

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, somewhat

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 35

Demographics:

Age: Above 35

Gender: Female

City: (Other)

Role: Parent (Caregiver)

Cystic Fibrosis and Trikafta

A. Awareness and Access to Trikafta:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Media (TV, internet, print)

Is Trikafta available to you or your loved one in North Macedonia?

Yes, but with difficulty

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost, Lack of medical authorization;

B. Experience with Trikafta:

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. Awareness and Perception:

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Frequently

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Online news websites;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Fair

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Significantly

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 36

Demographics:

Age: 25-34

Gender: Female

City: Skopje

Role: Patient

Cystic Fibrosis and Trikafta

A. Awareness and Access to Trikafta:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Healthcare provider

Is Trikafta available to you or your loved one in North Macedonia?

Yes, but with difficulty

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost; Lack of medical authorization;

B. Experience with Trikafta:

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. Awareness and Perception:

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Occasionally

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television; Social media;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Good

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Significantly

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

We would like easy access to the treatments for all patients with CF.

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 37

Demographics:

Age: 25-34

Gender: Female

City: Skopje

Role: Patient

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Healthcare provider

Is Trikafta available to you or your loved one in North Macedonia?

Yes, but with difficulty

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost; Lack of medical authorization;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

Very satisfied

How does Trikafta compare to other treatments you or your loved one have used?

Much better

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Occasionally

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television; Social media;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Good

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Significantly

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

We would like easy access to the treatments for all the patient with CF.

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 38

Demographics:

Age: 18-24

Gender: Male

City: Skopje

Role: Patient

Cystic Fibrosis and Trikafta

A. Awareness and Access to Trikafta:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Media (TV, internet, print)

Is Trikafta available to you or your loved one in North Macedonia?

No

If Trikafta is not available, what are the main barriers? (Select all that apply)

Lack of medical authorization; High cost;

B. Experience with Trikafta:

For those using Trikafta, how satisfied are you with its effectiveness?

I don’t have acesss to Trikafta

How does Trikafta compare to other treatments you or your loved one have used?

I don’t have access to Trikafta

Media Coverage of Cystic Fibrosis

C. Awareness and Perception:

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television; Online news websites; Social media;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Fair

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Slightly

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, somewhat

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 39

Demographics:

Age: 18-24

Gender: Male

City: Other

Role: Patient

Cystic Fibrosis and Trikafta

A. Awareness and Access to Trikafta:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Healthcare provider

Is Trikafta available to you or your loved one in North Macedonia?

No

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost; Lack of medical authorization; Supply issues;

B. Experience with Trikafta:

For those using Trikafta, how satisfied are you with its effectiveness?

I don’t have access to Trikafta

How does Trikafta compare to other treatments you or your loved one have used?

I don’t have access to Trikafta

Media Coverage of Cystic Fibrosis

C. Awareness and Perception:

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television; Newspapers; Online news websites; Social media;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Fair

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one’s understanding of cystic fibrosis and its treatments?

Slightly

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, somewhat

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 40

Demographics:

Age: 18-24

Gender: Male

City: Struga

Role: Patient

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Media (TV, internet, print)

Is Trikafta available to you or your loved one in North Macedonia?

No

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost; Lack of medical authorization; Supply issues; Lack of information;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

I don’t have access to Trikafta

How does Trikafta compare to other treatments you or your loved one have used?

I don’t have access to Trikafta

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Occasionally

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television; Social media;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Good

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, somewhat

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 41

Demographics:

Age: 25-34

Gender: Male

City: Skopje

Role: Patient

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Media (TV, internet, print)

Is Trikafta available to you or your loved one in North Macedonia?

No

If Trikafta is not available, what are the main barriers? (Select all that apply)

Supply issues; Lack of medical authorization;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

I don't have access to Trikafta

How does Trikafta compare to other treatments you or your loved one have used?

I don't have access to Trikafta

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Occasionally

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Social media; Television;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Good

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Slightly

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 42

Demographics:

Age: 18-24

Gender: Male

City: Other

Role: Patient

Cystic Fibrosis and Trikafta

A. Awareness and Access to Trikafta:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Healthcare provider

Is Trikafta available to you or your loved one in North Macedonia?

No

If Trikafta is not available, what are the main barriers? (Select all that apply)

Lack of medical authorization; Supply issues;

B. Experience with Trikafta:

For those using Trikafta, how satisfied are you with its effectiveness?

I don’t have access to Trikafta

How does Trikafta compare to other treatments you or your loved one have used?

I don’t have access to Trikafta

Media Coverage of Cystic Fibrosis

C. Awareness and Perception:

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television; Online news websites; Social media;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Excellent

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Slightly

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 43

Demographics:

Age: 18-24

Gender: Female

City: Other

Role: Patient

Cystic Fibrosis and Trikafta

A. Awareness and Access to Trikafta:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Healthcare provider

Is Trikafta available to you or your loved one in North Macedonia?

No

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost; Supply issues;

B. Experience with Trikafta:

For those using Trikafta, how satisfied are you with its effectiveness?

I don’t have access to Trikafta

How does Trikafta compare to other treatments you or your loved one have used?

I don’t have access to Trikafta

Media Coverage of Cystic Fibrosis

C. Awareness and Perception:

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Occasionally

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television; Social media;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Fair

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Slightly

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, somewhat

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 44

Demographics:

Age: 25-34

Gender: Male

City: Skopje

Role: Patient

Cystic Fibrosis and Trikafta

A. Awareness and Access to Trikafta:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Media (TV, internet, print)

Is Trikafta available to you or your loved one in North Macedonia?

No

If Trikafta is not available, what are the main barriers? (Select all that apply)

Lack of medical authorization; Lack of information;

B. Experience with Trikafta:

For those using Trikafta, how satisfied are you with its effectiveness?

I don't have access to Trikafta

How does Trikafta compare to other treatments you or your loved one have used?

I don't have access to Trikafta

Media Coverage of Cystic Fibrosis

C. Awareness and Perception:

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Occasionally

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television; Online news websites;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Good

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, somewhat

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 45

Demographics:

Age: 18-24

Gender: Female

City: Tetovo

Role: Patient

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Healthcare provider

Is Trikafta available to you or your loved one in North Macedonia?

No

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost; Supply issues;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

I don't have access to Trikafta

How does Trikafta compare to other treatments you or your loved one have used?

I don't have access to Trikafta

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television; Online news websites; Social media;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Fair

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, somewhat

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 46

Demographics:

Age: 18-24

Gender: Female

City: Skopje

Role: Patient

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Healthcare provider

Is Trikafta available to you or your loved one in North Macedonia?

No

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost; Supply issues;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

I don't have access to Trikafta

How does Trikafta compare to other treatments you or your loved one have used?

I don't have access to Trikafta

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television; Online news websites; Social media;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Good

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, somewhat

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 47

Demographics:

Age: 25-34

Gender: Male

City: Skopje

Role: Patient

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Patient support groups

Is Trikafta available to you or your loved one in North Macedonia?

No

If Trikafta is not available, what are the main barriers? (Select all that apply)

Lack of medical authorization;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

I don’t have access to Trikafta

How does Trikafta compare to other treatments you or your loved one have used?

I don’t have access to Trikafta

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Occasionally

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Good

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Moderately

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, somewhat

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 48

Demographics:

Age: 25-34

Gender: Male

City: Other

Role: Yes

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Healthcare provider

If you are aware of Trikafta, how did you first learn about it?

No

Is Trikafta available to you or your loved one in North Macedonia?

No

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost; Lack of medical authorization;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

I don’t have access to Trikafta

How does Trikafta compare to other treatments you or your loved one have used?

I don’t have access to Trikafta

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Occasionally

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television; Online news websites; Social media;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Good

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one’s understanding of cystic fibrosis and its treatments?

Slightly

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, somewhat

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/

Respondent 49

Demographics:

Age: 25-34

Gender: Male

City: Other

Role: Patient

Cystic Fibrosis and Trikafta

A. **Awareness and Access to Trikafta**:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Media (TV, internet, print)

Is Trikafta available to you or your loved one in North Macedonia?

No

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost; Supply issues;

B. **Experience with Trikafta:**

For those using Trikafta, how satisfied are you with its effectiveness?

I don’t have access to Trikafta

How does Trikafta compare to other treatments you or your loved one have used?

I don’t have access to Trikafta

Media Coverage of Cystic Fibrosis

C. **Awareness and Perception:**

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television; Newspapers; Online news websites; Social media;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Fair

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Slightly

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, somewhat

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

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Respondent 50

Demographics:

Age: 18-24

Gender: Male

City: Skopje

Role: Patient

Cystic Fibrosis and Trikafta

A. Awareness and Access to Trikafta:

Are you aware of Trikafta as a treatment for cystic fibrosis?

Yes

If you are aware of Trikafta, how did you first learn about it?

Healthcare provider

Is Trikafta available to you or your loved one in North Macedonia?

No

If Trikafta is not available, what are the main barriers? (Select all that apply)

High cost;

B. Experience with Trikafta:

For those using Trikafta, how satisfied are you with its effectiveness?

I don’t have access to Trikafta

How does Trikafta compare to other treatments you or your loved one have used?

I don’t have access to Trikafta

Media Coverage of Cystic Fibrosis

C. Awareness and Perception:

How often do you encounter news or media coverage about cystic fibrosis in North Macedonia?

Rarely

What types of media do you rely on for information about cystic fibrosis? (Select all that apply)

Television; Social media;

How do you rate the overall quality of media coverage on cystic fibrosis in North Macedonia?

Good

D. Impact and Effectiveness:

Has media coverage influenced you or your loved one's understanding of cystic fibrosis and its treatments?

Slightly

Do you think media coverage has helped improve awareness and support for cystic fibrosis in North Macedonia?

Yes, greatly

Additional comments:

What additional information or improvements would you like to see in media coverage of cystic fibrosis?

/

Do you have any other comments or suggestions regarding Trikafta, cystic fibrosis treatment, or media coverage in North Macedonia?

/