

# RESEARCH REPORT

## THE SITUATION OF PATIENTS WITH RARE DISEASES FROM UKRAINE WHO FLED THE WAR

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EDU



**Research conducted by:**



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Katowice, 2022

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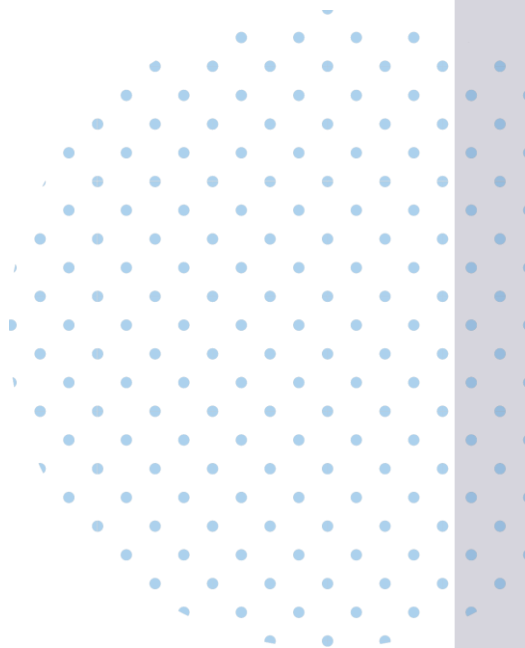
Supporting rare diseases patients fleeing the war in Ukraine projects supported  
by funding from Amicus Therapeutics UK Limited

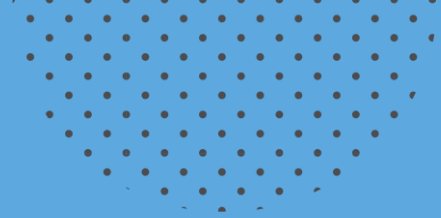
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0.

# Contents





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1.

# Introduction

Since the beginning of the war, the Healthcare Education Institute has been helping patients with rare diseases fleeing the war in Ukraine.

We are doing our best to prevent them from feeling abandoned and left to deal with their difficulties alone. We support them in many ways: we help them cross the border and obtain refugee status, we secure their treatments in Poland or other European countries, and we provide information and offer legal services.

As we want to better adjust our activities to the patients' needs, we have conducted research among the Ukrainians with rare diseases that we have supported in terms of their current situations, their unique perspectives, their access to treatment, and their needs.

Who are rare disease patients?

A disease is rare when it affects less than 1 in 2,000 citizens in a given country. But so far, over 6,000 different rare diseases have been identified, which in total affect 3.5 – 6% of the worldwide population.

That is why rare diseases are not that rare; in Ukraine, there are approximately 1.5 – 2.5 million people with rare diseases.



RD affect  
<1:2000  
people



Around  
1.5–2 mln  
RD patients  
live in Ukraine

# Form of research

Research in the form of online self-administered questionnaires was conducted in June and July of 2022 among adult patients and parents of underage patients with rare diseases who fled the war in Ukraine and are currently in Poland or other European countries.

The questionnaires were completely anonymous.

The respondents were asked about such subjects as:

- the period of stay outside Ukraine
- received medical assistance related to their illness
- financial support received by refugees
- greatest difficulties faced abroad
- current housing and work situation
- plans for the future

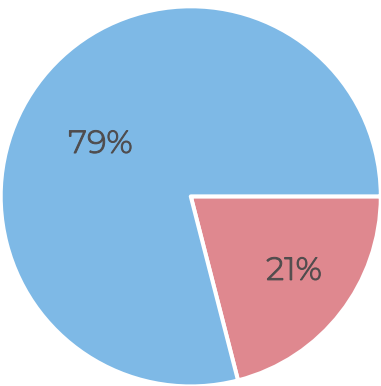
## Group of respondents

The respondent group consisted of:

- 6 adult patients with rare diseases
- 22 parents of children with rare diseases

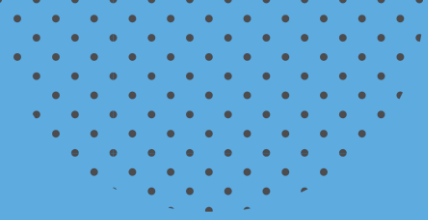


22 parents  
of children with  
rare diseases



6 adult  
patients with  
rare diseases





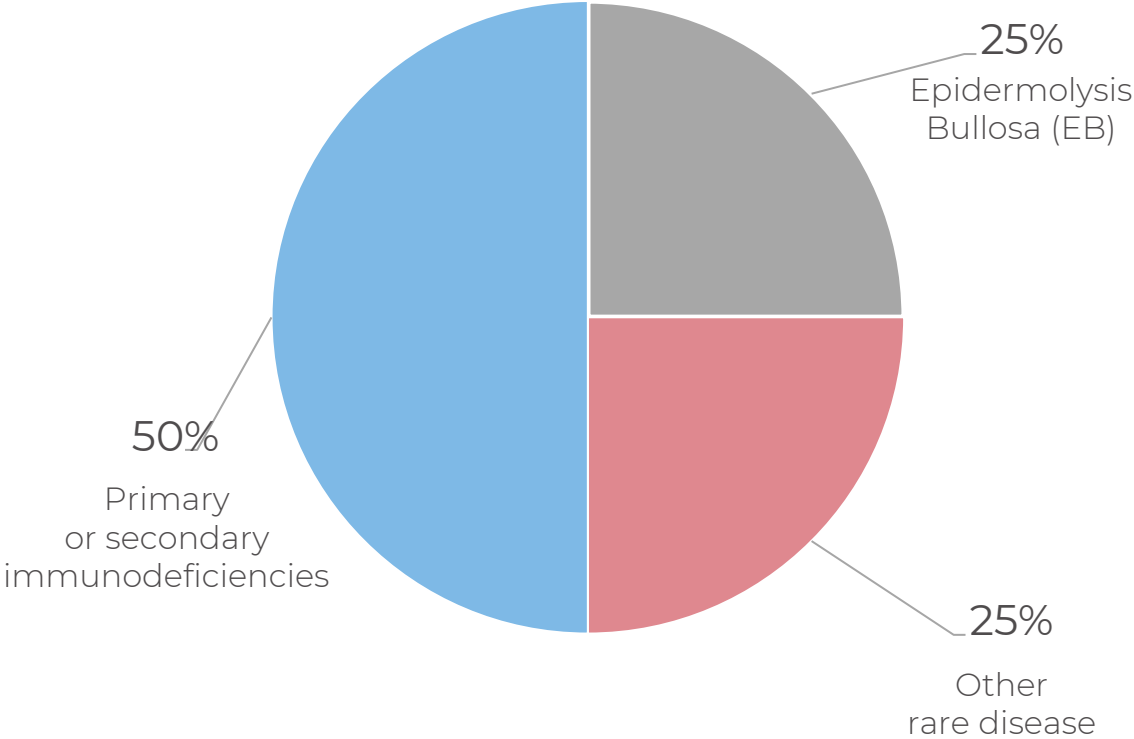
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2.

Results

# CHART 1.

## Types of rare diseases among patients

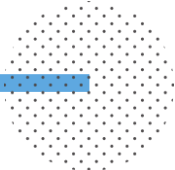


N=28

The questionnaire participants were adult patients or parents of underage patients.  
**50% of respondents were representatives of families in which patients suffer from immunodeficiency, 25% from Epidermolysis Bullosa (EB), and 25% from other rare diseases.**

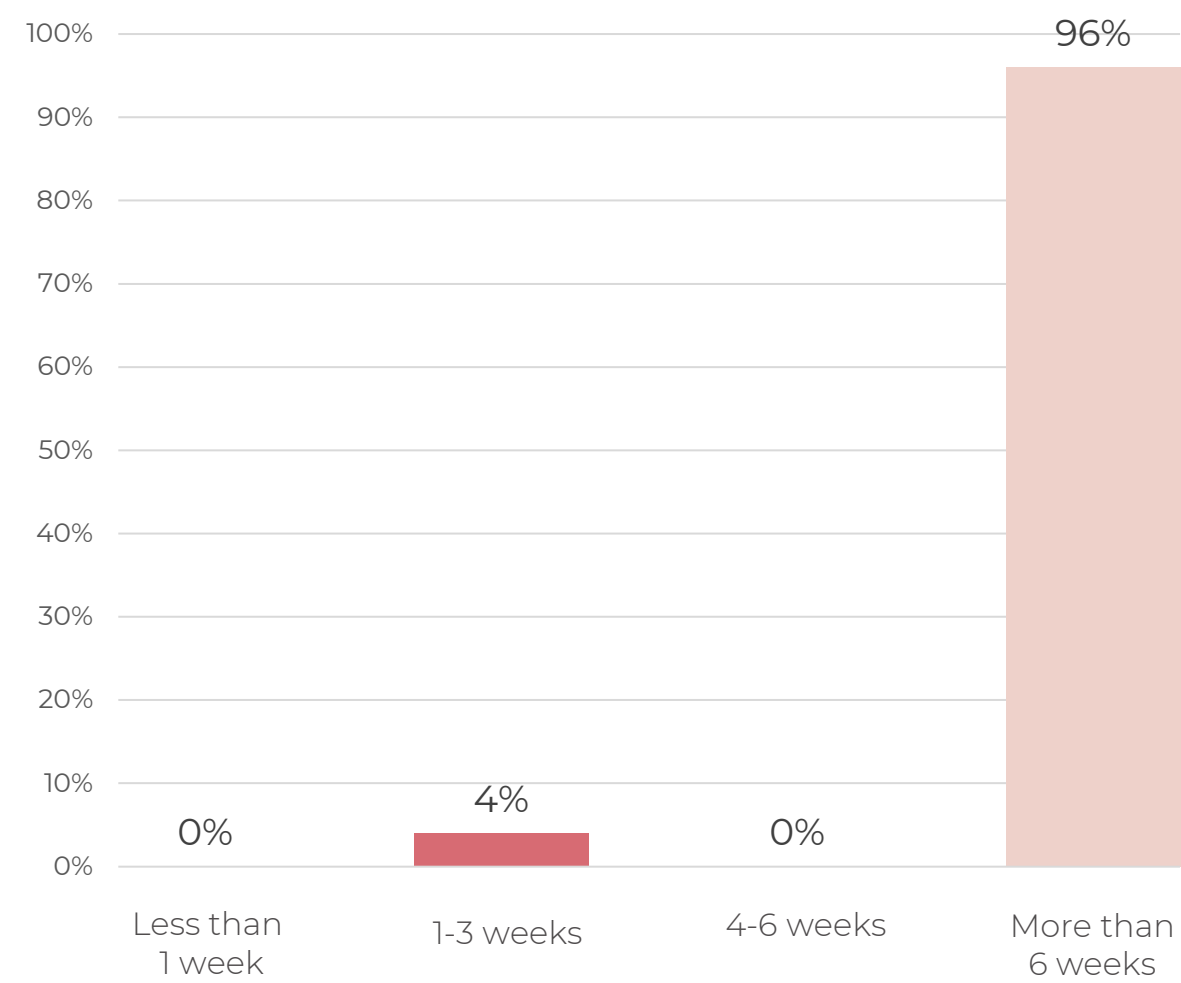
A.Q1: What rare disease do you have?  
C.Q1: What rare disease does your child have?





# CHART 2.

## The time that has elapsed since leaving Ukraine



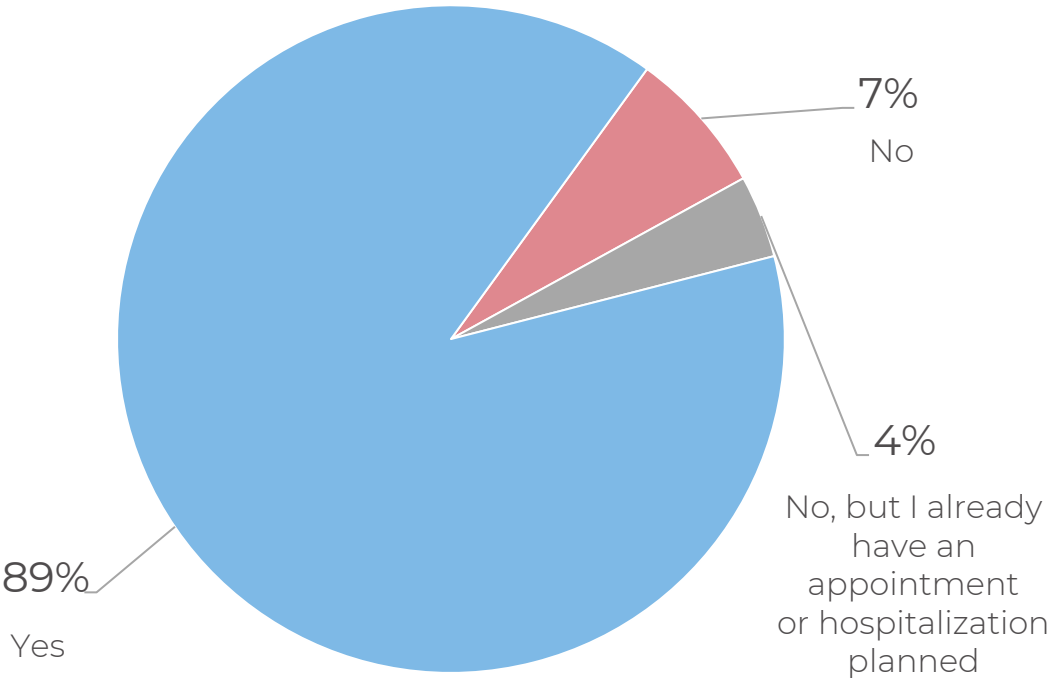
N=28

Most of the families who participated in this research left Ukraine more than 6 weeks ago, so they have been abroad for a long time. **Only one of the respondents has been abroad for less: 1-3 weeks.**

A.Q2: How long have you been outside Ukraine?  
C.Q2: How long have you been outside Ukraine?

# CHART 3.

## Receiving medical assistance while remaining outside Ukraine



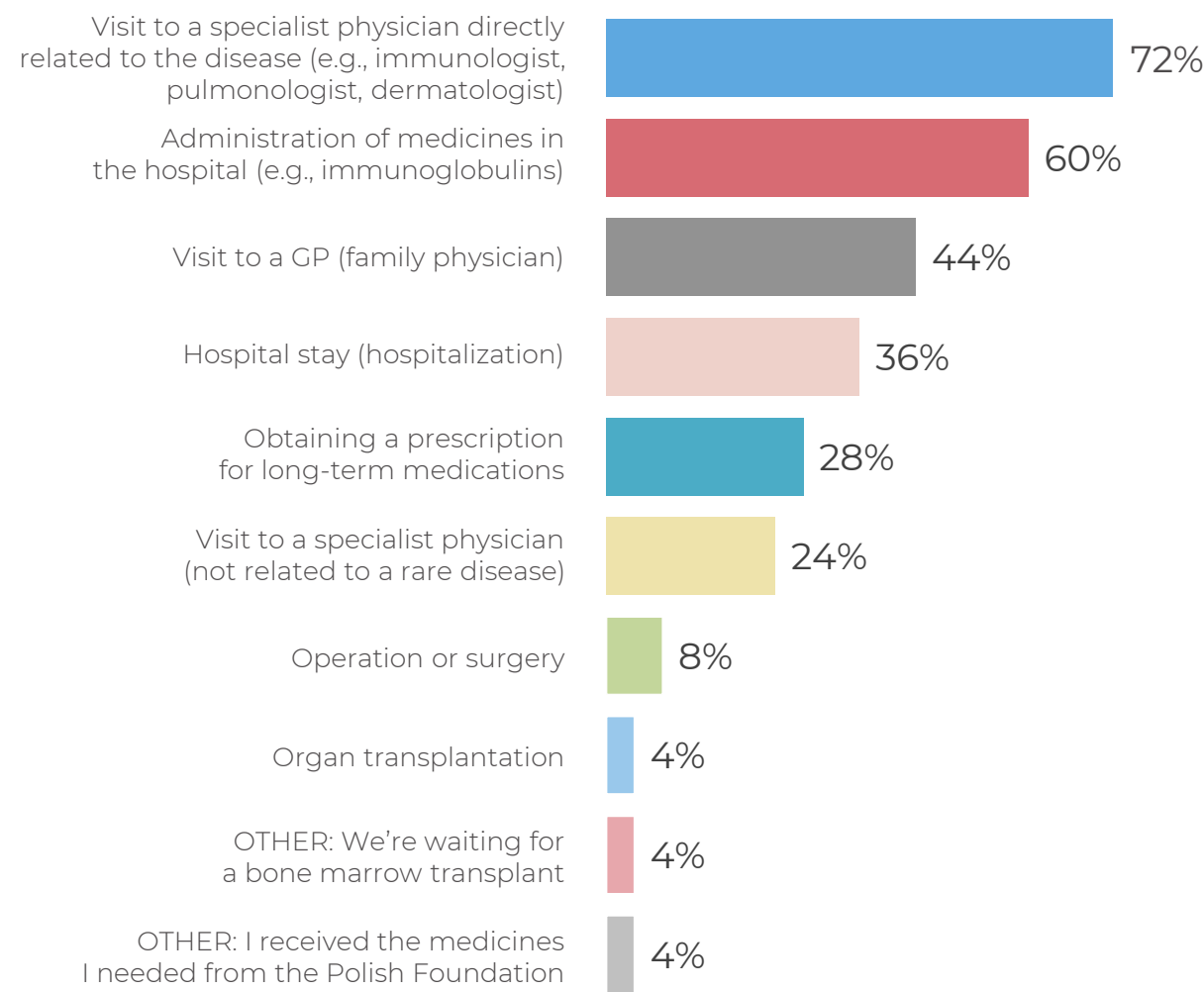
N=28

An important finding from the research is that the vast majority of respondents have already received medical assistance during their stay abroad (89%) or have an appointment with a physician or hospitalization planned (4%). Only 7% of respondents haven't yet received medical treatment in the country they are in.

A.Q3: Have you received medical assistance during your stay abroad?  
C.Q3: Has your child received medical assistance during their stay abroad?

# CHART 4.

## The type of medical assistance received by patients



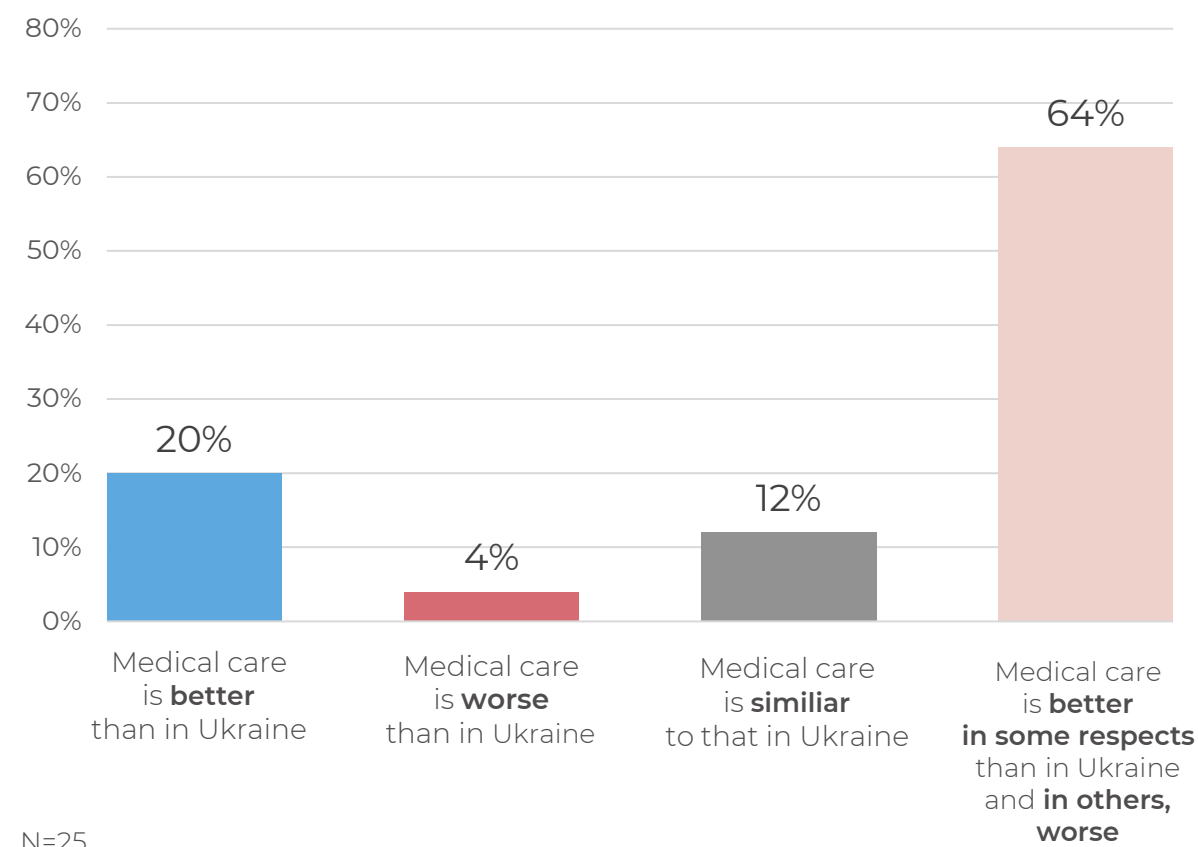
N=25

**The most common types of medical assistance patients have received are a visit to a specialist physician directly related to the disease (72%), an administration of medicines in the hospital (60%), and a visit to a GP (44%).** It's worth mentioning that some patients have benefited (or plan to) from highly specialized types of medical assistance, such as surgery or even organ or tissue transplantation (16% of patients in total).

A.Q4: What kind of medical assistance have you received? Select all correct answers.  
C.Q4: What kind of medical assistance has your child received? Select all correct answers.

# CHART 5.

## Assessment of medical care in the country of stay compared to Ukraine



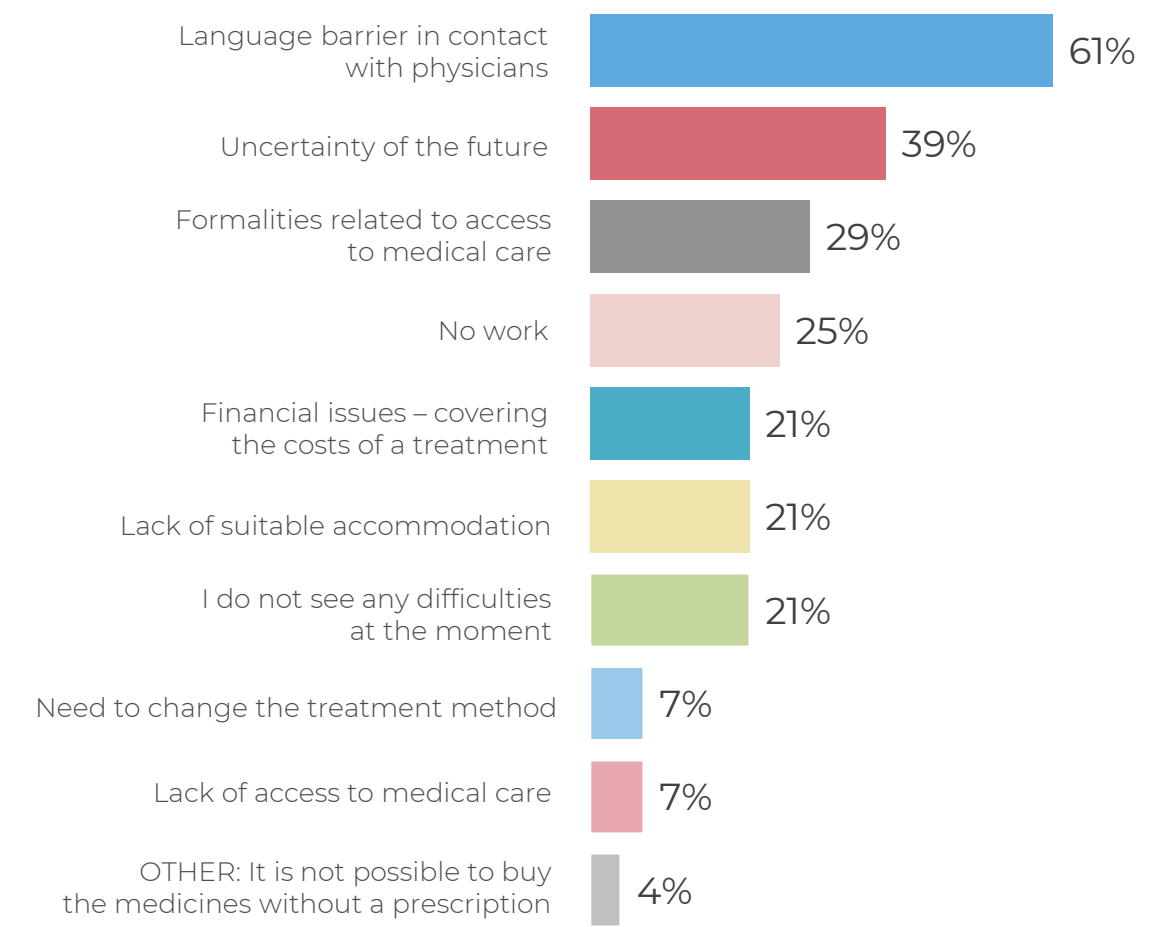
Patients with rare diseases often use medical care and are very familiar with it. They're naturally used to specific solutions and approaches in medicine. Meanwhile, medical care in individual European countries varies significantly in terms of access to specialists, reimbursement, bureaucracy, etc.

**This is probably why the majority of patients (64%), when assessing medical care in the country where they're currently staying, claim that in some respects, it's better than in Ukraine, and in others, it's worse.** One fifth of respondents consider the current medical care they receive as clearly better than in Ukraine, 12% as similar to that in Ukraine, and 4% as worse.

A.Q5: How do you rate the current medical care related to your disease?  
C.Q5: How do you rate the current medical care related to your child's disease?

# CHART 6.

## The greatest difficulties related to the disease after leaving Ukraine



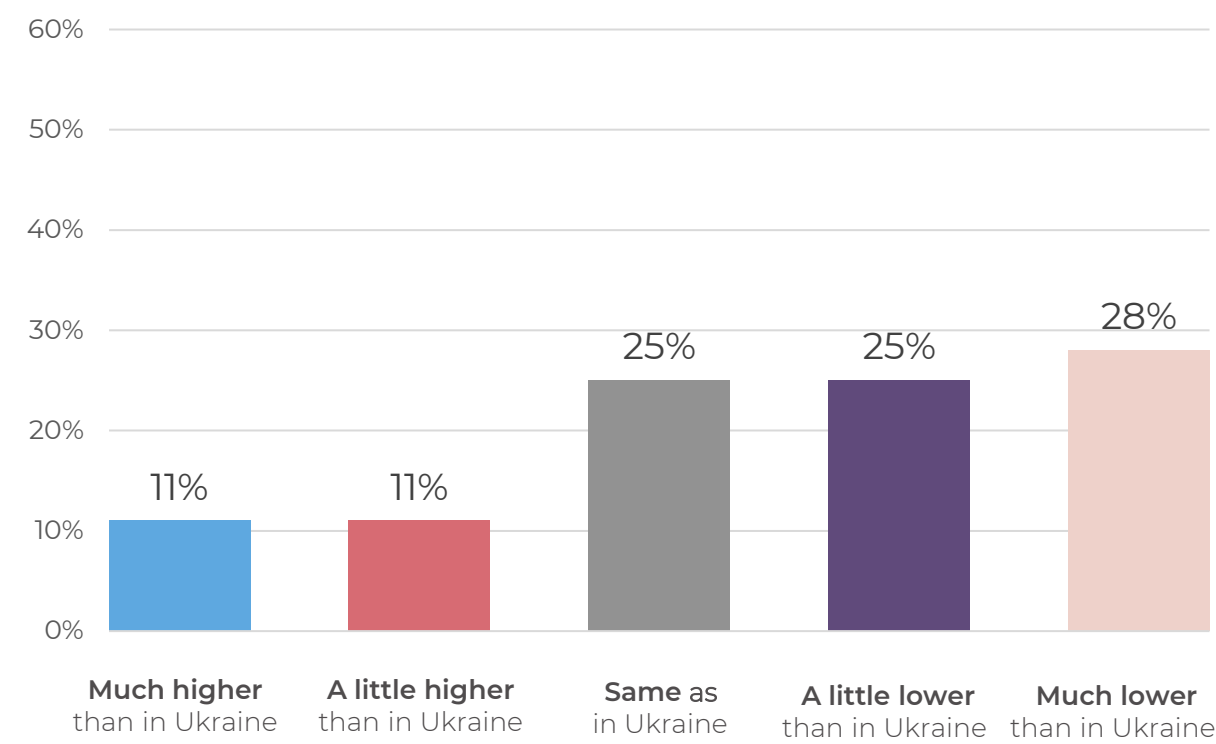
N=28

Patients and their families, while staying in a foreign country, experience many difficulties related to their illnesses. **The respondents indicated that the largest ones include: a language barrier in contact with physicians (61%) and uncertainty of the future (39%).** Difficulties also relate to social and financial security (no job, medical expenses, or lack of adequate accommodation). On the other hand, one fifth of the respondents indicated that they don't see any difficulties at this point.

A.Q6: After leaving Ukraine, what is currently the most difficult for you in connection with your illness? Select up to 3 answers.  
C.Q6: After leaving Ukraine, what is currently the most difficult for you in connection with your child's illness? Select up to 3 answers.

# CHART 7.

## The current financial costs related to the patient's disease compared to the costs in Ukraine



N=28

Patients and their families assess the financial burden related to their diseases very differently. This could be for several reasons. The level of burden may depend on:

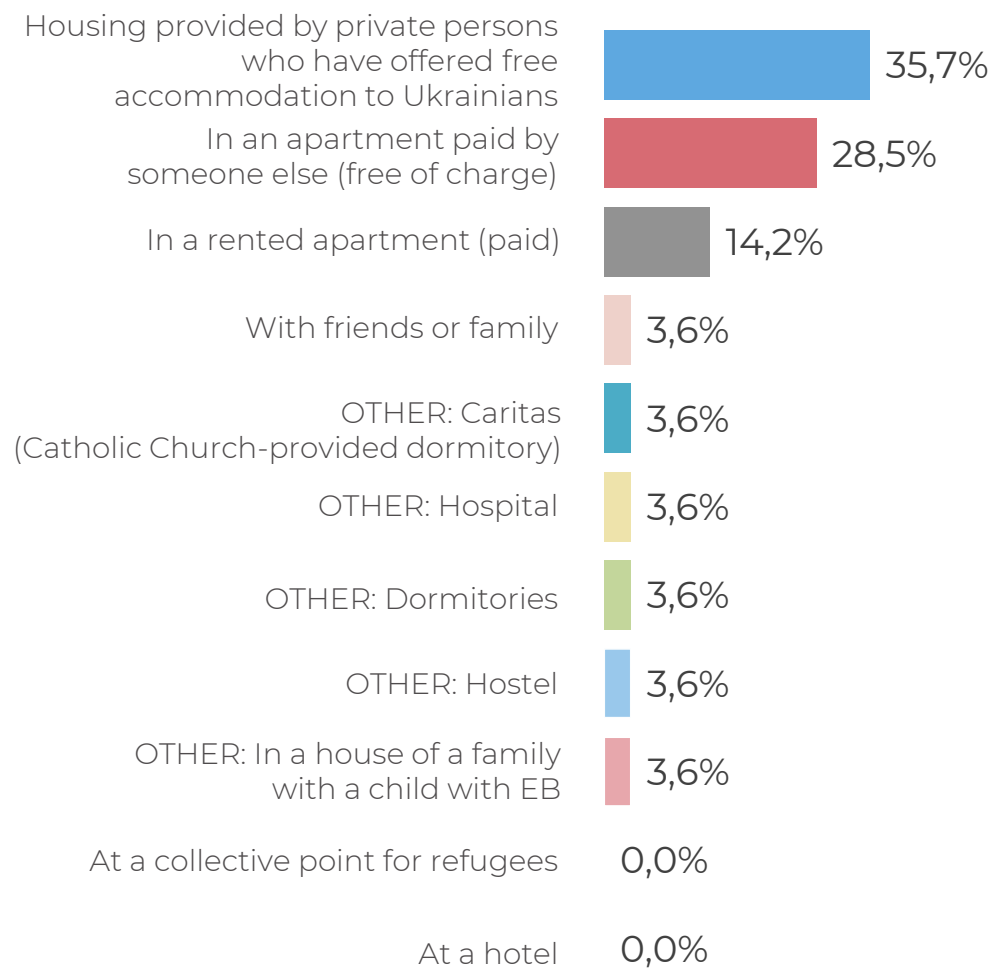
- the country in which they are located,
- the disease they suffer from,
- their health,
- the financial situation of the family.

**For the vast majority of patients (79%), the financial burden related to the disease is currently similar or smaller than in Ukraine.** It is worth noting that nearly one third of respondents indicated that the financial burden is much lower than in Ukraine.

A.Q7: What are the financial costs associated with your illness currently (purchase of medicines, dressings, medical equipment, visits to the physician, hospitalization, and all other costs related to the disease)?  
C.Q7: What are the financial costs related to your child's disease currently (purchase of drugs, dressings, medical equipment, visits to the physician, hospitalization, and all 14 other costs related to the disease)?

# CHART 8.

## The current place of accomodation for the patients and their families



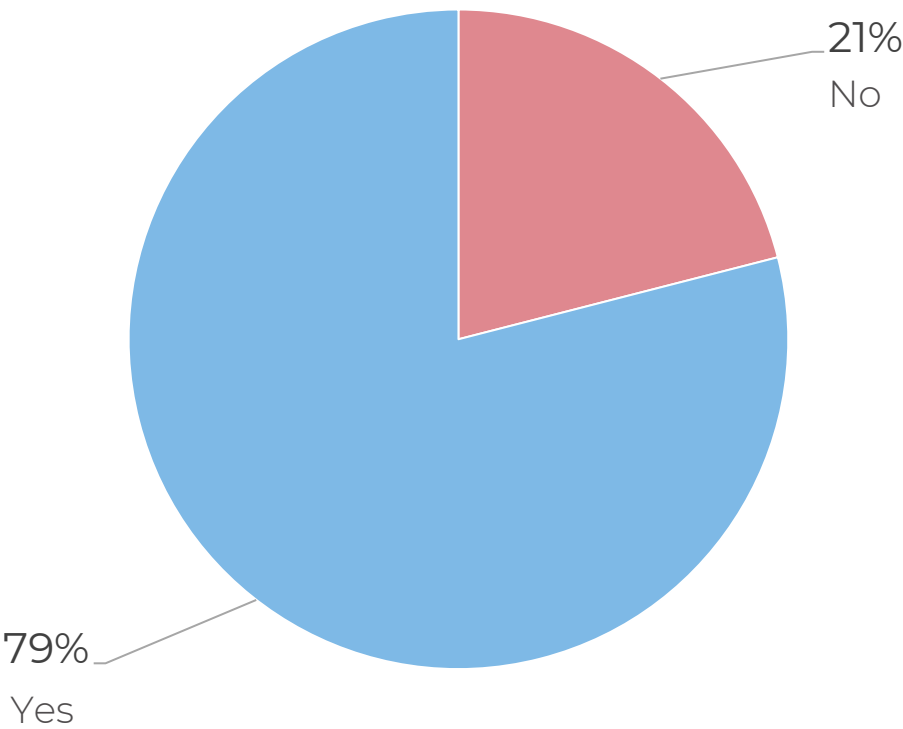
N=28

The housing situations of the respondents is very diverse, while the answers show that most of them don't pay for their place of residence. **The most common type of accommodation is housing provided by private persons who have offered free accommodation to Ukrainians or in an apartment paid for by someone else (free of charge).**

A.Q8: Where are you and your family currently living?  
C.Q8: Where are you and your family currently living?

# CHART 9.

## Receiving official financial assistance in the country where a patient is staying

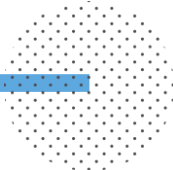


N=28

**Four-fifths of respondents have received some form of official financial assistance in the country where they’re staying.** In the next chart, we’ll see in detail what kind of help the patients have received.

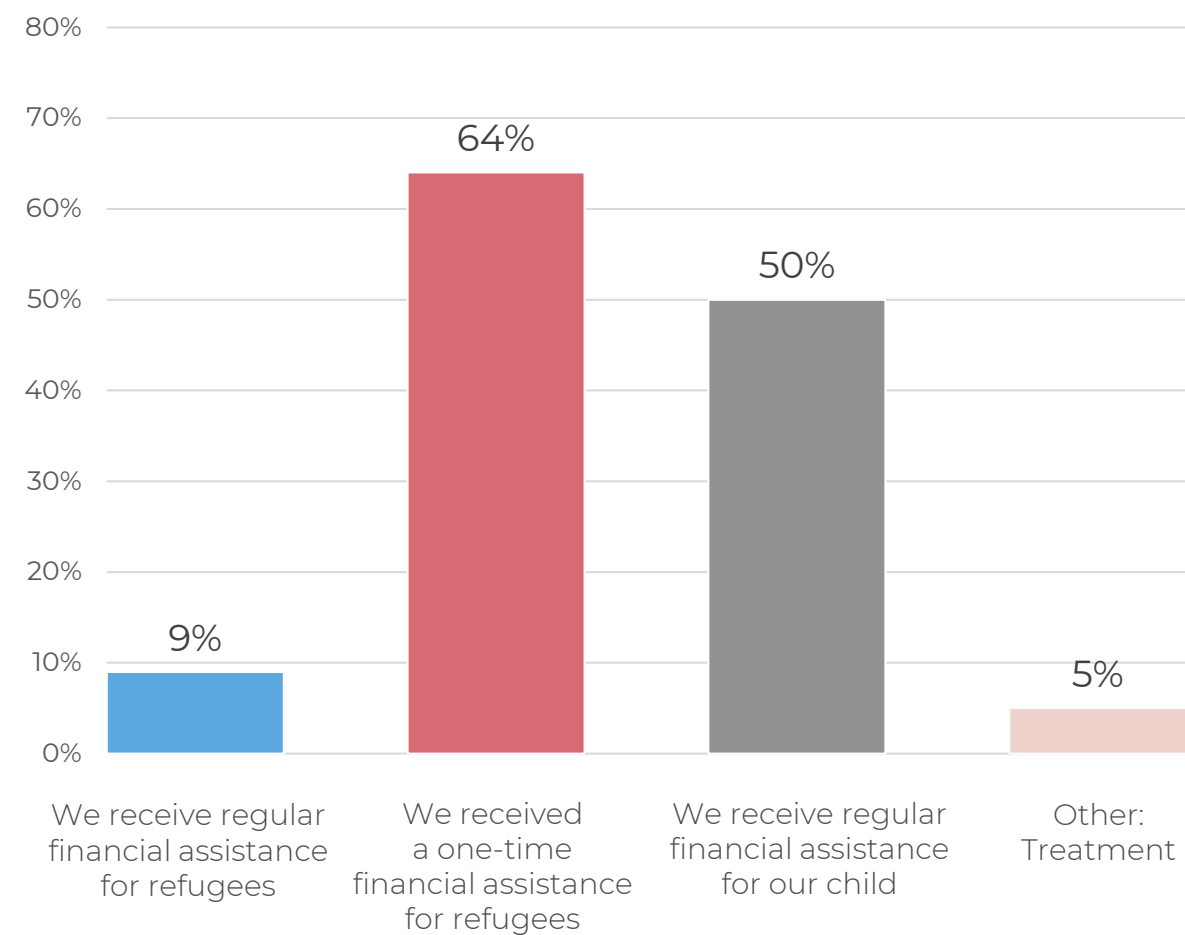
A.Q9: Have you already received any official financial assistance in the country where you’re staying?  
C.Q9: Have you already received any official financial assistance in the country where you’re staying?





# CHART 10.

## All types of financial assistance received by families



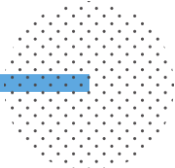
N=22

**The most common form of financial assistance received by respondents was a one-off benefit for refugees (64%). Half of them also receive regular child benefit.**

9% receive regular financial assistance for refugees. Again, the differences in the forms of support may depend on the country they're in and the type of assistance provided to refugees.

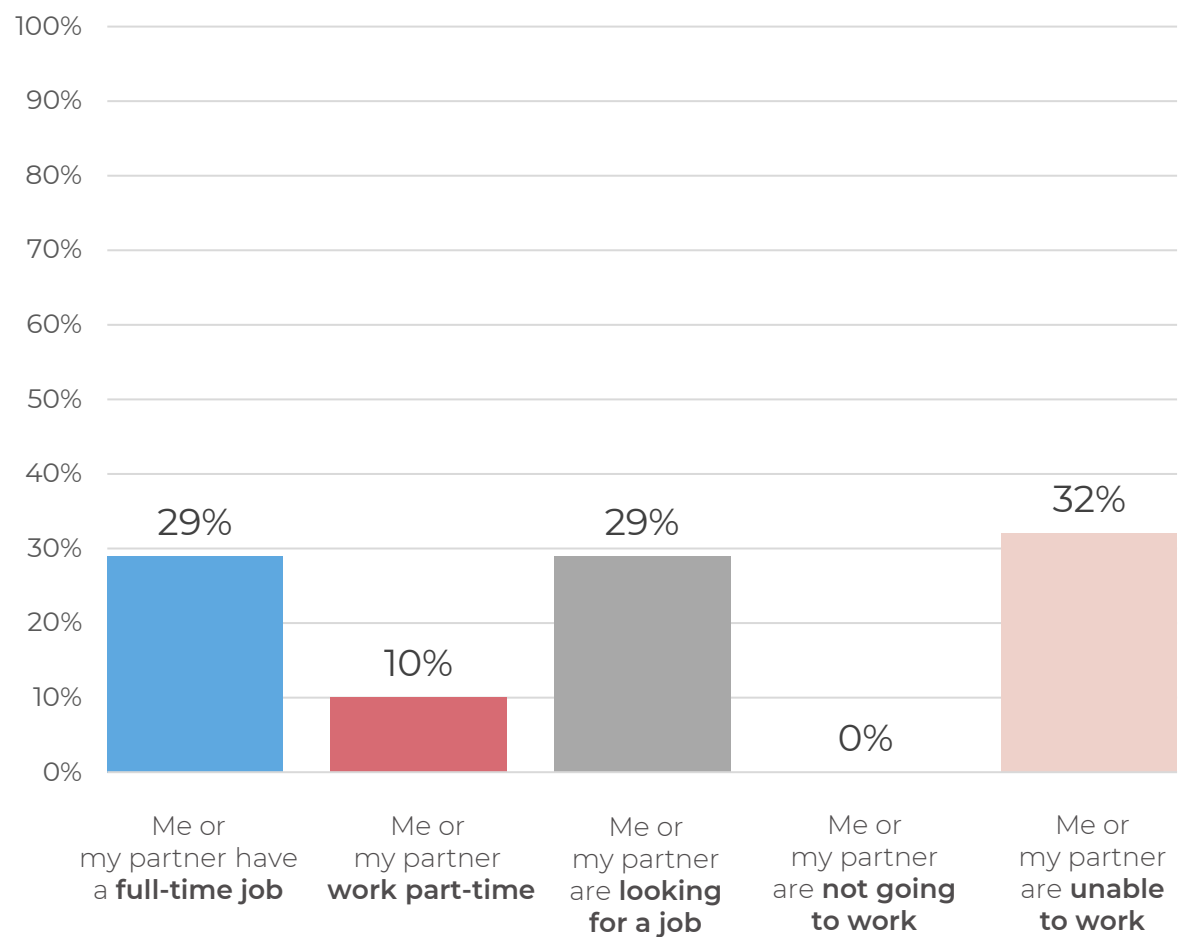


A.Q10: What kind of financial assistance have you received?  
C.Q10: What kind of financial assistance have you received?



# CHART 11.

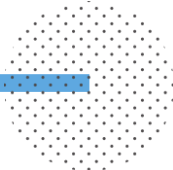
Possibility to work in the countries where families currently reside (answers from adult patients and parents of underage patients)



N=28

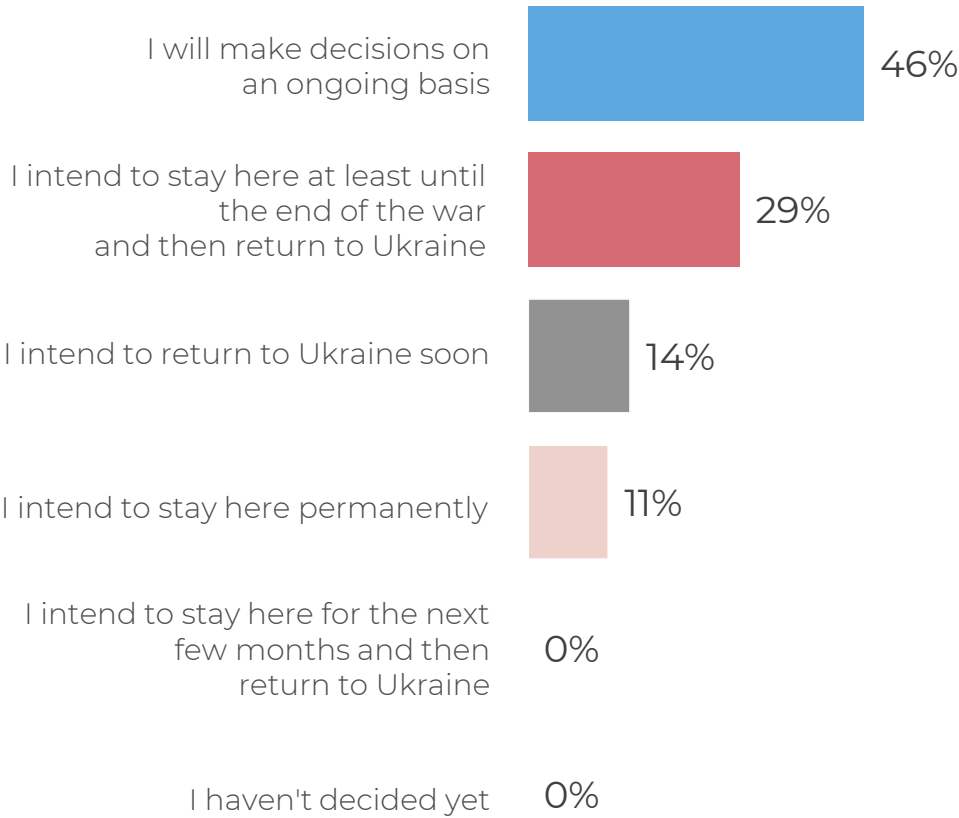
The work situation also varies greatly. In the questionnaire, we asked whether at least one adult in the family was working or looking for a job. **40% of respondents indicated that they or their partner already have a job, full-time or part-time; another 29% are looking for a job. One third of respondents indicated that they're unable to work.**

A.Q11: Are you or your partner currently working in the country you're in?  
C.Q11: Are you or your partner currently working in the country you're in?



# CHART 12.

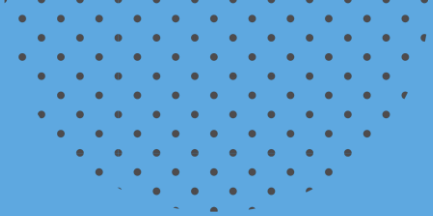
## Plans related to further stay abroad or return to Ukraine



N=28

A very important issue that we asked about are plans for the future related to staying abroad or returning to Ukraine. **Almost half of respondents indicated that they'll make decisions on an ongoing basis (46%).** Only 11% of respondents replied that they would like to stay abroad permanently. The remaining people intend to return to Ukraine soon (14%) or only after the end of the war (29%).

A.Q12: What are your plans for your future stay abroad?  
C.Q12: What are your plans for your future stay abroad?



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3.

Conclusions and  
recommendations



## I.


Undoubtedly, an important observation from the research is the fact that the vast majority of respondents have received medical assistance in the country where they're currently staying (89%) or have already made an appointment with a physician or hospital (4%). **This shows that the countries receiving people fleeing the war in Ukraine are effectively responding to their needs in the field of medical care.**

## II.

People who have received medical assistance (89%) indicated a visit to a specialist physician (72%) and administration of medicines in a hospital (60%) as the most frequent forms. This is confirmed by the fact that the countries receiving refugees from Ukraine manage to effectively provide patients with care adequate to their health conditions and needs. **Moreover, even people who, due to their illnesses, need highly specialized and costly medical procedures, such as surgeries or even transplantations, are guaranteed them in the countries they came to.**

## III.

Most of respondents (64%) assess the medical care in the country where they currently stay as better in some respects than in Ukraine, and in others, worse. It's understandable because medical care in individual European countries differs significantly in terms of such issues as access to specialists, refunds, and the level of bureaucracy, and patients are used to specific solutions and approaches in medicine. **However, the fact that only 4% of respondents rated medical care in their host countries as worse than in Ukraine shows that most countries provide patients with medical care at a satisfactory level, adequate to their needs.**



## IV.

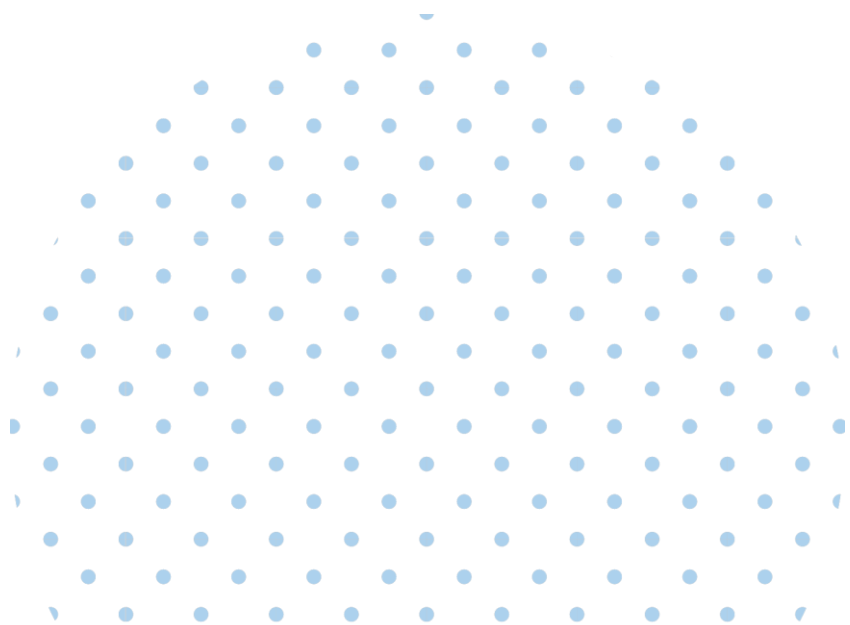
As many as 61% of respondents indicated that one of the greatest difficulties related to their disease that they had to face after leaving Ukraine was the language barrier in contact with physicians. **Therefore, it seems right to create educational materials in Ukrainian and to undertake other initiatives aimed at facilitating communication between physicians and patients.**

## V.

For the vast majority of patients (79%), the financial burden related to their disease is currently similar to or smaller than in Ukraine. It's worth noting that nearly one third of respondents indicated that the financial burden is much lower than in Ukraine. **We can see, therefore, that countries receiving refugees are trying to create solutions that allow patients to use many elements of the healthcare system free of charge (access to specialists, reimbursement of medicines, etc.), so that it doesn't overburden people fleeing the war.**

## VI.

The vast majority of respondents use free forms of accommodation: with private persons, in flats paid for by someone else, or in collective refugee centers. **This means that the issue of accommodation isn't a burden on their budgets.**



## VII.

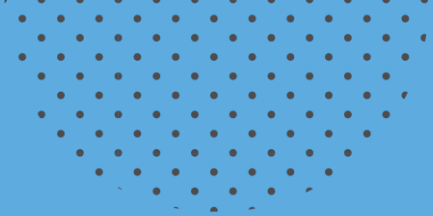
Almost 4/5 of respondents (79%) indicated that they had received financial assistance in the country where they're currently staying, but **in the majority (64%), it was only a one-time financial assistance for refugees. Taking into account these results and the fact that almost all respondents have been outside Ukraine for at least 6 weeks, it seems necessary to think about more long-term forms of support for refugees with rare diseases in the countries that host them.** This applies in particular to the most vulnerable groups, such as patients with rare diseases, a situation in which neither themselves nor their carers are able to take up gainful employment due to the specificity of the disease.

## VII.

Almost half of respondents (46%), when asked about their plans for further stay abroad or return to Ukraine, replied that they made decisions based on current events. 29% of respondents intend to return to Ukraine only after the end of the war. Only 11% indicated that they would return to Ukraine soon. **Thus, it can be seen that the majority of patients suffering from rare diseases plan to stay abroad until the situation stabilizes. They want to stay in a place where they can count on constant medical assistance and the continuation of their therapies.**

## IX.

On the other hand (which is also worth noting), despite the guaranteed access to medical care, only 11% of the respondents declared that they intend to stay permanently in the country where they're currently staying. It can therefore be assumed that **most patients will return to Ukraine when it's possible.**



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4.

Learn more about  
our activities



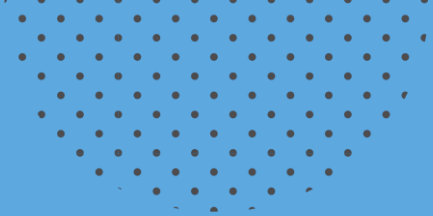
If you would like to learn more about the activities we undertake for Ukrainian patients with rare diseases, you can download the newest report about our help by clicking the cover below or visiting our website:

[eduinstitute.org/help-Ukraine](https://eduinstitute.org/help-Ukraine)

There, you can find further details, photos, statistics, and testimonials.

Click here!





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5.

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of the report



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