

# RESULTS OF THE STUDY **COST(LESS) MEDICINE**



**USAID**  
FROM THE AMERICAN PEOPLE

 **PATIENTS OF  
UKRAINE**



This study is made possible by the support of the American People through the United States Agency for International Development (USAID). The contents are the sole responsibility of the CF “Patients of Ukraine” and do not necessarily reflect the views of USAID or the United States Government.

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For many years, Ukrainians have been living in a dual reality. On the one hand, we live in a fantasy world of the Soviet Union, where «in state and municipal health care institutions medical care is free» (Article 49 of the Constitution of Ukraine). On the other hand, in most cases, every Ukrainian somehow pays for medical services. This is mainly under-the-table “thank you” payments in the form of cash (mostly dollars), liquor or chocolate presented to doctors in public hospitals, or official (and quite high!) fees in private clinics.

**OLGA STEFANYSHYNA,**  
EXECUTIVE DIRECTOR  
CF «PATIENTS OF UKRAINE»

The numbers presented in this report reflect the real situation with «free» medicine in Ukraine. It is also illustrated by true stories from patients — sincere interviews that will not leave you indifferent. We believe that by joining efforts with the patients who desperately fight for their lives in Ukraine, we will get the health care reform moving and fundamentally change the policies of drug provision for people. We hope that the government will become our reliable partner.



The U.S. Agency for International Development (USAID) developed the “Cost(less) Medicine Project” to provide the Government of Ukraine with reliable data that will drive evidence-based decision-making and help strengthen the national system for procuring pharmaceuticals as part of its larger health reform effort. The study focuses on access to treatment, household spending on pharmaceuticals, and the resulting impact of these two issues on quality of life.

**SUSAN K. FRITZ,**  
DIRECTOR  
**USAID REGIONAL MISSION  
TO UKRAINE, BELARUS & MOLDOVA**

The study's focus is on patients and its approach makes it unique and important for Ukraine during this critical time in which the country is undertaking significant reforms in health service delivery. The study shows the health system through the eyes of Ukrainian patients who address vital patient issues, such as availability and affordability of medicines, patients' trust in doctors, and attitudes towards the existing pharmaceutical sector policies. Each patient's story encapsulates the larger issues in the health system of Ukraine. Each individual's subjective perception about his/her access to treatment reflects the general image of the health system in the eyes of the nation. Ukraine can use the results of the study to inform, develop, and implement reforms targeted at solving the problems of individual patients and thus the nation as a whole.

Studies such as this one are critically needed and should be conducted regularly to monitor the level of satisfaction of Ukrainians with the health system. Ultimately, Ukraine's citizens deserve a health system that works for and is responsive to their needs. This study is an important tool for developing, implementing, and monitoring healthcare reform that delivers such a citizen-driven system.



# ABOUT THE PROJECT

**A P R I L**  
2016 • 2017

The health care advocacy project “Cost(less) Medicine” was implemented between April 2016 and April 2017.

## OBJECTIVE:

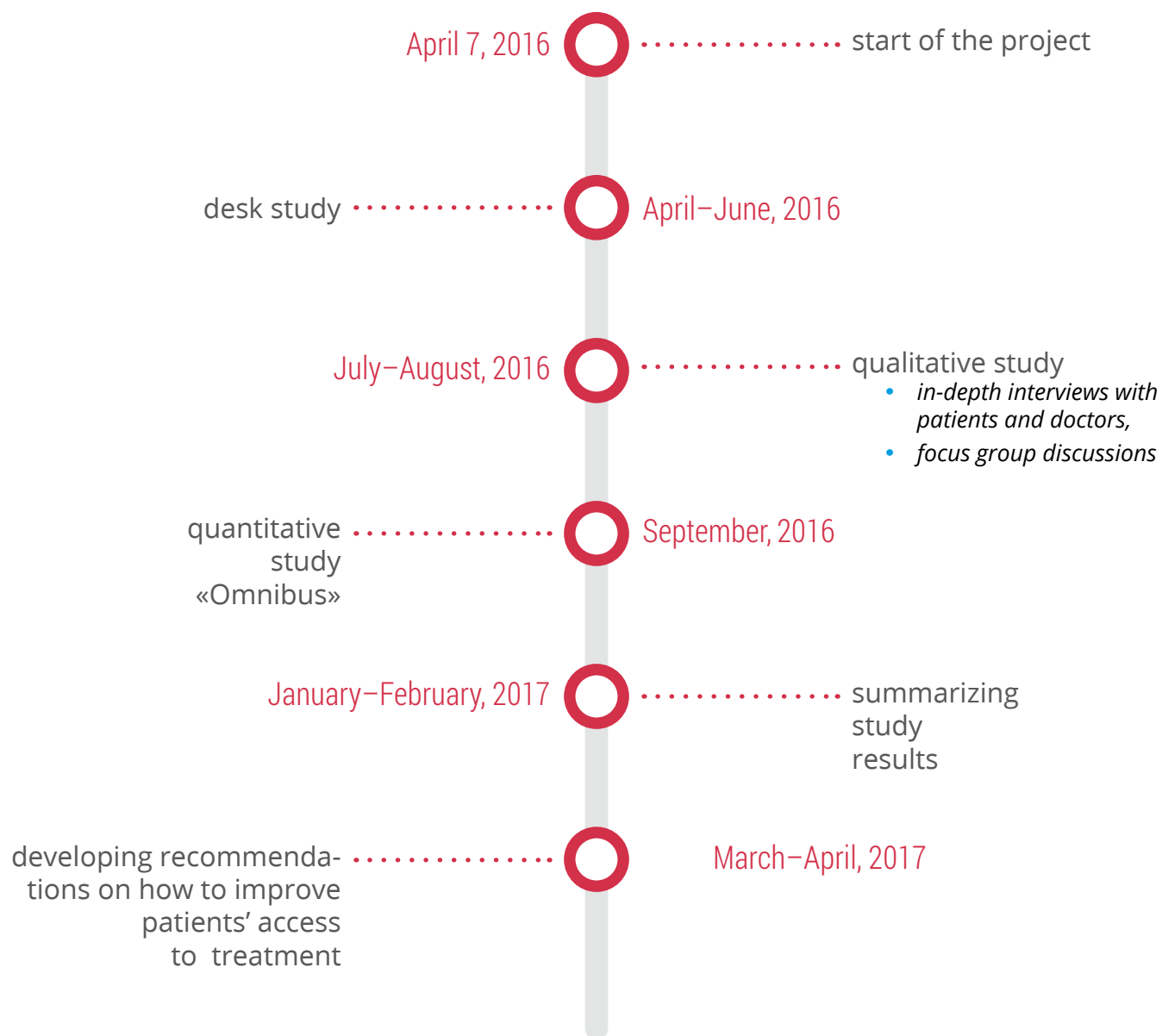
- *to analyze the amount of money Ukrainian families spend on medication, the affordability of medical treatment and the attitude of patients to the existing policy of drug provision*
- *to develop recommendations to improve access to medication*

## TO REACH THIS OBJECTIVE, THE FOLLOWING METHODOLOGY WAS USED:

- *desk study*
- *qualitative study*
- *quantitative study*

- *In addition, the results of the national survey “Health Index. Ukraine 2016” were partially used.*





# PATIENTS' OUT-OF-POCKET EXPENSES ANALYSIS

Out-of-pocket payments made by patients for medical care, medicines and medical devices are the main source of funding in Central and Eastern Europe. This also applies to Ukraine: in 2014, **46%** of total health care costs were covered by out-of-pocket payments<sup>1</sup>, whereas in Poland it is **24%**, in Lithuania **31%**, in Belarus **32%**. Most of the money spent by patients is on medicines. Patients' expenses for medical services account for much smaller share of the total out-of-pocket payments<sup>2</sup>. At the same time, Ukraine spends a total of 35% of its state budget on medicines, whereas in other countries this percentage varies — in Moldova it is 6%, in Belarus 45%<sup>3</sup>.

The results of previous studies prove the difficulty to ensure all patients in Ukraine receive the medicine they need:

**47%** of respondents in Ukraine in 2010<sup>4</sup> stated that they “always” or “sometimes” have to limit their medicine consumption, while in Belarus, Russia and Kazakhstan this percentage does not exceed 33%.

In 2011, in Ukraine, 78% of patients who experienced inpatient treatment during that year indicated that they brought medicine with them to the hospital, while in Hungary this number does not exceed 16%, in Lithuania — 20%<sup>5</sup>.

**In Ukraine, the average amount of out-of-pocket payments made by inpatients is 62 euros. That's compared to 16 euros in Hungary and 9 euros in Lithuania.**

**91%** of patients who received inpatient care in Ukraine in 2012, 80% in Russia in 2010 and 63% in Moldova in 2011 paid for the medicine because the state health care facilities were unable to cover such costs<sup>6</sup>.

The main goal for a health care system is to offer patients financial protection in case of illness. Out-of-pocket payments, especially if not regulated and monitored, can limit the access to treatment. This eventually leads to the emergence of such negative phenomena as self-medication. That is why it is important to implement an effective policy on patients' expenses for medicine and treatment.

<sup>1</sup>Data is presented at the World Bank website: <http://data.worldbank.org/indicator/SH.XPD.OOPC.TO.ZS?locations=UA>

<sup>2</sup>Richardson E. (2014) Health financing. In: Trends in health systems in the former Soviet countries. [http://www.euro.who.int/\\_data/assets/pdf\\_file/0019/261271/Trends-in-health-systems-in-the-former-Soviet-countries.pdf?ua=1](http://www.euro.who.int/_data/assets/pdf_file/0019/261271/Trends-in-health-systems-in-the-former-Soviet-countries.pdf?ua=1)

<sup>3</sup>Richardson E., Sautenkova N., Bolokhovets G.(2014) Pharmaceutical care. In: Trends in health systems in the former Soviet countries.

<sup>4</sup>Footman K., Richardson E., Roberts B., Alimbekova G., Pachulia M., Rotman D., Gasparishvili A. & McKee M. (2014). Foregoing medicines in the former Soviet Union: changes between 2001 and 2010. Health Policy, 118(2), 184-192.

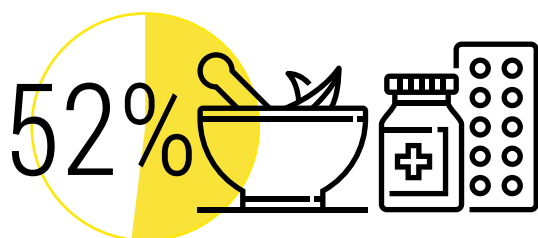
<sup>5</sup>Stepurko T., Pavlova M., Gryga I., Gaal P., & Groot W. (2016). Patterns of informal patient payments in Bulgaria, Hungary and Ukraine: a comparison across countries, years and type of services. Health Policy and Planning, czw147.

<sup>6</sup>Richardson E., Sautenkova N., Bolokhovets G.(2014) Pharmaceutical care. In: Trends in health systems in the former Soviet countries.

# STRATEGIES PURSUED BY PATIENTS WHEN THEY GET ILL

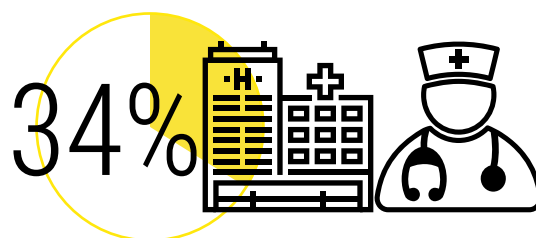
The results of the national survey “Health Index. Ukraine 2016” helped to quantify a scale of different patients’ strategies in case of a disease.

Only one third of respondents would contact a doctor in case of disease. More than a half of patients would choose to self-medicate. One of the highest responses to explain such a strategy is associated with the high cost of treatment. Some respondents do not trust medical personnel (7%, including those who would not contact the doctor). We receive similar distribution of responses in our qualitative research.



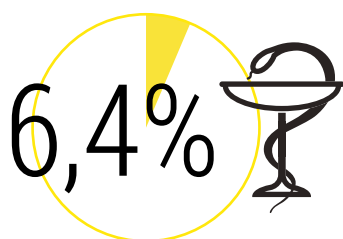
**OF RESPONDENTS WOULD NOT CONTACT A DOCTOR,  
CHOOSE TO SELF-MEDICATE:**

- **32,2%** — *using medications and drugs*
- **19,8%** — *using folk remedies*

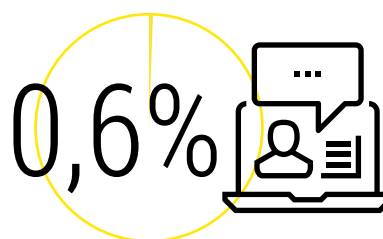


**WOULD CONTACT A DOCTOR FIRST:**

- **20,3%** — *would mainly contact a family doctor or a district physician*
- **7,3%** — *would directly contact a specialist*



**WOULD PRIMARILY  
CONTACT A PHARMACIST**



**SEARCH ONLINE FOR SIMILAR SYMPTOMS  
AND THEIR TREATMENT**

# WHY DO SICK PEOPLE AVOID CONTACTING A DOCTOR?

25%



TOO EXPENSIVE  
(SERVICES, MEDICATION,  
TRANSPORTATION)

DO NOT TRUST  
MEDICAL PERSONNEL



7%

13%



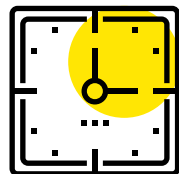
LONG WAITING TIME AT  
MEDICAL FACILITIES

KNOW THE RIGHT TREATMENT  
FROM THEIR PREVIOUS EXPERIENCE



58%

26%



EXPECT THAT THE ILLNESS  
WILL PASS

# SOURCES OF INFORMATION ON TREATMENT AND MEDICATION

To better understand the opinions of patients and clearly illustrate the context, qualitative research was conducted (individual interviews and focus group discussions).

From the interviews and focus group studies regarding medication and treatment regimens, patients mostly rely on the information they receive from **doctors, pharmacists and the internet**.

“

*...you look up the active ingredient online, then you can find cheaper and more expensive medicine, analogues, check what people say...*

**(a 23-year-old woman, Lviv)**

“

*They are super professional in our pharmacy — they can explain everything. Take this pill in the morning, this in the afternoon, and this one tomorrow. And you will be healthy. No one even wants to go to the doctor*

**(a 37-year-old man, Lviv region)**

“

*I check on the internet first and only then contact the doctors. And I double-check what they prescribe. Anything can happen. Once Noophen was prescribed to my baby, I checked and saw that this medicine is only meant for adults*

**(a 28-year-old man, Kharkiv)**

Due to the large volume of information and easy-to-use search engines, many respondents use the internet to learn about existing medication, read the instructions on contraindications, find analogues (generics), check the availability and cost of medicine in pharmacies, read reviews from other users, ask a doctor online and check the necessity of a prescription.

According to respondents, **doctors do not always provide detailed information about the prescribed medicine**, such as contraindications and possible analogues (regarding the financial status of the patient and his/her family). Therefore, patients use the internet, consult with pharmacists and, consequently, often change the doctor's prescription.



52%

TAKE MEDICATION RECOMMENDED  
BY FRIENDS OR FOLLOW ADVICE ONLINE

“

*Very often doctors prescribe expensive medication. Then you come to the pharmacy, and the specialist explains that there is a generic, much cheaper with the same effect*

**(a 32-year-old man, Lviv region)**

**OLGA VAKULA-FESHCHENKO,**

54 YEARS OLD, KYIV

“

The annual cost  
of treatment for  
one female patient is  
**500 000 UAH.**  
Every fourth woman  
requires treatment.  
It's not possible to find  
this sort of money  
in the budget

PHOTO BY VIKTORIA YASYNSKA



Once I found a huge breast tumor, the size of a goose egg and realized it was cancer. And it all started — tears, **lack of money, consultation visits to the two state clinics. There they were rude and indifferent.**

I realized that I had to live, indeed, that I have many friends who want me to live, because so many people helped me financially.

**For the middle-classes here, cancer treatment is unaffordable.** Targeted therapy is required for an aggressive form of cancer. **One ampoule in 2013 cost 2,500 dollars. I had to have 18 ampoules.** I did not know where I would get the money. My friends helped me, and I started knocking on all possible doors...

**Targeted therapy is expensive. Across the whole world they have some kind of insurance program.** I began to study different types of insurance programs all over the world. France appeared to have the best program. I cannot say that everything is that bad here — there are the surgeons, for example, but unfortunately, surgeons cannot pay instead of people.

Cancer is a systemic disease. In addition to surgical care, it is necessary to have treatment and observation. **In oncology clinics, a person should be able to call the doctor any time, and the doctor must be both a psychologist and a qualified specialist.**

I also learned that the annual cost of treatment for one female patient is 500,000 UAH. Every fourth woman requires treatment. It's not possible to find this sort of money in the budget. **Jointly with CF "Patients of Ukraine" and CF "Pink Ribbon of Ukraine" we are fighting for the patients' right for the treatment.**

**To solve all the problems with cancer in our country, it is necessary, first, to implement preventive measures, starting from school.**

**Secondly, it is the health insurance. It is necessary to explain the importance of health insurance to people.** Searching for funds for treatment is also an important issue. If a person receives adequate treatment, they will have good quality of life as they will be supervised by specialists.

***During 16 month of treatment Olga spent about 600,000 UAH. Now she has to go through regular expensive examinations to control the disease.***





# FINANCIAL (UN)ACCESSIBILITY OF MEDICINE

**T**here is a significant financial burden on patients. **65%** of respondents in individual interviews and **61%** of focus group participants had **to borrow money or sell valuables to cover the cost of medication** over the last month. The largest amount is required for patients with cancers and hepatitis.



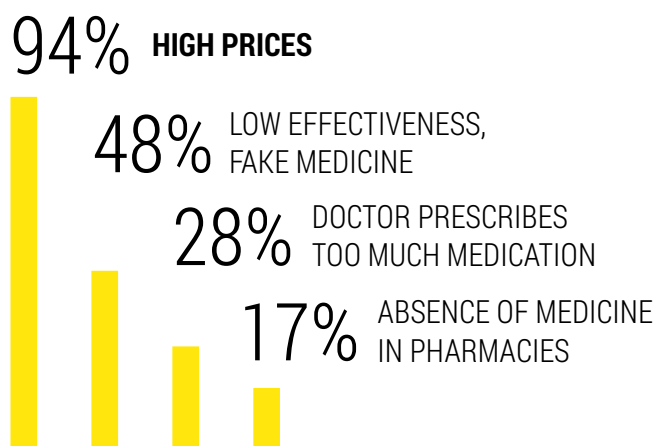
*It is all on credit. Thank mother's credit card... We borrowed money, took loans. You take others' money, and give back yours*

**(mother of a child suffering from sugar diabetes, Mykolaiv)**

## THE MAIN PROBLEMS WITH MEDICATION SUPPLIES IN UKRAINE:



### FOCUS GROUP DISCUSSIONS:



# FINANCIAL (UN)ACCESSIBILITY OF MEDICINE

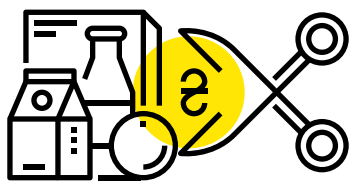
ALMOST ALL RESPONDENTS HAD TO:



SAVE ON OTHER ITEMS IN THEIR BUDGET  
(VACATION, PURCHASE OF EQUIPMENT OR CLOTHING)



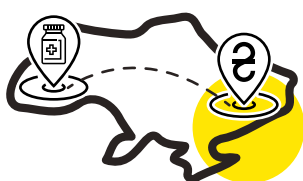
USE SAVINGS FOR TREATMENT



SAVE ON FOOD  
(ESPECIALLY VILLAGERS AND PATIENTS  
WITH BELOW AVERAGE INCOME)



USE CREDIT FUNDS



ASK RELATIVES AND FRIENDS  
LIVING IN OTHER REGIONS OR COUNTRIES  
TO BUY THEM MEDICATION,  
BECAUSE OF LOWER PRICES OR AVAILABILITY



ASK FOR FINANCIAL  
OR OTHER MATERIAL  
SUPPORT FROM RELATIVES AND FRIENDS

“

*We borrowed everywhere. What other options are there? You pay utility bills and have to borrow money for medicine... My husband gets them from abroad. Even “Plavix”, medicine for heart disease. Here it costs up to 1,000 UAH, and abroad only 300 UAH!*

**(a 53-year-old woman with hypertension disease, Lviv region)**

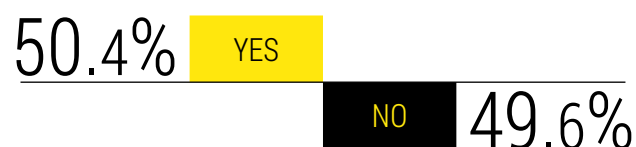
# FINANCIAL (UN)ACCESSIBILITY OF MEDICINE

During the all Ukrainian quantitative survey, patients showed **various strategies for overcoming financial barriers**. Out of all the respondents, 68% indicated that they or someone in their family fell ill over the last year.

HAVE YOU EVER REFUSED TREATMENT  
BECAUSE OF FINANCIAL CONSTRAINTS?



HAVE YOU EVER POSTPONED TREATMENT  
BECAUSE OF FINANCIAL CONSTRAINS?



HAVE YOU EVER REDUCED YOUR DOSAGE  
OF PRESCRIBED MEDICATION OR TOOK  
ONLY PART FOR FINANCIAL REASONS?



HAVE YOU EVER ABANDONED TREATMENT  
FOR FINANCIAL REASONS?



HAVE YOU EVER BORROWED MONEY  
FOR TREATMENT OR SOLD VALUABLES?

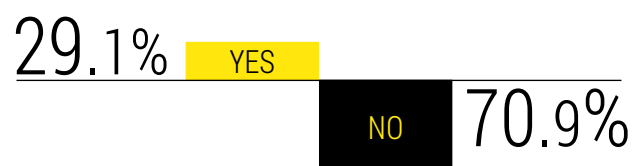


# FINANCIAL (UN)ACCESSIBILITY OF MEDICINE

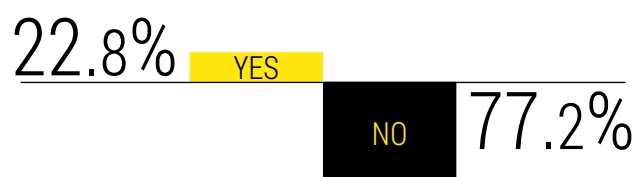
Moreover, 29% indicated that relatives helped them to pay for treatment, and 23 % stated that they helped their relatives to cover the cost of treatment.

In addition to various behavioral strategies pursued for financial reasons, there is the inefficient use of medication: 31% of patients **not only take medication prescribed by their doctor**, but also something they picked up on by themselves, 52% **take medication recommended by friends or follow advice online**.

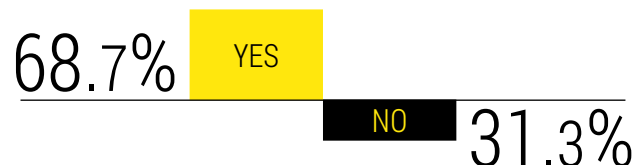
HAVE YOUR RELATIVES  
EVER PAID FOR YOUR TREATMENT?



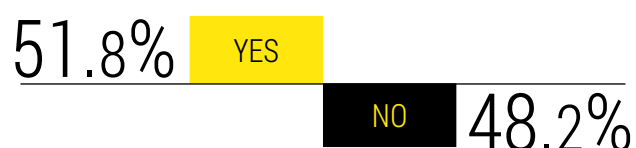
HAVE YOU OR MEMBERS OF YOUR FAMILY  
EVER PAID FOR THE TREATMENT OF YOUR RELATIVES  
FOR FINANCIAL REASONS?



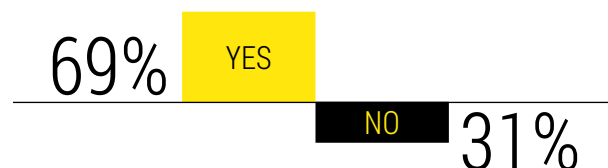
HAVE YOU EVER SELF-MEDICATED  
WITHOUT CONTACTING A DOCTOR  
FOR FINANCIAL REASONS?



HAVE YOU EVER TAKEN MEDICATION  
RECOMMENDED BY YOUR FRIENDS  
OR FOLLOWING ADVICE ON THE INTERNET?



DO YOU ONLY EVER TAKE THE MEDICINE  
PRESCRIBED BY A DOCTOR?



# **NINA ASTAFOROVA-YATSENKO,**

THE MOTHER OF AN 8-YEAR-OLD GIRL SUFFERING FROM HEMOPHILIA



The one week preventive treatment for this form of hemophilia, as Nonna has, costs about **11 300 UAH** for two injections. You can't buy them in the pharmacies but then again, almost no one can afford them anyway

PHOTO BY VIKTORIA YASYNSKA

When my daughter was six she had over 20-25 nosebleeds, we had terrible six months of life. We almost lived in the hospital. The worst is when blood does not flow from the nose and goes into her stomach, you cannot see anything, but on the third day she vomits blood. We had such a case. We had to do a blood transfusion.

She has a severe form of the disease. On Mondays and Thursdays, we do intravenous injections - clotting factor. For a person with hemophilia when small vessel burst, it leads to the global bleeding that is why a high level of coagulation factor is very important for us.

In Europe, there is no concept of being "disabled" because of this disease because people are fully protected. From childhood, they receive coagulation factor injections. **But here, people often become disabled because the disease prompts bleeding into the joints bags. Two or three hemorrhages and it collapses, and then the joint is destroyed.**

Today, all medication is kept at the hospitals, so twice, or three times a week children go there after school or instead of school. **In Europe, children at 9-10 years do injections by themselves because it's necessary for them to live their lives.**

Now in Kyiv all children with this form of disease are on a preventive list. **The one week preventive treatment for this form of hemophilia, as Nonna has, costs about 11,300 UAH for two injections. You can't buy them in the pharmacies but then again, almost no one can afford them anyway.** The only way it can be bought is through state tenders.

Now, for example, this medication is not

procured for those who have been diagnosed with the disease this summer. There is also such a thing as a quota. **Ideally, the number of necessary drugs must be calculated for the individual patient, but here medicine procurement is based on the allocated budget.**

**2016 was the first year when Kyiv allocated a significant amount for the city program "Health of the people of Kiev", but in the regions everything is awful.**



**Currently I'm heading CF "Children with Hemophilia", and jointly with CF "Patients of Ukraine" we are standing for the implementation of the new state program on the hemophilia treatment. And we are talking not just about the budget, but about such measures as: approval of hemophilia treatment guidelines, rehabilitation, home treatment.**

**The first thing** to organize in the country is a complete provision of medication including preventive treatment. One of the key steps is to create a Patient Register.

**Secondly**, medication should be issued to each person directly. Injections can be done by parents, or a nurse. And children should be able to do it by themselves. All this should be agreed on an official level.

**Currently, the need in funding medicine procurement for adults is about 700 million UAH per year; in 2016 only 130 million UAH were allocated of the needed 700 million UAH.** However, in 2017 they have promised it will be 421 million UAH.



# THE (UN)AVAILABILITY OF MEDICINE FOR OUTPATIENT TREATMENT

According to data from "Index of Health. Ukraine 2016," **97% of outpatients who were prescribed medication (89% of all outpatients got a prescription) paid for their own medicine.** Only 78% bought the prescribed medication, the rest bought only part or did not buy medicine at all. Patients explain this was because of financial constraints or that, in their opinion, they do not need all the medication prescribed, or the pharmacies were out of stock.

HAVE YOU PAID FOR MEDICINE AS AN OUTPATIENT?



WERE YOU GIVEN A PRESCRIPTION?



DID YOU BUY ALL OF THE MEDICINE PRESCRIBED?



5.9%

NO



16.5%

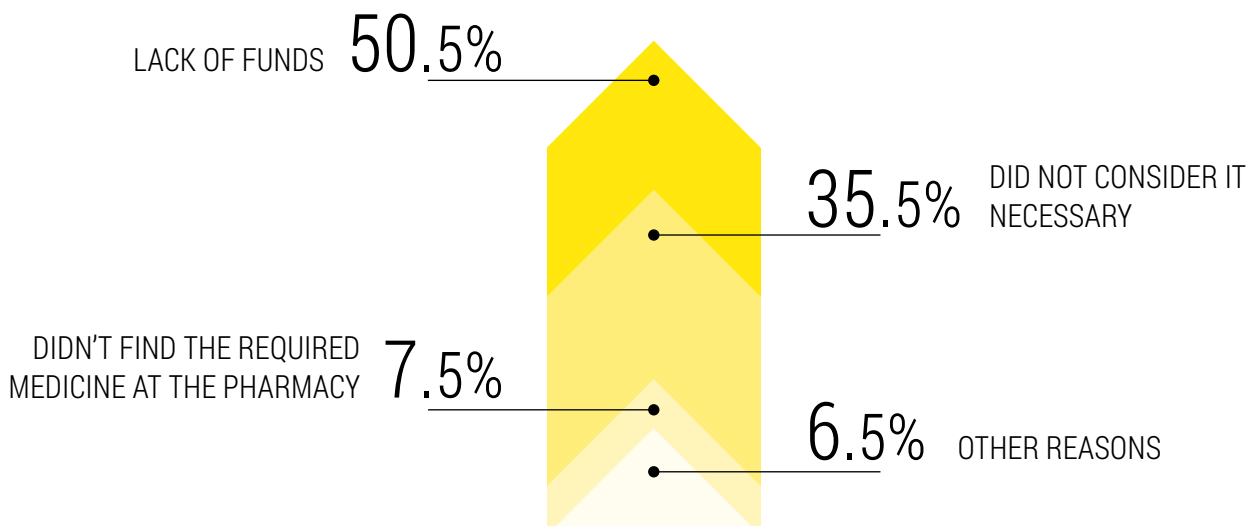
BOUGHT ALMOST  
ALL THE MEDICINE



77.6%

BOUGHT  
ALL PRESCRIBED MEDICATION

WHY DID YOU NOT BUY ALL THE MEDICATION PRESCRIBED?





# THE (UN)AVAILABILITY OF MEDICINE FOR INPATIENT TREATMENT

**97% of inpatients at hospitals paid for their medication themselves. 84% of respondents, who were hospitalized in the last year and paid for medicine, said that it was difficult or impossible to find the necessary money for medicine.**

Though 17% said that they received free medicine at the hospital. But when given the medicine they agreed they would pay for it later (5% of them paid up to 500 UAH and 11% paid 500 UAH or more).

HAVE YOU PAID FOR MEDICINE  
WHILE STAYING AT A HOSPITAL?

97% YES

DID YOU BUY ALL THE MEDICINE PRESCRIBED?



3.3%

NO



11.5%

ALMOST ALL



85.2%

YES

WHY DID YOU NOT BUY ALL THE PRESCRIBED MEDICINE?

LACK OF FUNDS 55.2%

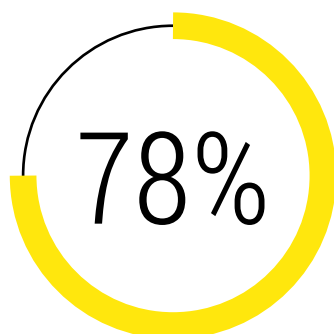
NOT AVAILABLE  
AT THE PHARMACY 10.4%

27.6% DID NOT THINK IT  
WAS NECESSARY

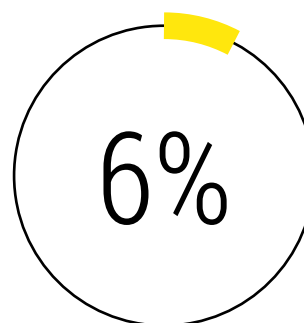
6.8% OTHER

# THE (UN)AVAILABILITY OF MEDICINE FOR INPATIENT TREATMENT

HOW DIFFICULT WAS IT FOR YOU AND YOUR FAMILY TO FIND MONEY FOR MEDICINE  
WHILE STAYING AT THE HOSPITAL?

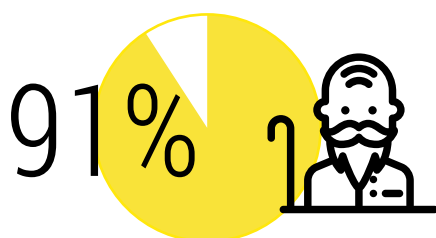


**DIFFICULT**

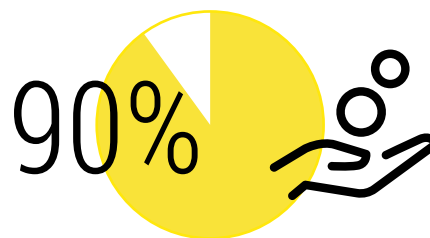


**IMPOSSIBLE**

WHO HAS THE BIGGEST DIFFICULTIES TO FIND NECESSARY MONEY FOR THE MEDICINE?



**60-YEAR-OLD RESPONDENTS AND OLDER**



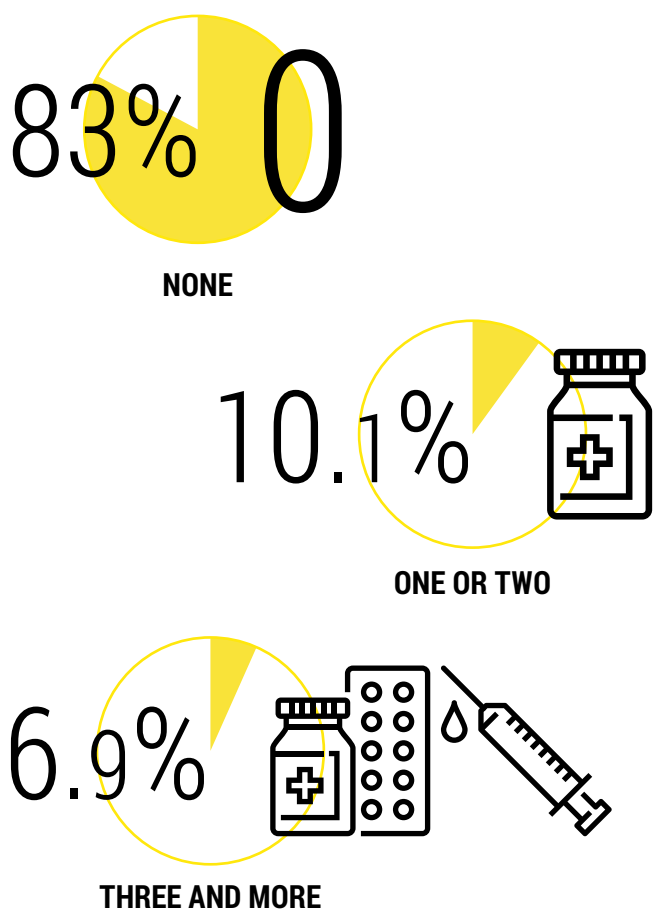
**RESPONDENTS WITH THE TOTAL MONTHLY INCOME  
LESS THAN 1,500 UAH PER ONE ADULT**



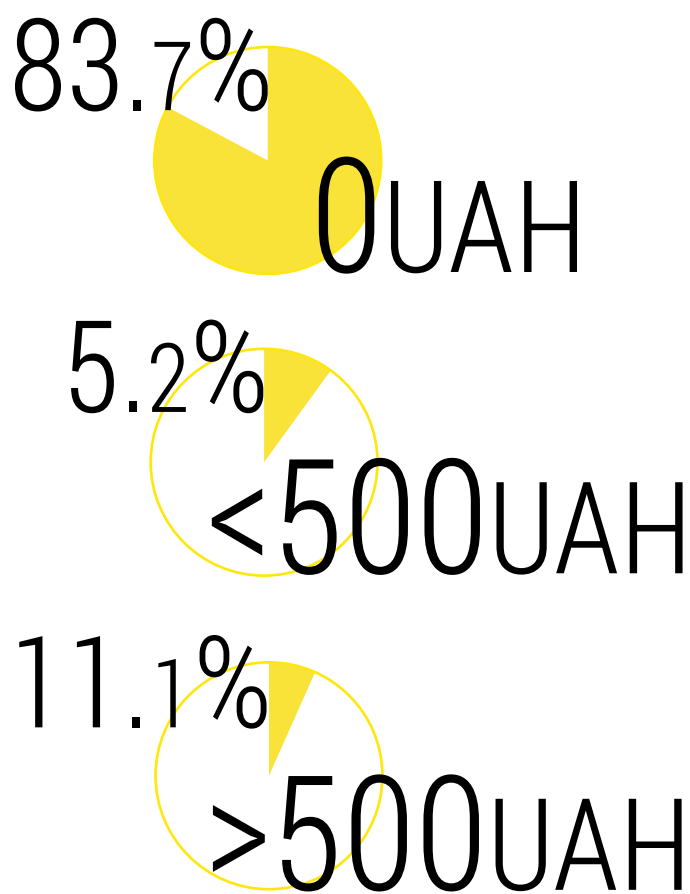
*The survey was conducted among respondents who reported hospitalization during previous 12 months and had drug expenditures.*

# THE (UN)AVAILABILITY OF MEDICINE FOR INPATIENT TREATMENT


HOW MUCH MEDICATION  
HAVE YOU RECEIVED FOR FREE?



HOW MUCH DID YOU PAY FOR MEDICINE  
GIVEN TO YOU DURING  
YOUR HOSPITAL STAY?



**IRYNA REVENKO,**  
KYIV



**“  
A serious disease  
like mine  
with no stable income  
or miracles  
creates a cycle of debt**”

PHOTO BY VIKTORIA YASYNSKA

Once, at the age of five, I woke up and felt very bad: My spine began to hurt and it was difficult to move. I was carried to the hospital. For two weeks, doctors were trying to understand what happened to me. **As a result, I was sent to Okhmatdyt. The diagnosis was acute lymphoblastic leukemia.**

For nine months, I had chemotherapy. I was so thin, that when it was necessary to put a catheter through the right atrium, the doctors could only do it after the third attempt. The painful treatment was followed by stomatitis. Then I had to drink even more of the unpleasant drugs.

In the end, after the course of chemotherapy I managed to beat the cancer. **However, after two blood transfusions during the treatment I got two hepatitis B and C.**

In high school, during my last treatment for hepatitis, the doctor asked me to leave and talked to my mom. **But I heard what he said: No need to continue the treatment, it is impossible to beat the virus.** Because of the treatment I lost 60% of my hair, which has not grown back — it was really stressful for me.

**A serious disease like mine with no stable income or miracles creates a cycle of debt.**

**When I was 18, I was deprived of my benefits, and we're talking about a small amount of money. They said it was because I was not sick enough. I was insulted.** My mom said they wanted money, but she refused to pay the bribes. **Now the state does not help. I continue to receive treatment for hepatitis and spend a lot of money.**

If a weak immune system requires to spend at least 500 UAH to cure a simple cold, for hepatoprotectors it is needed **about a**

**1,500 UAH per month, depending on the medicine. Sometimes it takes up to three months to get better.**

**However, there is a state program for treatment of hepatitis. For one and a half years, I was in the queue.**

The doctors told me that there is a medicine which shows almost a 100% cure rate, and that I can continue treatment using it, but the problem is that I need to take two drugs on top of that. Since I did not get onto this standard state scheme, we agreed that I would buy one more medicine, which is not registered in Ukraine, by myself, on the "black" market.

**There is effective medication for hepatitis, which has not passed the registration process in Ukraine because there are people who do not want it entering our market.**

**For now I don't have hepatitis. In the year 2016 I received a new medicine, procured with the assistance of the international organizations. And CF "Patients of Ukraine", where I'm working currently, helped to make this reform and procurement via the transparent institutions real.**

For many years, I was thinking I am going to die. The thought of death followed me everywhere, until I understood that I am not going to die of hepatitis or leukemia. It is not something that will kill me. And this is such a relief, when death stops breathing down your neck.



# ADVERTISING MEDICATION

The level of trust in advertising as a source of information about medicine among those, who were interviewed in the frames of the qualitative research, is generally low. The attitude to the advertising of medicine varied **from extremely negative to neutral**.

The most negative aspect of advertising of medicine, according to its opponents, is that it encourages self-medication.

“

*I am, actually, very negative about advertising. It feels like only bad products are advertised, because a good quality product does not need any advertising*

**(a 55-year-old man, Lviv region)**

“

*It just provokes uncontrolled medicine intake, and this is very dangerous*

**(a 35-year-old woman, Kharkiv)**

Advertising is one of the reasons for high out-of-pocket payments by patients. **They are buying medicine they do not need.** Often this is unproven efficacy medicine.

“

*There should be a total ban (on advertising). ...Medication should be prescribed by a doctor, and not advertised*

**(a 36-year-old man, Kharkiv region)**



# TRUST IN DOCTORS

Trust in doctors is a key and very important factor for patients while choosing their treatment strategy. The steps that patients will undertake are determined by their trust or mistrust for medical personnel: address other medical institutions or doctors, adhere to given prescriptions or seek alternative treatment. Many respondents said that they went to three or four medical institutions before they found a decent doctor. The more serious the problem is the more important the trust factor.

## KEY DRAWBACKS STATED BY PATIENTS:

### 1 **Doctors' incompetence and indifference**

*I came to doctor's appointment with my child. And the doctor explained to him, that he should stop crying. That it was too late. She convinced my child that his mother was almost dead!*

**(a 32-year-old woman  
with cancer,  
Kharkiv)**

### 2 **Overburdened medical facilities** (which, according to some patients, may partially explain the indifference)

### 3 **High level of informal payments** (patients were particularly impressed by cases where doctors do not provide emergency care until relatives pay for medication)

*When my kidney had to be removed it was clearly said: we have to pay 30,000 UAH for the surgery. Informally, of course, in an envelope. This amount covers only the surgery, not the cost of medicines. There is a Ph.D. in Medical Science, or Associate Professor, whom you pay just in case he is needed, just for his presence. Anesthesiologists always take money separately. They have different fees, someone takes 500 dollars for surgery, another 1,000. It differs*

**(a 26-year-old woman  
with cancer,  
Mykolaiv)**

### 4 **Cooperation between doctors and drug companies** (financial incentives for doctors when increasing prescription for a particular medication).



**W**hen I was 34 years old, I became ill with chronic myelogenous leukemia. There are no evident symptoms of this disease. I learned that I had blood cancer by chance. I had a regular medical examination at work which included blood analysis. I gave my blood sample, like everyone else, and went home. The next day I got a call to come to work immediately because I have some problems with blood.

**I saw the cost of medicine that can effectively treat cancer — a thousand dollars per month, and it's life-long treatment course. Then I realized that everything is really bad: Not only am I sick but I cannot afford the treatment.**

I went to Poltava to the regional hematologist. I already knew how to treat this disease. I knew about the medicine, and knew the price and that there is a state program providing medicine for patients like me. Only eleven out of forty patients registered at that time in Poltava region could receive medication from state for free.

When I understood that in Poltava region I will never get onto the state program, I moved to Dnipro city and created a non-governmental organization "Osanna" there. We found patients who were registered on the waiting list, wrote letters to the head of the regional state administration of Dnipro oblast. Thanks to our efforts three million hryvnias was directed to treat patients with chronic myeloid leukemia in Dnipro.

**When I got sick, the treatment cost a thousand dollars per month.** I had to take one pill a day together with a concomitant therapy which included medicine that helps the liver overcome the side effects, as well as medicine for my heart, and medicine to raise my hemoglobin levels, etc.

In 2015, so-called generics entered the Ukrainian market and the cost of treatment decreased almost ten times. **Treatment of blood cancer with generics costs 3,400 UAH per month. This allows the state to provide drugs for more patients.**

In 2015, I registered the charitable fund "A Drop of Blood", which today consists of almost three thousand patients with blood cancer. At the time when I became sick, medicine was provided to approximately 400 patients with blood cancer. **We have ensured that 1,200 people receive medication. Still another fifteen hundred are on the so-called waiting list.**

We also aim to prove **to patients that generics can be used.** They are not much different from the original and much cheaper. **In the United States, 35% of medication are generics.**



**Jointly with CF "Patients of Ukraine", which assists us in our fighting for the right for life, we have started the dialogue with the pharmaceutical companies.** We need more medicine on our market in order to increase the competition, to decrease prices and to give the opportunity to choose better schemes of the treatment. **CF "Patients of Ukraine" also managed to implement the state procurement of the medicine via the international organizations. It helped to decrease the prices drastically, in some cases — up to 40%!**

**We aim to teach patients to work with the state and to fight for their rights.** Here is advice for people who have just been diagnosed: Do not be afraid, find out information about the disease, find people who have had a positive experience with treatment, find doctors who can diagnose and treat effectively. Get state treatment. Everything is possible.

**IVAN ZELENSKY,**  
41 YEARS, DNIPROPETROVSK



“

I saw the cost of medicine  
that can effectively treat cancer –

**1 000\$** per month,  
and it's life-long treatment course.  
Then I realized that everything  
is really bad:

Not only am I sick  
but I cannot afford  
the treatment

# COOPERATION OF DOCTORS WITH PHARMACEUTICAL COMPANIES

As mentioned earlier, patients are aware of the cooperation between doctors and pharmaceutical companies. On the one hand, doctors report periodic visits by pharmaceutical company representatives, or cases when they attend conferences organized by pharmaceutical companies. However, doctors do not believe that this practice demands they prescribe certain medication. Only one out of ten doctors surveyed admitted receiving cash considerations from cooperation with pharmaceutical companies, which he said was motivated by his low salary.

“

*We see this many times. And our relative who are doctors say the same: “Well they come to us interested by percentages from the sales and we just prescribe the ‘right’ medicines”*

**(a 49-year-old man, Kharkiv)**

# FREE MEDICATION

**P**atients with **HIV, tuberculosis, hepatitis** can receive free treatment in Ukraine. However, according to the following categories of patients, the treatment is not totally free, and they have to spend about **20%** of their monthly family budgets on medication. Expenses for patients with other diseases, where free treatment is not available or limited are much higher (as, for example, in cases of **cancer and cardiovascular diseases**). Patients with cancers staying in hospital receive one type of medication for free, but this aid is small compared to the total cost of treatment.

Patients and their relatives often **do not have access to information about their rights, free medication, conditions or criteria for receiving** medication although it is available in hospitals.

“

*They gave us glucometer. They said they also had to give stripes. Six-eight sets. At least five. But we did not get a single one. In addition, they told us to buy batteries. However, there is medication. When we had IV, I saw in the closet the solutions and dialipon. I know children under one years old receive free medication. Then you should buy it yourself... In intensive care each day they wrote us a list. There were antibiotics, solutions, gloves. We bought everything by ourselves*

**(a mother of a child with diabetes, Mykolaiv)**

“

*Almost each month we have a course of chemotherapy. And there are so many patients. Well, I understand there is not enough medication. We were given medication two or three times. But it made up 3-5% of the amount we have spent*

**(a 72-year-old man with a daughter-patient, cancer, Mykolaiv)**

Some oncological patients say that they do not participate in free cancer treatment programs provided for a month. A month is not enough for the full treatment course. That is why patients do not even try to enter those programs and they do not believe that they will be admitted without “connections”.

Patients with sugar diabetes confirm receiving information about free medication and medical products from doctors. However, most did not use it for various reasons.



**W**hen Tymur was three, he was diagnosed with autism. I had to teach him many simple things: to walk, to behave calmly in shops, on transport. The child goes from pillar to pillar and cannot turn. He eats only specific types of food, and has a very limited diet. For example, it has to be a certain type of cheese and only in this jar, otherwise he refuses to eat.

In order to interest Tymur in life, my husband and I were forced to make huge changes in our world. We started with nature. **The environment is a nightmare for them, when there is no one and nothing. Something that ordinary children learn themselves, children with autism should be taught, and taught for years.**

Currently Tymur is studying in an ordinary school. His problems today are his perception and reactions to behavior of others. For people like him, it is not always clear why people behave in a certain way. **They don't understand humor, metaphors. They do not understand when people say one thing and do another, they cannot lie.**

For five years, I've been heading the "Parents Association for Children with Autism". It's not enough to know people's stories, you should understand and know how to help them. It's not enough to stay calm and stubborn, you need to have knowledge in many fields. For instance, my presence in the group of the state medicine procurement has become a real challenge for me. At the beginning I have not understood anything. **And the cooperation with CF "Patients of Ukraine" is of a big use to me. They are conducting trainings, which give necessary knowledge, the possibility to understand difficult issues and to systemize existing information.** One of the most difficult challenges I faced was **the problems with medical treatment for autism in Ukraine.** In fact, it's not about treating autism, but about the drug-induced effect on related conditions or diseases — epilepsy, hyperactivity, and behav-

ioral disorders. Our current program does not cover all those who need this support.

There are regions that never order medicine and it is concluded that there are no autistic children there. However, this cannot be true. **According to the world statistics, every 68th person is on the autism spectrum.**

There is a new tendency formed in the world, where autism is not a disease, it is a state of being. And the state of being cannot be treated, it can be compensated. **In our country, autism is still treated, because a person, who behaves differently, not like everyone else or "badly", is considered to be a patient of a psychiatric hospital.** This situation needs to change. Because if you treat the problem of bad behavior with pills, it becomes cemented, not solved. **Help means early detection, competent diagnostics, and responsible prescription of medication.**

Children must be taught to express themselves in a different ways, starting from their needs. Many children who are not able to speak are suffering from pain — they have headache, stomachache, toothache, and they cannot explain it, no one teaches them how to use alternative means of communication.

**Early detection and referral to appropriate specialists in development, remedial teachers, and doctors is the type of help a family should receive.** Each our conversation with government officials begins with their question: "How many people with autism are there in Ukraine?" Sorry, but who should count — parents and non-governmental organizations? **Our children are the citizens; they have to study, receive medical or technical assistance, relax, play sports, and be able to get some sort of job. And we have to ask — where are the statistics? Why do we still not have them? Who is personally responsible?** And this is when the conversation begins not only about people with autism...



# **YEVHENIA PANICHEVSKA,**

A MOTHER OF A 10-YEAR-OLD BOY DIAGNOSED WITH AUTISM, KYIV

“

**In our country,  
autism is still treated,  
because a person,  
who behaves differently,  
not like everyone else  
or “badly”,  
is considered to be a patient  
of a psychiatric hospital**

PHOTO BY IVAN LIUBYSH-KIRDEI

# FREE MEDICATION PROGRAMS RUN BY THE STATE

Most respondents mentioned programs providing **free or reimburse for hypertension, diabetics or cancer medication**. In most cases, patients learnt about these programs from their doctors. That means people with certain chronic diseases, who buy medicine by themselves and do not visit the doctor regularly, **might not even know about the opportunity to save money**. Overall, state programs providing free or partial reimbursement for medication receive positive feedback from patients.

“

*They gave such medicines to asthmatics, but you can just throw them in the trash. The same goes for medication for hypertensive people. I remember they called all the retired and hypertensive people in; they came and took the medication. Then people got angry because they did not react well to the medicine. Clearly they give out anything that's cheap*

**(a 49-year-old man, Kharkiv)**

“

*Well, we received Diaglizide free of charge in May. Of course, it is not enough, only two plates, but anyways, it helps*

**(a 52-year-old woman, Poltava region)**

“

*I have diabetes and once a month I go to the hospital to get medicine free of charge. Sometimes I buy on my own. While we are waiting in line at the hospital, we talk. People say that they bring over medicine from Italy, Germany. And they really help their diabetes. And I take that free state-provided medicine: One in the morning one in the evening, and cannot bring down my blood sugar. That's the medicine*

**(a 62-year-old woman, Lviv region.)**

However **not all patients have positive experiences of using the medication via such programs**: Sometimes free or reimbursed medication was ineffective or caused allergic reactions.

State programs aimed at reducing the financial burden in the treatment of certain diseases (through provision of free medicine to certain categories of patients), according to respondents, have numerous disadvantages: **lack of information, lack of physical access to medicines, and limited selection**.



# GEOGRAPHICAL ACCESS AND (UN)AVAILABILITY OF MEDICINE IN PHARMACIES

**In a qualitative study, one in five respondents said they believe that the lack of medicine in pharmacies is a major problem for health care in Ukraine.** An additional barrier to treatment for people from regions and villages is access to medicine: **often there are no pharmacies in small villages.** Patients have to travel to the regional center or ask relatives or neighbors to buy something they need in the city. Also, patients **try to fill their medical kit in advance**, to be on the safe side, but because of their low incomes, they do not always manage to do this.

Often it is difficult to buy medicine even in the big cities or regional centers. Mainly we talk about **rare medicine or medicine not yet registered in Ukraine.** In such cases patients buy medicine through the internet via **unofficial intermediaries** or bring it from neighboring countries (themselves or ask relatives or friends).

“

*The first time I had no problems. The next time, when I came to the hospital in three weeks, they said there was no medicine. It was being re-registered I had to wait one or two weeks. And later my friends got me the medicine — they sent them from Spain*

**(a 62-year-old woman with cancer,  
Lviv region)**

“

*I don't have access to medicine. Only if one of my relatives goes to town. My cousin has a car, sometimes I go with him because I don't have to pay for the trip and I can buy something in advance*

**(a 47-year-old man with HIV,  
Kharkiv region)**

**LESIA GEICHENKO,**

20, KYIV



“

**With the right treatment,  
the disability  
can be reduced  
to almost zero.  
JRA is not a life sentence**

PHOTO BY IVAN LIUBYSH-KIRDEI

Everything started over ten years ago. I was nine when a joint began to hurt. One month later and one more joint, then one more. It is good that we contacted a rheumatologist in time, who quickly diagnosed me with **juvenile rheumatoid arthritis (JRA)**.

My knees became swollen and red. They hurt almost all the time. It was hard to sleep, to walk. **I was immediately prescribed the therapy which was used at that time in Ukraine. It was a basic therapy with methotrexate, and no steroidal anti-inflammatory drugs.** It gave me some relief, but it was not a solution.

**The cause of this disease is unknown, and it cannot be cured. JRA is an autoimmune disease that attacks the immune tissues of an organism, often this means the connecting tissue.** In my case, it has attacked the connective tissues of the joints.

In 12, I could not get out of the bed. For a few years I did not go to school. It was a very difficult time. The only thing that saved me was people close to me, books and the internet.

**The modern medicine tries to reject hormones because they affect other organ systems. So children stop growing.** Buying hormones is inexpensive, and at first, they act well. **However, "prednisone" and its analogs reduce the level of calcium in the bones.**

When I was 14 years old, the first **biological therapy** appeared in Ukraine, and I got into a test group. **At that time, in the rest of the world biological therapy existed for ten years, but it was very expensive.** It was a sponsored project, not funded by the state. **This medication has helped me greatly. It was the first time it was really easy to walk.** I started to go to school. At 11th grade, my orthopedic problems got worse, and again, I almost could not walk.

I had two knee surgeries. A third one is planned to replace the joint, because, unfortunately, I cannot straighten my leg. I continue to take medicine.

**During the first years of my illness, there was no such medicine in Ukraine, not even analogues, and I was treated with what was available. And in 2013, a state program was introduced which officially provided medicine to children. But, unfortunately, only for children under 18. When I turned 18, the dollar exchange rate jumped significantly and medication became very expensive. I needed around 40,000 hryvnas per month.** I am grateful to my parents who gathered money wherever they could, and also to my friends, who helped.

Now we are looking forward to the introduction of the city program "Health of the People of Kyiv". I must say that local programs are very helpful in providing children with medications, **because the Ministry of Health program in 2016 covered 30-40% of the needs of the country; the rest of the money came from local budgets.** There are cities and regions with 100% coverage of all needs. These are Lviv, Kyiv, Kharkiv...

**We are working with CF "Patients of Ukraine" not for the first year. We have joined their policy of the patient organizations mutual support and fighting for the patient community rights. We have also taken part in their actions and are grateful for their assistance in providing medicine to the JRA patients.**

In general, **there are about 25,000 children with JRA in Ukraine. Four-hundred and fifty-one of them should officially receive biological therapy, because nothing else works. There is no statistics for adults, but we can assume that there are 10-15,000 patients.**

**We would like Ukraine to purchase medicine that is purchased by countries with stiff pharmaceutical regulations — Japan, Australia, USA and the EU.**

With the right treatment, the disability can be reduced to almost zero. **JRA is not a life sentence.**



# ORIGINAL MEDICINE VS GENERICS, ANTIBIOTICS

According to patients, doctors have two practices when prescribing medication. They suggest medicine of different prices and **recommend cheaper analogues** or they insist the patient **buys only the prescribed medicine**. In the second instance, patients say that either it is because **the medicine really differs in its effect and quality**, or **the doctors receive a percentage on the sale from pharmaceutical companies**. The latter has been proven by cases when doctors told patients which pharmacy to buy medicine from.

“

*Often, it happens when you have a list of medicine, and at the pharmacy they tell you “why do you need this, take this, it is ten times cheaper. That costs 500, and this one — 50 UAH. If you do not believe me, read the ingredients”*

**(a 53-year-old man, Poltava region)**

“

*First, the doctor recommends the pharmacy near the oncological center. But the prices there are 30% higher*

**(a 26-year-old woman with cancer, Mykolaiv)**

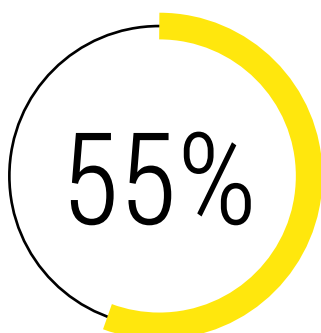
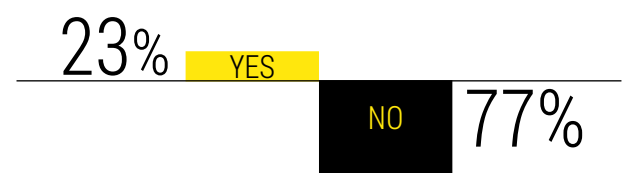
*Nowadays doctors prescribe a lot of expensive medicine, and when you come to the pharmacy, the pharmacist says that there is a generic which is much cheaper with the same effect*

**(a 32-year-old man, Lviv region)**

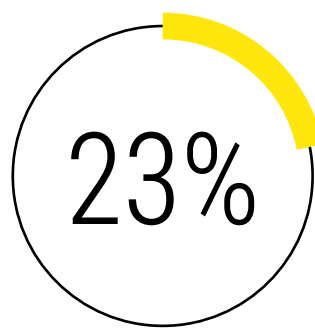
DID THE DOCTOR, WHEN PRESCRIBING MEDICATION, OFFER YOU BOTH CHEAPER AND MORE EXPENSIVE OPTIONS?



DID THE DOCTOR PRESCRIBE YOU THE ACTIVE INGREDIENT, NOT A SPECIFIC BRAND MEDICINE?



THE DOCTOR OFFERED BOTH CHEAPER AND MORE EXPENSIVE OPTIONS WHEN PRESCRIBING MEDICATION



THE DOCTOR PRESCRIBED THE ACTIVE INGREDIENT

# ORIGINAL MEDICINE VS GENERICS, ANTIBIOTICS

**M**ost of the patients know the term “generic” and are positive about it. Some patients said generics had better effect than original medicine prescribed. The main concern is about medicine produced in Ukraine: patients are afraid of fake and bad quality medicine. In general, the patients decision to choose the original or generic is made based on their own experiences or the experience of friends, or a doctor’s opinion.

Focus group participants say that doctors often **prescribe antibiotics, especially to children**. Sometimes the prescription is made without doing an analysis only based on existing symptoms (e.g., fever for a prolonged period of time).

The majority of respondents (who have extensive experience in treatment) **are very cautious about antibiotics**. Their main argument is that such medication has many side effects: They destroy the immune system, lead to disruption of micro flora and problems with digestion.

“

*Antibiotics are evil. One should not take them at all. Only in the worst possible situations*

**(a 22-year-old man, Lviv)**

“

*It happens very often. Doctors do not even think of something more gentle, and immediately prescribe antibiotics. Then you check on the internet whether you can give your child something other than antibiotics. What else should I do? Destroy their immune system from childhood?*


**(a 26-year-old woman,  
Kharkiv region)**

Doctor-respondents said that patients are poorly informed about **“the proven effectiveness” of some medicine** and often buy well-advertised ineffective medicine. In some cases, patients even **refuse to buy the prescribed medication and instead spend money on medicine “that cures everything”**.



# VIRA VARYGA,

KYIV



“  
Now there are many people  
diagnosed with HIV,  
and it is important  
to provide therapy to everyone.  
But I think that with  
advocacy organizations such as  
“Patients of Ukraine” and  
“100% of Life”,  
the state soon  
will buy enough medication

PHOTO BY IVAN LIUBYSH-KIRDEI



When I was 16, I got into very interesting circles. Once I was offered a drug and I didn't even hesitate. Later, I got married. My husband and I moved to Russia, where my sisters lived. I studied to be a financier; we had a family business.

I was 24 when my mother was diagnosed with cancer. My mother died in my arms. Soon our business was on the brink. That was then when I tried heroin. I was sure I could control it. However, I could not.

My dad came and took me back to Ukraine. I got into real drug-addict circles and fell to the very bottom. After a while, I realized that I was pregnant. My dad took me by my hand to the antenatal clinic. They took all the necessary tests, did ultrasound and said that it was too late for abortion. **When we came to the hospital the next time the doctor shouted from the hallway that I am an "AIDS woman" and how can I even think of having children.**

I was one of the first with HIV in our town. I knew nothing about HIV. Then there was no internet, and the doctors did not give me any information. **My doctor gave me a maximum of five years to live and said that a child will not make it past a year.** The doctor said that the best way out in our situation was to abandon the child.

In the maternity hospital, I was in a special "AIDS-box". Words AIDS, AIDS, AIDS were written everywhere. **I realized that here no one would do anything for me, and I just left the hospital.** The day before I was called to a lawyer and asked how I would call the baby. I called him Danyil. They were convinced that a HIV-positive drug addict and can never become a mother. **That is the double stigma, which almost always leads to internal stigma in the affected person.**

We buried our dad. My sister began to seek a way out for me and learned about AIDS center in Kharkiv. **It was the first time when I was in a medical facility, and no one pointed at me.**

It turned out that the AIDS center

oversees an orphanage with children from HIV-positive parents who abandoned them or have died. I decided to take Danya back.

Marina is from the All Ukrainian Network of People Living with HIV/AIDS. Both she and the network helped me a lot. **I went to rehabilitation. Then took Danya home. We did analysis tests and discovered that Danya was absolutely healthy.**

In 2008, I got married for the second time. I got pregnant and started taking therapy. Kostya loves our sons – Danya and Yasha.

**Antiretroviral therapy is free. You only need to register at the Center for AIDS. This therapy serves as a preventive treatment for pregnant women.** It blocks viruses and a woman has a 98% chance of giving birth to a healthy baby.



**Now there are many people diagnosed with HIV, and it is important to provide therapy to everyone. But I think that with advocacy organizations such as "Patients of Ukraine" and "100% of Life", the state soon will buy enough medication.**

You cannot interrupt the treatment. **If you do take the medicine within 12 hours, the shell dissolves, the virus spreads quickly "identifies" the type of medication, and mutates.** Then the medication no longer works. Life without treatment for HIV-positive people doesn't exist, but it is always threatened.

If we talk about doctors, they have to understand that they cannot refuse to treat HIV-positive people. **Many representatives of medical personnel find excuses to deny treatment, through some manipulation of the facts.** I believe that in the near future the level of stigma in society towards HIV-positive people will decrease dramatically.

# PROVIDING MEDICATION AND ITS (UN)AVAILABILITY FOR PATIENTS: DOCTORS' OPINION

Doctors interviewed say that **polyclinics lack medicine the most. Inpatient departments are more equipped:** Primarily with medicine for emergency care. The state health care facilities for HIV and tuberculosis are **almost 100% equipped**.

*Today our institution is fully equipped with medicine delivered through state procurement... We also have medicine for opportunistic infections. There are antibiotics. This is most necessary treatment and it is prescribed for free*

**(an infection disease doctor,  
Lviv region)**

Cardiological institutions are only partially equipped with medicine — the situation differs from institution to institution. Medical institutions **treating cancer, almost do not receive any medicine from the state**. Therefore, the main financial burden rests on patients..

*We are working according to this principle: the patient arrives and gets everything from the ambulance. This includes catheter syringes, drip, probes, urinary catheters, solutions, antibacterial and other essential medications. If there are relatives — the burden falls on their shoulders. If the patient is alone we continue the treatment with our supplies*

**(an anesthesiologist, Kyiv region)**

**Some doctors say that they start treatment only when they know the patient has money.** This primarily **refers to cancer patients**, for whom treatment is the most expensive.

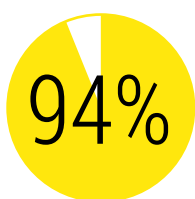
*The cost of treatment per month, according to the prices today, is about 40-50,000 UAH. And the treatment for a cancer patient takes 6 to 8 months*

**(an oncologist, Kyiv)**

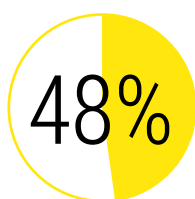
# ATTITUDE OF THE PATIENTS TO THE EXISTING POLICIES FOR MEDICATION

According to 94% of the focus group participants, the high cost of medicine is the main obstacle to treatment in Ukraine. The second most important problem, according to the groups, is ineffective and counterfeit medicine. Corruption takes third place (46% of respondents said it is one of the three major problems, 24% of whom consider it the most important). Among other important issues, according to respondents, is incompetent medical personnel (38% of respondents, 15% of whom put the problem in first place). The respondents rarely indicated the large volumes of medication prescribed as the main problem (28% of respondents in the focus groups). Similarly 17% considered the lack of medicines in pharmacies as the main problem.

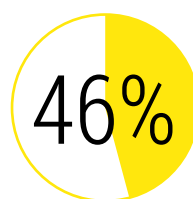
## THE MAIN PROBLEMS RELATED TO MEDICINE IN UKRAINE:



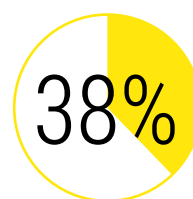
HIGH PRICE



INEFFECTIVE,  
COUNTERFEIT MEDICINE



CORRUPTION



INCOMPETENT  
MEDICAL PERSONNEL

**Patients in individual interviews also stressed the poor quality of medicine produced in Ukraine. Doctor-respondents mostly share this opinion.**

“

*Sometimes doctors themselves say: “It may come out that you buy a “soother”. It is not my fault”*

**(a 40-year-old woman, Lviv)**

However, patients noted positive changes in state medicine policies. People in Odessa consider an initiative to **improve transparency regarding the availability of medicines in health facilities** a significant achievement. This is the initiative E-liky that allows each patient to check the site [eliky.in.ua](http://eliky.in.ua) for the availability of medicine in their hospital purchased by the state.

“

*I know that in Odessa there is this website, where you can go and check which polyclinic or hospital you need. Then specifically which medicine you need, and you can trace which hospital has it, bought with state funds. Doctors do not have the right to refuse to help the patient or give out that medicine. In the rest of Ukraine, the situation is miserable. The information is hidden, you cannot even ask for medicine*

**(a 33-year-old woman  
with HIV,  
Lviv)**

**NATALIA TITOVA,**

25 YEARS, KYIV

“

**A doctor offered to treat me  
with deep brain stimulation.**

**This surgery is free,  
but the operating equipment  
itself costs**

**25 000\$**

**For us  
it is just an unrealistic amount**

PHOTO BY IVAN LIUBYSH-KIRDEI



**M**y disease is torsion dystonia, which is considered a rare disease. I was born a healthy child, but when I was about four, the first symptoms started to show up. I was running around and suddenly fell to my knees. That was the beginning of our endless trips to the hospitals. **We visited all the major medical facilities, institutes, hospitals in Kyiv and Kyiv region, but no one could give us an accurate diagnosis.**

There were many different, but unconfirmed diagnosis. **If you look at my medical history, you will see a file as thick as “War and Peace”.** The disease progressed, it was difficult to walk and write. I always fell down. **At school and at the playground children mocked and insulted me. Teachers and nurses also did not want to babysit me much.** My social life came to an end. I talked only to close relatives, doctors and teachers who came to our home.

**I was 11, when doctors suggested hormone therapy. And in just a few months, from a skinny little girl I turned to a huge fat lady. I started using a wheelchair.**

When I was 16 or 17 years, we went through a regular medical examination. There was a doctors’ meeting with many professionals who had a long argument. Finally, on the sheet of paper, where they supposed to write the diagnosis, the doctor put a huge question mark and pierced the sheet with a full stop. He told my mother “to go and get ready to bury your child.” This did not stop my mom but encouraged her to continue to fight.

When I was 19, I could no longer eat on my own, hold a spoon or cup. **It was then, when we accidentally went to the Institute of Neurosurgery, where a doctor diagnosed me with torsion dystonia.** He offered to treat me with deep brain stimulation. **This surgery is free, but the operating equipment itself costs 25,000 dollars.** My mother works from home as a seamstress, and I have disability benefits. Twenty-five thousand dollars for us is just an unrealistic amount.

**I was the first patient to have this type of surgery in Ukraine.** My mother and I began to collect money for it. We created groups on social networks. Journalists did a

story about me. We collected money for two years and I call it a miracle that we finally got the right amount.

**I had a surgery on May 23, 2012. I came back home on my own feet.**

**After the surgery, you have to start learning many things from scratch, walking, for example. And how to live in society.** A year later, in 2013, I started university. I am a fourth-year student now. I study document management. I want to receive a master degree in psychology.

**Last year, in May, I founded a public organization “Association of Torsion Dystonia Patients.” We fight to ensure that the state finances our operations because our disease cannot be cured with medicine. Deep stimulation helps the brain. It does not cure the disease, but it removes the symptoms and a person can live a full life.**

There is one drawback, though. **Every 4 to 5 years you need to change the generator, which operates the system. The cost is about 20,000 dollars.** When the battery is low, the disease returns with renewed vigor.

**Yet there has been no case when the state covered the costs equipment or replacement of a generator. The state must be interested in us being full citizens of our country, able to work and bring benefits.**

*Natalia Titova is the only person in Ukraine diagnosed with segawa disease. This is a variation of torsion dystonia. Overall, there are about 15 people in Ukraine officially diagnosed with torsion dystonia.*

# ANALYSIS OF THE 100 MOST SOLD MEDICINES IN UKRAINE

An additional component of the overall study was to analyze the importance and necessity of the TOP 100 medications sold over the last three years (WHO methodology: vital, essential and non-essential). The medicine was analyzed both in monetary terms and in packages. Over the last three years **the share of medicine in the TOP 100 which was 'non-essential', ranged from 50 to 54%. In monetary terms, more than 3 billion UAH annually or 9.5-10.75% of the total market (half the value of the top 100 sold).**

## ANALYSIS OF THE TOP 100 MEDICATIONS, UKRAINIANS PAY FOR IN PHARMACIES FROM THEIR OWN POCKETS

*\*Source: "Business Credit"*

	I-III quarter 2016	2015	2014
<i>% from total amount of TOP 100</i>			
Vital	21%	20%	17%
Essential	29%	29%	29%
<b>Non-essential</b>	<b>50%</b>	<b>51%</b>	<b>54%</b>
Total	100%	100%	100%



# ANALYSIS OF THE 100 MOST SOLD MEDICINES IN UKRAINE

	Total amount of medicines sold, 1 000 UAH	% from the total value of TOP 100	% from the total market share
<b>3/4 2016</b>			
Vital	1 176 496,51	18,9%	3,5%
Essential	1 883 760,02	30,3%	5,7%
<b>Non-essential</b>	<b>3 148 816,40</b>	<b>50,7%</b>	<b>9,5%</b>
Total TOP-100:	6 209 072,93	100,0%	18,7%
Total on the pharm market:	33 201 637,38		
<b>2015</b>			
Vital	1 375 421,96	18,8%	3,6%
Essential	2 136 078,53	29,1%	5,5%
<b>Non-essential</b>	<b>3 822 457,25</b>	<b>52,1%</b>	<b>9,9%</b>
Total TOP-100:	7 333 957,74	100,0%	19,0%
Total on the pharm market:	38 600 146,94		
<b>2014</b>			
Vital	1 042 955,53	16,21%	3,18%
Essential	1 863 112,10	28,96%	5,68%
<b>Non-essential</b>	<b>3 526 715,14</b>	<b>54,82%</b>	<b>10,75%</b>
Total TOP-100:	6 432 782,78	100,0%	19,60%
Total on the pharm market:	32 818 395,14		

# CONCLUSIONS

The qualitative research concluded that **the high cost of medicine** was the most important problem faced by the patients interviewed. The quantitative research indicated the same: 63% according to the "Health index. Ukraine 2016" national survey, said the high cost of medicine was their biggest problem. To cover the cost of medicine in case of illness, families pursue different strategies: delay treatment, opt for part-time treatment courses, **borrow money, and sell valuables**. The latter applies to those outpatients and patients of the polyclinics, who state that it has been difficult to cover the cost of medication and treatment (64%). Inpatient care is also unavailable for the majority of patients: 43% of inpatients borrowed money to cover the cost of treatment and 82% of patients hospitalized indicated substantial financial difficulties in buying medicine. These results confirm that the pharmaceutical policy in Ukraine is inconsistent and that there is a lack of improvement for patients: the financial burden lies on the patient. The situation is complicated by the fact that Ukraine lacks reliable sources of information about medicine.

As shown by qualitative research, **HIV positive patients, and those diagnosed with hepatitis and tuberculosis received free medicine more frequently**. However, the results of the "Health index. Ukraine 2016" survey show some of the quantitative indicators of this practice: Only 3% of outpatients and those treated in polyclinics indicated receiving free medicine. Other patients with serious illnesses (like cancer) said they had to spend significant funds on treatment. Often they think about whether it is worth starting treatment at all because the costs are unaffordable for most families.

The lack of trust in medicine in general and doctors in particular is also a very important problem for patients. Sometimes, instead of contacting a doctor and getting a prescription, patients seek advice from friends, the internet or pharmacists. This may result in ineffective treatment (self-medication often aggravates illness). The advertising of medicine on television and on the internet is also a reason why Ukrainian patients unreasonably spend large amounts of money on medicine.

# RECOMMENDATIONS ON HOW TO IMPROVE PATIENTS' ACCESS TO TREATMENT

## TRANSPARANCY

- Prolonging public procurement of medicines, vaccines and medical supplies organized by the MOH Ukraine through the international specialized organizations, which proved their efficiency at the national level, and which increase the access to the medicine, procured from the state budget funds.
- The procurement of medicines and medical products through ProZorro electronic system, if the law does not allow the procurement with the assistance of specialized international organizations.
- The transfer of medical records from paper to electronic form and the implementation of a global system of e-Health, which will include registries of patients, forecasting the need for medications, etc.
- To increase the transparency and accountability of how hospitals use medicine purchased by the state and local budgets: Publish information on the availability of medicine on websites accessible to patients, such as [eliky.in.ua](http://eliky.in.ua); and, to introduce an effective control system for the movement of medicines at all stages with the help of GS1 barcodes.

## INCREASE ACCESS TO TREATMENT

- The implementation of a transparent, well-organized and managed reimbursement system for all medicines included in the National List of Essential Medicines. This system should become a part of medical insurance program in Ukraine, and be based on a registry of patients, thoroughly calculated insurance coverage programs, and a clear system of monitoring the use of medicine.

- Switch to the international clinical guidelines on treatment and diagnosis.
- Implementing a practice for «unlicensed» treatment prescription in exceptional cases, where there is a lack of the necessary medicine to treat for population.

## EFFECTIVENESS AND QUALITY OF MEDICINES

- The introduction of effective mechanisms for quality control of medicines at registration stage with the simultaneous elimination of bureaucratic obstacles in accessing medicines on the market in Ukraine, which exist as inefficient and duplicative procedures in the system of medicine registration.
- Approving and updating the National List of Essential Medicines based on the WHO Model List of Essential Medicines for treatment of patients with corresponding nosology in Ukraine, including rare diseases; and limiting procurement of medicines for the budget funds by the National List of Essential Medicines to avoid uncontrolled and inefficient budget spending.
- The introduction of a mechanism to control the sale of prescription drugs by pharmacies so that they are only sold on the prescription of a doctor, that is, according to a prescription. This minimizes the risks caused by self-medication and prevents excessive use of medications.
- To increase control over the advertising of medicine of any format to reduce expenses for medicine, enhance the rational use of pharmaceuticals, decrease the level of self-medication and the use of medicine that is not vital, and expensive.

# RECOMMENDATIONS ON HOW TO IMPROVE PATIENTS' ACCESS TO TREATMENT

## REDUCING PRICES OF MEDICINE IN UKRAINE

- To implement the practice of “parallel imports” for medicine in order to increase competition among suppliers of the pharmaceutical market in Ukraine. This will reduce the cost of medicine, as the prices for the imported medicines will reach the average prices of the European market.
- To improve and simplify the permit system for access of medicine to the Ukrainian market by eliminating duplicating procedures.
- To regulate the prices for medicine procured through local budgets using external and internal reference pricing methods.
- Conducting patent reform that includes overcoming the practice of “evergreen patents” (the artificial extension of patent monopoly) for medicines, as well as the possibility of using compulsory licensing in case of urgent needs.
- Supporting and actively implementing the international practice of generic substitution of medicine for the purpose of effective use of state funds, and funds of the population.

## FINANCING

- Provide funds for state procurement of essential medicine in accordance with actual needs. Consider directing revenues from excise taxes on tobacco and alcohol to financing the health care system, particularly the procurement of medicine and reimbursement.
- Cancelling 7% VAT on medicines. Due to financial unavailability of medicines for the majority population and the critical underfunding of the health care system, it is impractical to impose VAT on medicines at this stage in Ukraine.





<http://patients.org.ua>



<https://www.usaid.gov/uk/ukraine>



KYIV

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