**ANALYTICAL REPORT**

**PUBLIC MONITORING OF THE DELIVERY AND AVAILABILITY OF MEDICINES AT THE LOCAL LEVEL (2017-2020)**

**PROJECT No. HP/LVGA/2020/4**

**UNDP PROJECT ‘PROCUREMENT SUPPORT SERVICES TO THE MINISTRY OF HEALTH OF UKRAINE’**

**UNDP LOW-VALUE GRANT PROGRAMME**

**‘PUBLIC MONITORING OF THE DELIVERY AND AVAILABILITY OF MEDICINES AT THE LOCAL LEVEL’**

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* Patients Charitable Foundation ‘Drop of Blood’;
* NGO ‘Spark of Hope’;
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* Charity Children Fund ‘Give World to Child’;
* Charity Organization ‘100% Life Rivne’;
* All-Ukrainian Charity Organization ‘Initiative for Life’;
* NGO ‘Ukrainian community of people with multiple sclerosis’.

# Glossary of acronyms, abbreviations, and terms

|  |  |
| --- | --- |
| **ATBM** | –anti-tuberculosis medicines |
| **CSO** | – civil society organization |
| **DA** | – dispensary accounting |
| **HCF** | – health care facility |
| **HD** | – health department |
| **MoH** | – Ministry of Health of Ukraine |
| **MS** | – multiple sclerosis |
| **National List** | – National list of essential medicines |
| **NCR** | – National Cancer Registry of Ukraine |
| **NGO** | – non-governmental organization |
| **SoE** | – state-owned enterprise |
| **UNDP** | – United Nations Development Programme |
| **HBV** | – viral hepatitis B |
| **HCV** | – viral hepatitis С |
| **WHO** | – World Health Organization |

# Introduction

The UNDP Low-Value Grants project for the public monitoring of the local delivery and availability of medicines procured by UNDP for the Ministry of Health of Ukraine has two main goals. These are: 1) to undertake an independent, third-party assessment to provide UNDP with real-life information about the availability of and access to the treatments that UNDP procures, and 2) to develop the capacity of Ukrainian patients’ organisations to conduct autonomous, impartial studies, the results of which they can use as an advocacy tool.

Launched in 2017, this project involves working with non-governmental organisations to collect data on the procurement of medicines and medical products and their distribution to local health care facilities in different oblasts. It also aims to understand the overall level of satisfaction of patients and physicians with the volumes and timing of deliveries. The fourth round of monitoring, which took place in 2020, expands on the work done in 2019 by working with relevant NGOs concerned with selected diseases, assessing substantially more medicines and nosologies in more oblasts, and collecting qualitative data from many more patients, staff of HCFs and representatives of HDs (Table 1).

**Table 1**

**Public monitoring of local delivery and availability of medicines: coverage by year, 2017–2020**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Review year** | **2017** | **2018** | **2019** | **2020** |
| Number of NGOs participating | 4 | 4 | 6 | 6 |
| Number of medicines assessed | 17 | 15 | 132 | 99 |
| Number of nosologies | 2 | 2 | 12 | 9 |
| Number of oblasts | 4 | 4 | 11 (24 for orphan diseases) | 18 |
| Number of patients surveyed | 537 | 304 | 1 408 | 2 755 |
| Number of HCF staff surveyed | 10 | 11 | 109 | 135 |
| Number of representatives of HDs surveyed | 0 | 0 | 0 | 79 |

To select executive partners (grantees), an open competition of the Low-value Grant programme was announced. Applications were received from a large number of candidates, but only the strongest were selected to conduct public monitoring. All selected executive partners are patient organizations with relevant experience in project implementation.

During data collection, the grantees interviewed patients (or their legal representatives) (2017-2020), staff of HCFs (2017-2020) and representatives of HDs (2020). In addition, they cooperated with other NGOs to collect data on the procurement of medicines for selected nosologies and their distribution among HCFs in various regions of Ukraine.

Public monitoring of the delivery and availability of medicines was designed to describe the main existing trends and identify problems. The data collected by NGOs are neither statistically reliable nor fully representative of the relevant patient group.

# Description of the Programme

UNDP is helping the MoH of Ukraine to reform the public procurement system of medicines and medical products. In the framework of the project ‘Procurement Support Services to the Ministry of Health of Ukraine’, 2015-2020, UNDP has procured a number of medicines and medical products under selected government programmes, ensuring their availability to patients at the local level.

Great emphasis is put on economic efficiency, transparency, and timeliness of procurement, as well as strengthening structural and human capacity to plan, forecast, supervise, and evaluate supplies to ensure transparent and cost-effective procurement by the MoH.

To monitor the supply and distribution of medicines procured centrally with UNDP's support between 2017-2020, UNDP launched the Low-Value Grant Programme ‘Public monitoring of the delivery, availability and use of medicines at the local level’. The programme is aimed at monitoring the actual situation with the availability and accessibility of medicines procured by UNDP through the budget of the MoH, as well as obtaining data on the timeliness and quantity of deliveries of medicines to warehouses and HCFs in the regions.

In particular, during the 2017-2020 public monitoring, the focus was on the following areas:

* experience of patients with selected diseases regarding the availability of medicines;
* experience of HCF staff regarding the timeliness of delivery and availability of medicines for patients;
* experience of representatives of local government regarding the timeliness of delivery and availability of medicines;
* number of medicines ordered and received, per disease area;
* delivery times from the central warehouse to the regional and/or HCF warehouses;
* problems encountered with the supply of medicines;
* number of patients who need treatment, per disease area;
* other issues related to the delivery of medicines (level of awareness of physicians and patients about the existence of free medicines, best practices, etc.);
* provision of recommendations for further development of the system for medical procurement in Ukraine.

Based on the results of the open competition for low-value grants, the grantees (executive partners) were selected. All selected executive partners were patient organizations with relevant experience in project implementation.

**Grantees of the 2017 programme:**

4 selected grantees (executive partners) participated in the Low-Value Grant Programme. Public monitoring of selected diseases (Annex 1) was conducted in Lvivska, Poltavska, Kharkivska and Cherkaska oblasts (Annex 2).

**Grantees of the 2018 programme:**

4 selected grantees (executive partners) participated in the Low-Value Grant Programme. Public monitoring of selected diseases (Annex 1) was conducted in Vinnytska, Dnipropetrovska, Zaporizka and Chernihivska oblasts (Annex 2).

**Grantees of the 2019 programme:**

4 selected grantees (executive partners) participated in the Low-Value Grant Programme. Public monitoring of selected diseases (Annex 1) was conducted in Vinnytska, Volynska, Zhytomyrskа, Lvivska, Mykolaiv, Rivnenska, Ternopilska, Khersonska, Khmelnytska, Cherkaska and Chernihivska oblasts; for orphan disease, public monitoring was conducted in 24 oblasts and in the city of Kyiv (Annex 2).

**Grantees of the 2020 programme:**

4 selected grantees (executive partners) participated in the Low-Value Grant Programme. Public monitoring of selected diseases (Annex 1) was conducted in Vinnytska, Volynska, Dnipropetrovska, Zhytomyrskа, Zaporizka, Kyivska, Kirovohradska, Lvivska, Mykolaivska, Odeska, Poltavska, Rivnenska, Ternopilska, Kharkivska, Khersonska, Cherkaska, Chernihivska oblasts, and in the city of Kyiv (Annex 2).

The study was based on a qualitative approach, which is not inherently representative. In this regard, the study findings have certain limitations associated with the transfer of the results to the general population, although they may be relevant in relation to other similar situations.

# Capacity development of civil society organizations in Ukraine

Given that UNDP defines capacity-building as its comprehensive contribution to development, the programmes and initiatives it supports should contribute to sustainability at the national/local level[[1]](#footnote-1).

UNDP identified five functional abilities that are important for determining the outcomes of an organization’s development efforts:

* capacity to engage stakeholders;
* capacity to assess the situation and determine a vision;
* capacity to develop policies and strategies;
* capacity to plan/cost, manage and implement activities; and
* capacity to evaluate.

Therefore, organizations which took part in the Programme in 2017-2020 (the “grantees”) were invited to take part in a survey by filling a questionnaire based on the UNDP’s approach to capacity development outcomes. The grantees' representatives were asked to rate their organization’s public monitoring capacity in areas such as:

* capacity to determine needs for information, frequency of its collection, sources and methods for obtaining information;
* capacity to develop and test data collection tools, hire and train staff responsible for data collection and monitoring;
* capacity to collect identified data and oversee monitoring;
* capacity to analyse and compare data;
* capacity to document the collected data and the findings of their analysis, and to share the findings with stakeholders.

The link to the online assessment (questionnaire) was disseminated among 15 NGOs. Completed questionnaires were received from 11 organizations that demonstrated a high level of follow-up and indicated a high level of their interest in grant programmes.

The results of the survey showed that most of the organizations which took part in the survey rated their organization’s public monitoring capacity ‘satisfactory’ (score ‘3’) or ‘good’ (score ‘4’). While the average mark in that regard before the organizations took part in the Programme was 3.7 points, grantees rated their progress following the organization’s participation in the Programme at 4.7 points, which is close to ‘excellent’ (score ‘5’).

7 grantee representatives mentioned that participation in the Programme was fairly useful in broadening their organization’s network of partners. For 4 organizations, their participation in the Programme resulted in a significantly broadened network of partners (media representatives; CSOs; international organizations; representatives of communities living with diseases; representatives of HDs).

In addition, 6 organizations took part in activities aimed at sharing experience of performing public monitoring or providing technical assistance to other CSOs. According to the grantees, the skills honed during the implementation of the Programme which they consider the most valuable to share with other CSOs include *developing and conducting analytical research*, *communication with clients during the survey*, *monitoring of HCF activities,* *analysis of the supply of medicines, information-gathering skills, advocacy, data presentation and compilation of analytical reports.*

6 grantee representatives mentioned that participation in the Programme helped their organizations to expand their client base. For instance, the number of clients of the Civic Union ‘Orphan Diseases of Ukraine’ increased from 24 to 47. The NGO ‘Creative Association Nivroku’ managed to expand its client base from 500 to 800 clients. The children's charity fund ‘Give World to Child’ broadened both its client base and the specific nosologies it works with. Until 2018 this fund worked only with patients living with cancer and those requiring palliative aid. Since 2019, they have also focused on haemophilia, autistic spectrum disorders and cerebral palsy.

All grantees agreed that participation in the Programme helped their organizations to improve the quality of life of the patients interviewed in the course of the monitoring. 6 grantees mentioned that they provided patients with information relevant to the treatment of their nosology, and 5 grantees kept working directly with them afterwards or referred them to relevant NGOs or patient communities.

It was also revealed that grantees' participation in the Programme had equipped patients with information on their nosology. Namely, patients increased their awareness of the possibility of receiving medicines free, developed their ability to stand up for their rights to free treatment and gained better understanding of the specificity of their nosology, the treatment protocols and medicines. In addition, patients are now more aware of the availability or absence of medicines and the quality of health care.

All of the grantees indicated an increase in their organizations’ advocacy capacity in relation to HDs, HCFS and communities of people living with diseases. However, only 5 organizations mentioned that they succeeded in strengthening advocacy relations with the MoH.

Grantees also highly valued improvement in the visibility of patients’ organizations. Based on their responses, the average visibility rate of organizations before their participation in the Programme was 3.9 points out of 5. 7 grantees stated that after participating in the Programme their visibility became ‘very high’. All grantees noted a considerable rise in the reputation of their organization and recognition of its expertise after it had taken part in the Programme, which they estimated as ‘very high’. The same is true of the expertise and skills of the employees or staff involved: an average of 3.5 points out of 5 increased to 5 points.

In general, the Programme had a positive impact on the patient organizations’ financial capacity, accounting, financial analysis, human resources management and decision-making:

‘*Participation in the Programme provided project staff and members with the opportunity to master research tools and establish communication links with patient communities. We widely inform the public about access to free medicines and the possibility of obtaining information about their availability’ (Initiative for Life).*

‘*Participation in the Programme had a positive impact on our NGO, increased our self-confidence, contributed to the development of the team and to adjustment of our own policies related to institutional arrangements’ (Association of Palliative and Hospice Care).*

# Scope and methodology

**Goal of the studies**: conduct public monitoring of delivery and availability of medicines for selected disease areas at the local level, between 2016-2019.

**Task of the studies**: obtain data regarding the delivery of medicines procured by UNDP from the MoH's budget to warehouses and HCFs in the regions: timeliness of delivery and availability of medicines for patients.

**Diseases covered in the 2017 study** (Annex 1, 3)**:**

* + - oncology and oncohaematology;
		- children with chronic viral hepatitis.

**Diseases covered in the 2018 study** (Annex 1, 3)**:**

* + - paediatric oncohaematology;
		- adults with haemophilia.

**Diseases covered in the 2019 study** (Annex 1, 3):

* + - paediatric oncology;
		- HBV, HCV;
		- adults with haemophilia;
		- children with haemophilia;
		- children with mental and behavioural disorders (autism spectrum disorders, schizophrenia, affective disorders, hyperkinetic disorders);
		- juvenile rheumatoid arthritis;
		- reagents for mass screening of newborns for phenylketonuria, congenital hypothyroidism, cystic fibrosis and adrenogenital syndrome;
		- orphan diseases (bullous epidermolysis, pulmonary hypertension, cystic fibrosis, mucopolysaccharidosis).

**Diseases covered in the 2020 study** (Annex 1, 3)**:**

* + - children with cerebral palsy;
		- adults with haemophilia;
		- children with haemophilia;
		- adults with HBV and HBC;
		- children with HBV and HBC;
		- MS;
		- treatment of tuberculosis;
		- adult oncology;
		- paediatric oncology.

**Data collection approach used in 2017-2019 studies**

For the 2017-2019 studies, questionnaires with 2 sections were developed and used. To collect the data, the grantees used phone interviews, interviews through private groups in social networks or individual self-completion of the questionnaire.

For Section A, ‘Supply of medicines’, the data were collected from the websites of MoH and regional HDs, the websites <http://eliky.in.ua> and <http://liky.ua>, as well from official requests to the HDs and applications in the regions.

For Section B, ‘Use of medicines’, the data were collected from the heads of HCFs and from patients or their legal representatives.

**Data collection approach used in the 2020 study**

For the 2020 study, separate questionnaires were developed and used for three target groups (for patients or their legal representatives; for medical staff (physicians) or administrative personnel of the HCFs; and for representatives of HDs in oblast (or city) state administrations). The questionnaires had a standard structure and content, which allowed comparable data to be obtained on the delivery and availability of medicines at local level, based on the results of surveys of the three groups of respondents. The interviews were conducted by qualified interviewers.

Each questionnaire consisted of 3 mandatory sections, to be completed with the answers of the respondents:

Section A. data on the socio-demographic characteristics of the respondent, in particular: age, sex, education, place of residence, type of employment, income level, membership of vulnerable groups, etc.

Section B. data on the supply of medicines, in particular: the availability and accessibility of medicines, free medicines, the method of obtaining medicines, problems with obtaining medicines, etc.

Section C. Other details, in particular: conditions of storage of medicines, awareness of the availability and range of medicines among patients, etc.

Also, to perform the tasks of the study, a data collection tool on the supply and availability of medicines at regional level was developed for each individual disease area and used accordingly.

Given the situation with social distancing restrictions imposed in connection with the COVID-19 pandemic, different data collection methods were used (face-to-face or phone interviews). Priority was given to personal interviews with target group respondents.

To ensure representativeness, a mechanism for regional quotas on the number of surveys was applied to grantees, based on their capacity and the local prevalence of the researched diseases.

After receiving the completed questionnaires from the respondents, the grantees verified the collected data by conducting additional control interviews (20% of all questionnaires and 100% of data collection tools). These interviews included questions about the procedure for and specifics of completing the questionnaires by the respondents. Also, at the verification stage, respondents' understanding of the essence of the questionnaire was checked, because this directly affects the quality and reliability of the final data.

**Results of the 2017-2020 studies** (may differ for different reporting periods)

The information collected allowed the specifics of delivery and availability of medicines at local level to be described. This made it possible to review:

* + - experience of patients with selected diseases regarding the availability of medicines;
		- experience of HCF staff regarding the timeliness of delivery and availability of medicines for patients;
		- experience of representatives of local government regarding the timeliness of delivery and availability of medicines;
		- number of medicines ordered and received, per disease area;
		- timescales of delivery from the central warehouse to the regional and/or HCF warehouses;
		- problems encountered during the supply of medicines;
		- number of patients who need treatment, per disease area;
		- other issues related to the delivery of medicines (level of awareness of physicians and patients about the existence of free medicines, best practice, etc.);
		- recommendations for further development of the system for medicinal procurement in Ukraine.

In addition, the data obtained cover the points of view of different target groups: patients, physicians / administrative staff of the HCF and representatives of HDs. This approach allowed the problems of delivery and availability of medicines at local level to be comprehensively encompassed, both geographically and in relation to specific diseases.

The results were used to formulate conclusions and recommendations for various stakeholders to improve the process of delivery of medicines at local level and to improve patients' access to medicines.

# Results of the 2017 study

**Oncology and oncohaematology**

The monitoring was carried out in four regions of Ukraine and covered 14 medicines, which are first-line chemotherapy medicines and are budget-generating (62% of the budget was spent on their purchase; USD 9.4 million) (Annex 4).

The total number of patients with oncology and oncohaematology who needed chemotherapy in the study regions was 152,358 persons. The grantees interviewed 472 patients and 6 heads of HCFs (Annex 5). 59% of interviewed patients were women, 41% were men. 60% of patients with cancer were aged between 50 and 70 years old (Annex 6).

Timescales for deliveries of medicines[[2]](#footnote-2): The study identified delays in the supply of medicines from the central warehouse to Kharkivska and Lvivska oblasts. In Poltavska, Cherkaska and Lvivska oblasts, deliveries are made directly to the HCFs (daily deliveries to the regional warehouse and to the HCF warehouse). The main delays occurred at the level of the central warehouse of the MoH. Thus, in Lvivska oblast, 41% of medicines purchased by UNDP (25 out of 61) were delivered to the HCFs more than a month after the UNDP transferred the medicines to the central warehouse of the MoH. The delay in the delivery of 13 medicines from the central warehouse of the MoH to the regional warehouse in Kharkivska oblast was identified as 28-38 days (Annex 7).

74% of the patients with cancer surveyed received medicines for their treatment free of charge (Annex 8).

Only 5% of the patients surveyed refused the medicines that were offered free of charge. The main reasons for refusal were the following: patients bought better medicines (with fewer side-effects); low efficiency of the medicines offered; side-effects after taking generics. Information on where medicines were purchased can be found in Annex 9.

10% of patients reported that they were asked to make a charitable donation in order to receive free medicines.

When patients purchased medicines themselves, they faced the following problems: difficulties in purchasing medicines that are not registered in Ukraine but are included in treatment protocols; difficulties in getting medicines delivered to the HCFs in compliance with temperature regimes; the high cost of medicines used to prevent side-effects.

Meanwhile, medical staff reported the following problems: the allocated quota for the treatment of patients with cancer corresponds to only 10% of existing needs; medicines ordered for 2016 were received in 2017, and not even the full number of medicines; there is no delivery schedule, which does not allow treatment to be planned accurately.

**Children with chronic viral hepatitis**

The monitoring was carried out in four regions of Ukraine.

Within the study, 65 parents who have children with chronic viral hepatitis and 4 heads of HCFs were interviewed (Annex 10).

Timescales for deliveries of medicines: In Cherkaska, Kharkivska and Lvivska oblasts, in 2016 and 2017, medicines for the treatment of children with hepatitis were received in the amounts ordered. Delivery times ranged from 12 to 22 days. Meanwhile, in Kharkivska oblast, the delivery of medicines from the region to the HCFs took up to 7 days. In Poltavska oblast the delivery time was 3-5 days. In Lvivska oblast, the MoH Order on the distribution of the ‘Unitron’ medicine throughout the regions was published on 06.06.2016, and the medicine was delivered to the regions only on 07.08.2016 (42 days later). Other medicines in the region were delivered within 16-21 days.

All interviewed heads of HCFs confirmed that the quantity of medicines that were purchased centrally meets the actual needs of the hospital.

According to the study results, doctors stated the following problems related to the delivery of medicines: delivery of Ribaverine without pegylated interferons does not allow treatment to be started on time; treatment of children under 5 years is complicated due to the lack of age-appropriate dosage; medicines start being delivered to the HCFs in the second half of the year, at which point some children have turned 18 and do not come under the Children with Hepatitis Programme.

All respondents received medicines free of charge. Only in Kharkivska Oblast Children's Clinical Hospital, 16 out of 30 patients refused treatment with the proposed medicines and chose to be treated with direct-acting medicines. Parents bought the medicines themselves.

97% of patients received medicines at the beginning of treatment. None of the patients was asked to make a charitable donation to the HCFs in order to receive free medicine.

The patients reported facing the following problems: in almost all cases, the beginning of the treatment process did not depend on objective need, but on delivery times and the availability of medicines in the HCFs; medicines with dosage for children from 3 years old cannot be included in the application to the MoH; if medicine is sought from the MoH for children over 17 years of age, it is probable that the child will not be given these medicines when they are actually delivered.

# Results of the 2018 study

**Paediatric oncohaematology**

The monitoring was carried out in four regions of Ukraine. The number of children with cancer registered in the study regions was 1 020 (Annex 11).

Regional quotas for the purchase of medicines for children with cancer are developed in accordance with the average number of patients per year, and in Chernihivska oblast, for example, for the last five years. According to doctors, the regional budget quota covers 90-110% of the need. When a need arises, there is an ‘informal’ rule that the most expensive medicines will be included in the application, as cheaper medicines can later be purchased either through local budgets or at the expense of patients.

The total number of surveyed children (or their legal representatives) is 203 respondents (Annex 12). The majority of respondents had no observations on the quality of purchased medicines. There were no cases of complete refusal of medicines.

None of the parents / legal representatives indicated that they were required to make charitable contributions in order to receive the medicines. If parents / legal representatives bought medicines, they were additional to the basic medicines for treatment (antibiotics, antifungals and consumables).

Timescales for deliveries of medicines: After medicines have been purchased and delivered to the ‘Ukrmedpostach’ warehouse, it takes from 2 weeks to 2 months until the relevant MoH Order is issued for the distribution of medicines to the regions. On average, 11 days pass from the issuance of the MoH Order for the distribution of medicines to the delivery of the medicines to the HCFs' warehouses (the longest duration was 18 days, the fastest, 3 days).

The interviewed medical staff reported the following problems with the supply of medicines: lack of methodology for calculating the region's needs; lack of information on delivery dates for previous applications does not allow them to plan the treatment of patients; impossibility to purchase additional medicines that are not included in the National List; lack of qualified doctors due to low wages.

In general, doctors stated that the situation with the provision of medicines for the treatment of children with cancer and haematological diseases is good. In the event that centrally purchased medicines are unavailable or deliveries are delayed, their needs are covered by the local budget and charitable foundations.

The interviewed parents / legal representatives reported the following problems: low level of professional training of paramedics; insufficient number of doctors; purchase of generic medicines while parents prefer original medicines (Annex 13).

**Adults with haemophilia**

The monitoring was carried out in four regions of Ukraine. The number of patients with haemophilia in the study regions is 326 respondents (Annex 14). The total number of respondents is 101 (Annex 15).

Timescales for deliveries of medicines: The longest delay in delivery (on average 3 weeks) is from the medicine's arrival at the SoE ‘Ukrvaktsina’ / State Supply warehouse until the MoH Order is issued. Due to the need for ‘cold chain’ compliance, medicines are delivered directly to the HCFs, with no storage at regional warehouses. The timescale for delivery of medicines from issuance of the MoH Order to arrival at the HCF warehouse is between 3 and 15 days.

The majority of patients in Dnipropetrovska (97%) and Zaporizka oblasts (88%) indicated that they received medicines free of charge.

37% of patients in Dnipropetrovska oblast and 38% of patients in Zaporizka oblast reported that they were asked to make a charitable contribution to the hospital. According to medical staff, the funds are used for laboratory tests and detergents. All patients in Vinnytska and Chernihivska oblasts reported that there was no need to make charitable contributions.

A significant proportion of patients with haemophilia refused to take the Ukraine-produced medicine ‘Bioclot A’ (29% of respondents in Dnipropetrovska oblast, 19% in Zaporizka oblast and 6% in Vinnytska oblast), due to side-effects and lack of therapeutic effect[[3]](#footnote-3).

Patients in Vinnytska and Chernihivska oblasts who live in district centers report that in fewer than 50% cases of bleeding do they seek assistance from the HCFs. Medicines are more accessible for patients living in oblast centers.

Patients with haemophilia indicated the following problems: lack of available diagnostic services to determine the factor level and the presence of inhibitors; lack of preventive treatment to avoid complications of haemophilia and allow adult patients to improve their quality of life; lack of a home-treatment model; absence of medicines in the HCFs at the place of residence; absence of coagulation factors in the pharmacy network; inability to have factor given in an emergency, at night, on weekends; no medicines for rehabilitation and endoprosthesis; HCFs are poorly equipped with additional medicines (syringes, cotton wool, bandages, reagents for analysis) and related medicines for the treatment of patients with haemophilia (tranexamic acid, haemostatic sponge, analgesic).

# Results of the 2019 study

**Paediatric oncology**

The monitoring was carried out in five regions of Ukraine and covered 18 medicines (Annex 16).

The total number of children with oncology in the regions where the monitoring was carried out came to 943.

188 parents (or legal representatives) and 5 physicians were interviewed as part of the monitoring.

Deliveries of medicines were found to take between 13 and 62 days from the date the MoH order was issued to their arrival at the HCFs’ warehouses.

Four of the five doctors interviewed thought that the need for medicines is not being met 100%. The medicines received accounted for only 55% of actual patient need in 2019. Despite these shortcomings, doctors’ level of satisfaction was 7.5 (on a 10-point scale).

All five doctors identified the lack of long-term planning of medicine supplies and supply delays as the main problems related to the supply of medicines; two mentioned that the budget for this nosology was insufficient.

Nearly all (99%) of the patients surveyed received medicines for free, although one indicated that they were asked to make a charitable donation in return for free medicines, and 83% purchased additional drugs. 11% indicated that they had refused free medicines at least once due to a lack of trust in the manufacturer (generic medicines) or due to side-effects. In such cases, they purchased medicines from pharmacies.

Among the most common challenges identified by patients were: insufficient quantity of medicines (42%); delays in deliveries of free medicines (34%); high prices for medicines in pharmacies (30%); and the lack of home treatment (25%) and preventive treatment (22%).

**HBV, HCV**

The monitoring was conducted in five regions of Ukraine and covered 8 medicines (Annex 16).

The total number of patients with HBV in the regions where the monitoring was carried out came to 4 563; for HCV it was 10 903.

369 patients and 34 physicians were interviewed as part of the monitoring.

Deliveries of medicines were found to take between 2 and 34 days from the date the MoH order was issued to their arrival at local warehouses. Orders were issued by regional health care departments in a timely manner.

Even though doctors noted that supplies of free medicine for the treatment of viral hepatitis have increased since 2018, 76% of the doctors surveyed confirmed that the quantity of medicines received does not match the amounts requested or the actual needs of hospitals based on the number of patients. According to the doctors, the level of provision of hepatitis medicines was 57% of the quantity needed.

Among other problems identified, 71% of doctors noted irregular supplies of medicines throughout the year, while 66% mentioned significant delays and interruptions in the flow of medicines, 31% mentioned the incorrect sequence of medicine deliveries, and 28% mentioned occasional lack of stock of medicines at health care facility warehouses. Other problems include the inability to plan long-term treatment courses for patients with viral hepatitis who are diagnosed between deliveries of medicines, and the limited availability of free diagnostic tests.

78% of the patients interviewed received free medicines procured from the central budget. Delays in the supply of free medicines were the most common problem, identified by 38% of respondents, followed by an insufficient quantity of free medicines at health care facilities (15%) and the prohibitive price of the medicines (14%).

**Adults with haemophilia**

The monitoring was conducted in one region of Ukraine and covered 24 medicines (Annex 16).

The total number of adult patients with haemophilia in the regions where the monitoring was carried out came to 33.

28 patients and one physician were interviewed as part of the monitoring.

According to the sole doctor interviewed, the quantity of medicines received covers only 40% of the total need, but this has increased compared to 2015 or 2016. The main reason is the insufficient allocation of funding for this nosology. The doctor complained about the lack of an officially approved formula for calculating the need for medicines; insufficient financial allocations to meet 100% of need; a lack of medicines for prophylactic treatment; the absence of a patient register; a lack of proper diagnostics; and restrictions on the National List of Essential Medicines. Delays in the delivery of free medicines from the MoH warehouse to hospital warehouses were between 14 and 23 days.

Nearly 71% of patients reported receiving medicines free of charge. 96% of patients had to buy additional medicines.

**Children with haemophilia**

The monitoring was conducted in five regions of Ukraine and covered 22 medicines (Annex 16).

The total number of children with haemophilia in the regions where the monitoring was carried out came to 135.

118 parents (or legal representatives) and 5 physicians were interviewed as part of the monitoring.

The actual availability of free medicines for children met about 50% of the real need calculated according to international standards[[4]](#footnote-4), and varied between 20% and 55% for certain items in the nomenclature.

It took between 6 and 50 days to deliver medicines from the central warehouse to regional warehouses and hospitals, with an average of 35.2 days. There was considerable variation in the time taken from the date the MoH order was issued to the receipt of medicines at regional warehouses. Also, neither the MoH, nor SoE ‘Ukrmedpostach’, nor SoE ‘Ukrvaktsina’ announce the dates when medicine will be delivered to the regions.

Physicians identified the following problems with the delivery system: lack of an officially approved formula for calculating the need for medicines; lack of diagnostics (3 physicians); insufficient financial resources allocated to purchase medicines to meet 100% of demand (5); irregular and unpredictable schedule of medicine deliveries during the year (5); periods when preventive medicines are out of stock; and the impossibility of planning treatment for 2–3 year-olds (5).

Their average level of satisfaction (on a 10-point scale) in 2019 with the volume of medicines purchased was 7.2 points, and with the stability of supply 6.0 points.

All of the patients surveyed received free medicines purchased from the state budget. The main problems they identified were delays in deliveries of free medicines (82% of patients), interruptions to their treatment (72%), and unavailability of medicines at pharmacies (67%).

**Children with mental and behavioural disorders (autism spectrum disorders, schizophrenia, affective disorders, hyperkinetic disorders)**

The monitoring was conducted in three regions of Ukraine and covered 20 medicines (Annex 16).

The total number of children with mental and behavioural disorders in the regions where the monitoring was carried out came to 1 040.

143 patients and 4 physicians were interviewed as part of the monitoring.

Deliveries of medicines took between 10 and 49 days from the date the orders were issued by the MoH to their arrival at health care facilities. Delivery of medicines by SoE ‘Ukrvaktsina’ to local warehouses took between 6 and 28 days, while onward distribution across the oblasts took a further 3–20 days. These medicines are used for outpatient and home treatment of patients.

Two thirds (64%) of the doctors said that the existing budget only covered about 80% of the need for free medicines for children. They identified as problems the absence of an officially approved formula to calculate the need for medicines and communication problems between the MoH, HDs and HCFs. A quarter of the doctors complained that the medicines delivered were close to their expiration dates.

77% of patients received free medicines, although a similar number also bought medicines.

It was found that free medicines procured from the state budget were available only to patients with autism spectrum mental disorders. Patients with other mental disorders only started to receive free medicines in 2018-2019 and previously had to buy them from their own pockets.

Among the main problems identified by patients were an insufficient quantity of medicines (59%), delays in deliveries (41%) and the high cost of medicines in pharmacies (41%).

**Juvenile rheumatoid arthritis**

The monitoring was conducted in five regions of Ukraine and covered 10 medicines (Annex 16).

The total number of children with juvenile rheumatoid arthritis in the regions where the monitoring was carried out came to 204.

83 patients and 4 physicians were interviewed as part of the monitoring.

Logistical delays occurred periodically between the date that the MoH order was issued and the dispatch of medicines from the central warehouse to the regions (up to 15 days). Thereafter, delivery by SoE ‘Ukrvaktsina’ and then Ukrmedpostach from the central warehouse is made within one day.

Three of the four doctors interviewed think the full need for medicines is satisfied. Two of them noted the problem of insufficient funding for this nosology and the absence of Etanercept/Enbrel from the National List of Essential Medicines. Three of the four doctors reported delays, interruptions and irregular deliveries of medicines. Two of the doctors mentioned that it was impossible to undertake long-term planning (2–3 years ahead) of medicine supplies.

The system for procuring, distributing and delivering medicines to treat children with resistant JRA does not yet ensure the provision of high-quality care for all patients. An important factor restricting patients’ quality of life and their satisfaction with treatment is the lack of home and outpatient treatment. Doctors and patients noted an insufficient quantity of medicines that are provided centrally, while parents (or legal representatives) considered it an even more significant problem that there is not a stable supply, which leads to interruptions in treatment. The absence of deliveries of medicines to the regions from September 2019 shows that this process depends on political will. Also, the availability of public information on the delivery and use of medicines varies by health care facility.

**Reagents for mass screening of newborns for phenylketonuria, congenital hypothyroidism, cystic fibrosis and adrenogenital syndrome**

The monitoring for this programme was performed in Cherkaska oblast, where 8,523 newborns were registered as of 31 December 2018. All babies were screened for rare orphan and genetic diseases, except for three cases when the parent refused to allow it.

There were shortfalls in deliveries of six of the seven reagents ordered in 2018–2019, ranging from 13% to 28%. There was only one reagent where deliveries met 100% of the actual need. Deliveries were delayed for up to 10 months, although the need for the current year was covered by the medicines delivered the previous year.

The doctor interviewed noted the erratic timing of deliveries, and the inability to predict the exact number of births and to calculate the exact need for reagents. Deliveries of reagents were not optimally distributed over time, and some reagents were close to their expiration date due to delayed delivery.

**Orphan diseases (bullous epidermolysis, pulmonary hypertension, cystic fibrosis, mucopolysaccharidosis)**

The monitoring was conducted in all regions of Ukraine and covered 41 medicines (Annex 16).

An online survey involved 47 doctors treating patients with orphan nosologies, as well as 13 health care departments of regional state administrations. The health care departments of Kyivska, Luhanska, Lvivska and Odeska oblasts did not provide any of the information requested in the survey.

A total of 479 patients from all oblasts of Ukraine were also interviewed, representing 29.4% of the 1,628 patients with orphan nosologies receiving treatment in the country.

The monitoring found that medicines and medical products/devices funded from the state budget failed to meet the full need of any of the orphan nosologies studied. For all nosologies, interruptions in deliveries of medical products were identified, caused by unjustified delays in deliveries from logistics operators to patients (up to 3–4 months from the time the order is issued by the MoH to the day they are received by the patient). The absence of patient registers makes it impossible to predict the need for medicines and observe their movement at all stages of delivery. Communication gaps between the MoH and the regions regarding expenditures for orphan nosologies, as well as between the regional health departments and specialized orphan disease centres, have been identified.

# Results of the 2020 study

**Treatment of patients with cerebral palsy**

The total number of patients with cerebral palsy in the study regions is 4,579 (as of 1 January 2020)[[5]](#footnote-5), while the prevalence is 2.56 per 1,000 live births. For the treatment of spastic forms of cerebral palsy, the following medicines are used: Botox, Botulax, Dysport, Xeomin, Lantox, Myotox, and Relatox (Annex 17).

The grantees interviewed 580 patients, 68 representatives of HCFs, 30 representatives of HDs in seven regions of Ukraine (see socio-demographic characteristics of the respondents in Annex 18).

The calculation of the need for medicines is based on data from the HD oblast (or city) state administrations on the number of children with cerebral palsy who need botulinum toxin therapy, broken down by administrative-territorial unit and indicating the month and year of birth and the diagnosis.

Key study results were the following: 24% of patients and 50% of HCF staff reported that HCFs was not provided with medicines to cover 100% of the need (80% of the HD representatives reported that the quantity of medicines ordered met 100% of the need); 69% of patients received information from the doctor about the delivery of their medicines to the HCF; 100% of patients received medicines in HCFs; 77% of patients refused to accept free medicines due to their low efficiency; 46% of patients are partially acquainted with the orders of the MoH, the nomenclature of medicines, relevant clinical protocols; 26% of HD representatives noted that the main problem was the significant delays to and interruptions in the receipt of medicines from the MoH (up to 21 days).

The main problems identified by the study were: insufficient number of medicines; lack of qualified specialists in the HCFs; insufficient rehabilitation support.

**Treatment of adults and children with** **haemophilia**

In Ukraine, according to the All-Ukrainian Register of Patients with Type A and Type B Haemophilia and von Willebrand disease, 1,730 adults and 633 children are enrolled inDA with various forms of inherited coagulopathies.

For the treatment of haemophilia and von Willebrand disease, human coagulation factor is used (Annex 17). Medicines for the treatment are not retailed and are procured exclusively within the state/oblast/city procurements.

In accordance with the orders of the MoH, medicines are distributed among regions in the amount proportional to the amount ordered by the region, without regard to the severity of the disease and the need for preventive treatment for patients with a severe form of disease[[6]](#footnote-6).

The grantees interviewed respondents in seven regions of Ukraine: for adults with haemophilia, 115 patients, 6 representatives of HCFs, 8 representatives of HDs; for children with haemophilia, 49 patients, 7 representatives of HCFs, 10 representatives of HDs (see the socio-demographic characteristics of the respondents in Annex 18).

Key study results for ‘adults with haemophilia’were as follows: 96% of patients received medicines intermittently; 97% of patients and 50% of HCF staff stated that 100% of need was not met (75% of HCF staff said that the reason is insufficient funding for this disease); 63% of patients bought medicines at their own expense on the black market (38% of the HD representatives were aware of such cases); 34% of patients received medicines in the inpatient facility of the HCFs (16% were given them for home treatment); 67% of HD representatives noted that the main problem was significant delays in and interruptions to the receipt of medicines from the MoH (on average the delay was up to 1 month).

Key study results for ‘children with haemophilia’ were as follows: 43% of patients received medicines intermittently; 96% of patients and 100% of HCF staff stated that 100% of need was not met (35% of HCF staff said that the reason is that there is no opportunity to plan supplies of medicines 2-3-years ahead); 33% of patients bought medicines at their own expense on the black market (57% of HCF staff and 40% of HD representatives were aware of such cases); 45% of patients received medicines in the inpatient facility of the HCFs and 35% were given them for home treatment; 67% of HD representatives noted that the main problem was significant delays to and interruptions in the receipt of medicines from the MoH (on average the delay was up to 1 month).

The main problems identified by the study were: absence of preventive treatment; absence of retail sale of medicines; delay in delivery of free medicines (from the MoH), which led to interruption of treatment; lack of free medicines; insufficient supply of medicines (patients reduce the dosage to economise on medicines); insufficient communication at all levels.

**Treatment of adults and children with hepatitis B and C**

According to unofficial data, as of 2018, about 3% of the population is infected in Ukraine, and in the period from 2008 to 2018 the incidence increased at least by a factor of 8. The main treatment of HCV consists of the use of direct-acting antivirals – viral protease and polymerase inhibitors (Annex 17). Medicines are procured centrally at the expense of the state budget.

Methodological recommendations for planning and calculating the need of medicines for patients suffering from chronic hepatitis B and C were approved by the MoH only in 2019[[7]](#footnote-7).

The grantee interviewed respondents in one region: for adults with hepatitis B and C, 150 patients, 3 representatives of HCFs, 6 representatives of HDs; for children with hepatitis B and C, 26 patients, 2 representatives of HCFs, 2 representatives of HDs (see socio-demographic characteristics of the respondents in Annex 18).

Key study results for ‘adults with hepatitis B and C’ were as follows: 87% of patients received medicines without interruption; all HCF staff noted the lack of medicines for the treatment of this disease; all representatives of HDs acknowledged the problem of insufficient provision of patients’ need in medicines (51-75% of the need for medicines is covered); 99% of patients are unaware of the existence of any local support programmes; 50% of patients received medicines in the inpatient facility of the HCF.

Key study results for ‘children with hepatitis B and C’ were as follows: 42% of patients received medicines without interruption; 46% of patients stated that 100% of their need was not met (HCF and HD representatives noted the coverage of need at 51%-75%); 42% of patients bought medicines at their own expense; in 100% of cases, representatives of HDs inspected left-over medicines in the HCFs.

The main problems identified by the study were: insufficient adherence of patients to treatment; lack of free medicines in HCFs; irregular supply of medicines during the year; significant delays and interruptions in supply; unavailability of medicines in the pharmacy; delays in the supply of free medicines; and the unaffordable price of medicines.

**Treatment of patients with multiple sclerosis**

According to the MoH, there are about 20,000 patients with MS in Ukraine, while in needs planning for 2019, the regions declared a need for only 3,500 patients[[8]](#footnote-8). Medicines are procured centrally at the expense of the state budget (Annex 17).

The grantee interviewed 572 patients, 14 representatives of HCFs, and 5 representatives of HDs in five regions of Ukraine (see socio-demographic characteristics of the respondents in Annex 18).

Key results of the study were as follows: 35% of patients received medicines intermittently; 87% of patients stated that 100% of their need was not met (100% of HCF staff noted an insufficient number of medicines); 57% of patients bought medicines at their own expense; 3 out of 5 HD representatives surveyed indicated that up to 25% of the need for medicines was met; 48% of patients received medicines while in hospital and 27% were given them for home treatment.

The main problems identified by the study were: interruptions in the supply of medicines, which led to interruption of treatment; inability to redistribute medicines to other HCFs; impossibility of giving medicines for home treatment; unaffordable price of medicines.

**Treatment of patients with** **tuberculosis**

According to available statistics, in 2019, more than 20,500 new cases of the disease were detected and, in 2018, 3,695 Ukrainians died from this disease.

The calculation of need for medicines to treat TB is based on standardized approaches for determining the need of each administrative-territorial unit; unused stock, guaranteed deliveries, and the list of first and second line ATBM; daily dose, frequency of reception, duration of treatment; formula for calculating gap between appointments for first and second line ATBM[[9]](#footnote-9).

The grantee interviewed 704 patients, 11 representatives of HCFs, and 5 representatives of HDs in five regions of Ukraine (see socio-demographic characteristics of the respondents in Annex 18).

Key results of the study were as follows: 95% of patients received medicines without interruption; 22% of patients and 82% of HCF staff reported that the HCF was not supplied with 100% of medicines to meet needs; 56% of patients received information from the doctor on the delivery of medicines to the HCF; 2% of patients reported that they bought medicines necessary to treat their main diagnosis at their own expense (18% of HCF staff and 40% of HD representatives were aware of such cases); 43% of patients received medicines in hospitals or HCFs, and 36% of patients were given them for home treatment.

The main problems identified by the study were: patients' needs for food, vitamins, financial assistance were not covered; patients' fear that the diagnosis would be disclosed; lack of psychological support for medical workers.

**Treatment of adults and children with** **oncology**

According to the NCR, as of 1 January 2019, about one million cancer patients (975,301 people) were registered in Ukraine. Every year in Ukraine, about 140 thousand adults and more than 1,000 children are diagnosed with cancer for the first time. In 2018, almost 65,000 people died of cancer, of which 35% are people of productive age. According to the MoH, the cancer rate shows a stable increase of about 3% annually. Medicines are procured centrally at the expense of the state budget (Annex 17).

For adults with cancer, the grantees interviewed respondents in six regions of Ukraine: 441 patients, 20 representatives of HCFs, 8 representatives of HDs; for children with cancer, in three regions: 118 patients, 4 representatives of HCFs, 5 representatives of HDs (see socio-demographic characteristics of the respondents in Annex 18).

Key study results for ‘adults with cancer’ were as follows: 24% of patients received medicines intermittently; 78% of patients, 70% of HCF staff and 5 out of 8 HD representatives stated that 100% of need was not met (56% of HCF staff said that the reason is insufficient funding for this disease); 21% of patients bought medicines at their own expense on the black market (70% of HCF staff and 50% of HD representatives were aware of such cases); 24% of patients received medicines in the HCF, 46% in the pharmacy.

Key study results for ‘children with cancer’ were as follows: 97% of patients received medicines without interruption; 94% of patients, 100% of HCF staff and 100% of HD representatives stated that 100% of the need was not met (27% of HCF staff said that the reason for this situation was the impossibility of planning medicine supply 2-3 years ahead); 7% of patients bought medicines at their own expense on the black market (100% of HCF staff and 60% of HD representatives were aware of such cases).

The main problems identified by the study were: irregular supply of medicines throughout the year; the impossibility of redistributing medicines to other HCFs in the region; significant delays to and interruptions in the supply of medicines; lack of medicines in HCFs at certain periods, as well as medicines being supplied that cannot be used in full due to their limited shelf life and expiration.

# Results of the 2017-2020 studies: analysis of changes and trends

Analysis of budget programme 2301400, ‘Provision of medical measures of certain state programmes and complex policy measures’, showed that state financing in 2017-2020 for most funding streams for common diseases increased in the course of the period when public monitoring was conducted (Annex 19). Thus, in 2019, state funding increased by comparison with 2016 for:

* budget line ‘children with oncology and oncohaematology’ – by 4.6 times (UAH 1 628.7 mln in 2019);
* budget line ‘adults with haemophilia’ – by 3.5 times (UAH 463.7 mln in 2019);
* budget line ‘children with haemophilia’ – by 2.9 times (UAH 484.7 mln in 2019);
* budget line ‘oncology’ – by 43% (UAH 568.8 mln in 2019);
* budget line ‘HBV, HCV’ – by 12% (UAH 135.9 mln in 2019).

At the same time, funding for certain budget lines decreased during the period when public monitoring was conducted. In particular, compared to 2016, state funding had decreased in 2019 for the budget line ‘children with chronic viral hepatitis’, by 61% (UAH 3.1 mln in 2019).

Also, the key performance indicators under budget programme 2301400, ‘Provision of medical measures of certain state programmes and complex policy measures’, were changed during the reporting period (Annex 20).Thus, in 2019 the target number for the population included in the budget programme increased, by comparison with 2016, only for children with haemophilia – by 26% (670 persons in 2019).

However, the target number for the population included in the budget calculations decreased in 2019, compared to 2016, for certain groups:

* adults with oncology – by 0.1% (134 330 persons in 2019);
* children with oncology and oncohaematology – by 13% (1 222 persons in 2019);
* adults with haemophilia – by 14% (1 633 persons in 2019);
* patients with viral hepatitis B and C – by 56% (6 000 persons in 2019).

**Results of the 2019-2020 studies: children with haemophilia**

In the 2019 study, the grantees interviewed 118 parents (or their legal representatives) and 5 representatives of HCFs (five regions) and, in the 2020 study, they interviewed 49 patients (or their legal representatives), 7 representatives of HCFs, and 10 representatives of HDs (seven regions).

The monitoring in the 2019 study covered 22 medicines, and in 2020, 20 medicines (the list differs from that of medicines for adults with haemophilia).

The results of the 2019 monitoring indicate patient satisfaction of their medicine needs at an average level of 50% (from 20% to 100% depending on the type of medicines). However, in the 2020 study, the patients rated their level of satisfaction with the volume of medicines and the stability of their supply at an average of 2 points (out of 10 possible).

Also, delays in supplying ordered medicines from the central warehouse to regional warehouses and HCFs remained the core problem, but the time significantly decreased: from 6-37 days (2019 study) to 1 month (2020 study).

For both reporting periods, similar problems were identified: absence of preventive treatment, absence of retail sale of medicines, delay in delivery of free medicines, lack of free medicines for acute cases.

**Results of the 2018-2020 studies: adults with haemophilia**

In the 2020 study, the grantees interviewed more respondents than in the 2018-2019 studies: in 2018, 101 patients, 5 representatives of HCFs (four regions); in 2019, 28 patients and 1 representative of HCF (one region) and, in the 2020 study, 115 patients, 6 representatives of HCFs, 8 representatives of HDs (seven regions).

The monitoring in 2019 24 medicines, and in 2020 20 medicines (the list differs from that of medicines for children with haemophilia).

Patients’ satisfaction with the volume of medicines and the stability of their supply remained very low, at an average of 2 points (out of 10 possible in the 2020 study), while in the 2019 study the average was 3 points.

Also, delays in supplies of ordered medicines from the central warehouse to the regional warehouses and HCFs remained the core problem and the length of the delay increased: from 7 days (2019 study) to 1 month (2020 study).

Some positive changes can also be found: in the course of the reporting period, it became possible to obtain medicines for ‘home treatment’. This results in a decrease in the percentage of hospitalizations of patients in critical bleeding conditions.

For the 2018-2020 reporting periods, similar problems were identified: absence of preventive treatment, absence of retail sale of medicines, delay in delivery of free medicines, lack of free medicines at HCFs.

**Results of the 2018-2020 studies: paediatric oncology**

The number of respondents interviewed within the monitoring in 2020 was lower than in previous rounds, due to the grantee’s decision to concentrate on monitoring in three regions in contrast to four regions in 2018 and five regions in 2019. Hence, 203 patients were interviewed in 2018, and 118 patients, 4 representatives of HCFs and 5 representatives of HDs in 2020.

The monitoring in the 2020 round covered 29 medicines, compared with 18 medicines in 2019.

Most of the medicines procured with funding from the 2018 budget were delivered to central warehouses during the first three months of 2019, which indicates a positive change in a medicine supply process previously characterized by significant delays. However, in 2019, the HCFs received medicines which had been ordered through the budgets of 2019 and 2018, and separate deliveries from 2017.

The monitoring carried out in 2019 revealed an insufficiency in the amounts of medicines, as a result of certain medicines not being included in the National List and of the limited funding allocated to the regions, which did not allow them to order the amount of medicines needed for the treatment. In 2020, interviewed HCF staff reported the same problem (50% of the staff noted that the need is covered up to 76%-99%, and 50%, up to 51%-75%).

None of the patients interviewed within all rounds of monitoring were asked for an illicit payment (so-called ‘thanks’) to receive or accelerate the receipt of medicines that the patient ought to receive free.

The number of patients who refused to receive medicines offered free of charge in 2019 decreased in comparison with 2018. According to the results of the monitoring carried out in 2019, 11% of parents refused to receive certain medicines (generics) due to their producers’ low credibility. In contrast, no respondents reported such cases in the 2020 monitoring.

The level of patients’ satisfaction with the quantity of medicines and the stability of supply was estimated at an average of 8 points (out of 10 possible) as regards both the 2016-18 period and 2019. The HCF staff rated satisfaction with the quantity of medicines at the same level, while satisfaction with the stability of the supply of medicines was assessed at 6 points in 2019 and 5 points in 2016-2018.

The major problem with the supply and provision of medicines that respondents mentioned in all years of the monitoring related to interruptions in the supply of medicines, the impossibility of planning medicine supply 2-3 years ahead, insufficient funding for this disease, lack of necessary medicines in the National List and lack of regulations for calculating 100% need of medicines.

**Results of the 2017 and 2020 studies: adult oncology**

The number of respondents interviewed within the monitoring was almost equal in both rounds of the monitoring: 472 patients and 6 representatives of HCFs in the 2017 study (four regions), and in the 2020 study, 441 patients, 20 representatives of HCFs and 8 representatives of HDs (six regions).

The monitoring in the 2017 round covered 17 medicines, compared with 29 medicines in 2020.

The monitoring conducted in 2020 reaffirmed the logistic problems revealed in 2017. In particular, major delays in supplies which took place in 2016 occurred at the level of the central warehouse of the MoH, with medicines having been delivered to the HCFs more than a month after they had been transferred to the central warehouse by UNDP. This problem persisted in 2018, as it took between one day and a month from the issuance of the order of the MoH to the receipt of medicines in the HCFs, and from 2 weeks to 9 months from the date of delivery to the warehouse of SoE ‘Ukrmedpostach’ to the delivery of medicines to the HCF. Irregular supply of medicines throughout the year, significant delays in the supply of medicines, lack of medicines in HCFs at certain times, as well as medicines being supplied that cannot be fully used, due to their limited shelf life, resulted in interruptions in the provision of medicines to patients.

It should be noted that in 2017 medical staff reported that the quota they were allocated for the treatment of patients with cancer corresponded to only 10% of the existing needs. Even though 70% of the HCF staff interviewed in 2020 also reported a lack of medicines, their estimates of needs coverage were more positive, compared to those made in 2017: 47% of staff thought that the coverage of the need was 51%-75%, 47% thought it was 26%-50% and 7%, up to 76%-99%.

In 2019, the level of patients’ satisfaction with the quantity of medicines and the stability of supply was estimated at an average of 6 points (out of 10 possible), compared with 4 points for the period from 2016 to 2018.

As revealed by the monitoring done in 2020, only 2 patients (1%) were asked for an illicit payment (so-called ‘thanks’) to receive or accelerate the receipt of medicines that the patient ought receive free. It is worth mentioning that, based on the results of the 2017 monitoring, the number of patients who had faced this problem came to 10%.

At the same time, the number of patients who refused to receive medicines offered free of charge in 2019 increased by 10%, compared with the data collected in 2017. The main reasons for their refusal were alleged side effects and low efficiency of the offered medicines.

Both reporting periods were also characterized by similar problems relating to insufficient funding for the procurement of medicines, lack of necessary medicines in the National List, insufficient awareness among patients of the nomenclature of medicines, clinical protocols related to the treatment of cancer, and the provision of medicines.

**Results of the 2017, 2019 and 2020 studies: children with viral hepatitis[[10]](#footnote-10)**

In the 2017 study, the grantees for the disease ‘children with chronic viral hepatitis’ interviewed 65 patients (or their legal representatives) and 4 representatives of HCFs (4 regions). And in the 2020 study, it was 49 patients, 7 representatives of HCFs, and 10 representatives of HDs (1 region).

The monitoring in 2020 it was 11 medicines (including 2 medicines for children with chronic viral hepatitis).

All studies identified delays in the supply of medicines in the surveyed region, from 7-42 days in the 2017 study to 2-34 days in the 2019 study. Moreover, this problem persists in the 2020 study – only 42% of respondents received medicines without interruption.

At the same time, the situation has worsened with covering the needs of patients with the appropriate amount of medicines: while in the 2017 study, the HCF staff reported that deliveries fully covered the needs of patients, in 2019 the coverage level was identified at 57%, and in the 2020 study it was 51-75%.

The situation also changed with patients' access to and usage of free medicines: in the 2017 study, 100% of the surveyed patients received medicines free of charge; in 2019, 78% of patients received them free of charge; and in 2020, 42% of patients bought medicines using their own resources.

In the context of the above, there was a change in the distribution of patients who receive medicines at the beginning of their treatment: 97% in the 2017 study and 85% in the 2020 study.

The level of patient satisfaction with the quantity of medicines and stability of supply in 2019 was estimated at an average of 7 and 9 points respectively (out of 10 possible), while the level of patients’ satisfaction with the quantity of medicines in 2016-2018 was estimated at an average of 8 points. The HCF staff assessed the level of satisfaction with the quantity of medicines and the stability of their supply at an average of 4 points.

The major problem with the supply and provision of medicines that respondents mentioned in all years of the monitoring related to irregular supply of medicines throughout the year, significant delays and interruptions in supply, lack of medicines in the HCF at certain intervals, incorrect sequence of supplies, and supplies of expired medicines.

# Effect of UNDP procurement on the delivery and availability of medicines at the local level

In the impact assessment of the UNDP Low-Value Grant Programme ‘Public Monitoring of the Delivery and Availability of Medicines at the Local Level’, 11 grantees participated who were involved in the public monitoring of medicines in the course of 2017-2020.

According to the survey results, 55% of grantees were involved in activities aimed at sharing their experience of performing public monitoring or providing technical assistance to other CSOs as the result of participation in the UNDP Low-Value Grant Programme. 45% of respondents were not involved in such activities.

In this regard, the grantees provided support and experience-sharing in the following areas:

* conducting analytical research (including data collection) and developing the resulting reports;
* conducting monitoring of medicines in HCFs;
* analyses of delivery of medicines while the regional application was being prepared;
* data collection skills and training interviewers.

In the medium- and long-term, this could mean that the experience of using methods, approaches, and tools in management and planning which have proven their effectiveness and success over time can also be applied to address similar problems in similar circumstances.

Also, it is important to note that, in 73% of cases, grantees named the involvement of CSOs in the process of monitoring medicine supply as one of the reasons for changes in the process of medicine supply and the amounts and availability of medicines in the regions.

Moreover, the effect of UNDP procurement on the delivery and availability of medicines at the local level could be described from the perspective of success gained by grantees through advocacy over the period from 2017 to 2020, particularly:

* participation in the development of local and regional programmes to provide patients with medicines for the treatment of certain diseases and with the aim of procuring social support services for the patients;
* participation in discussions focused on increasing state funding for existing budget programmes;
* participation in developing new budget programmes;
* participation in developing the ‘Concept of development of the system of medical care for citizens suffering from rare (orphan) diseases for 2021-2026’;
* conducting training events for medical practitioners to create a network of professionals across the regions;
* the gradual introduction of ‘home’ and preventive treatment;
* conducting awareness campaigns among the target population.

Along with this, the grantees highly valued the long-term effect of participation in the Programme. Thus, 8 out of 11 grantees will be able to implement similar public monitoring activities independently because these organizations have experience of cooperation with international organizations (systems of programme and financial reporting, monitoring and evaluation, learning new tools and working approaches). 2 other grantees will be able to implement similar public monitoring activities only with support from other donor organizations. For the future, when the programme is no longer available, the probability of maintaining positive effects in using the results of public monitoring remains high.

All respondents stated that participation in the Programme helped them not only to be involved in improvements in the quantities of medicines but also to influence the involvement of civil society in planning processes, working with patients, etc.

Respondents particularly mentioned the following positive effects:

* information received while conducting public monitoring was actively used in further advocacy work, and as result advocacy activities were successfully implemented;
* information collected on the actual use of medicines was taken into consideration when medicines were being planned as part of 5 state programs;
* during the public monitoring of medicines, communication links were established with patient communities;
* the public was widely informed about access to free medicines and the possibility of obtaining information about their availability.

In summary, it could be noted that the grantees surveyed appreciated their participation in the Programme in terms of the effect on the delivery and availability of medicines at the local level. Moreover, for many of them, this effect can also be measured by the possibility to collect, analyse, and present reliable and useful information on certain diseases. From a long-term perspective, this would give them the chance to be proactive at local level to actively participate in the decision-making process to improve the access and availability of medicines across the regions.

# Dynamics of supply chain processes: level of implementation of the report’s recommendations

Lack of financing for the procurement of medicines was noted by grantees as one of the key challenges which prevents the proper satisfaction of patients’ needs for medicines. 7 grantees stated that according to the results of the monitoring undertaken by them, an increase in the quantities of medicines was made possible through the support provided by UNDP within the project ‘Procurement Support Services to the Ministry of Health of Ukraine’, even with the existing shortfall in funding. According to 4 grantees, supplies of medicines increased by up to 25%. 2 grantees mentioned that amounts increased by 26%-60%, and 1 grantee, by 61%-75%.

The reasons which, according to grantees' responses, have facilitated the changes in the process of medicine supply and the quantities and availability of medicines include:

* a lower level of corruption in the process of medicine procurement;
* cost-effectiveness, transparency and timeliness of procurement due to involvement in the process of UNDP and other international partners;
* increased structural and human capacity to plan, forecast, control and evaluate deliveries to ensure transparent and cost-effective procurement; and
* involvement of CSOs in the process of monitoring medicine supply.

Although external (international) support may remedy the situation in the short term, improved governance over the long term must come from and belong to the country and its citizens. This is why civil society organizations (CSOs) play a critical role among those who participate in, legitimize, and approve public policies and actions. These organizations are also the watchdogs that oversee the activities of political regimes and public authorities. Finally, they contribute to national development efforts.[[11]](#footnote-11)

A consolidated report for each round of the Programme summarized the findings regarding needs of regions, distribution of medicines, quantity of medicines available at HCFs, patient satisfaction, difficulties encountered by patients and recommendations to the MoH, HCFs, HDs and NGOs.

9 of the grantees indicated that the recommendations provided by them as part of the Programme were taken into partial consideration when planning the demand and delivery of medicines in the years following the organization’s participation in the Programme. 2 grantees stated that their recommendations were not considered at all.

To trace the dynamics of implementation of the reports’ recommendations, grantees were asked to rate the level of implementation of the recommendations in the years following their organization’s participation in the Programme, on a scale from ‘1’ (not implemented at all) to ‘5’ (fully implemented) (Fig. 1).

|  |  |  |  |
| --- | --- | --- | --- |
| **Recommendations provided in 2017** | **Recommendations provided in 2018** | **Recommendations provided in 2019** | **Recommendations provided in 2020** |
|  |  |  |  |

**Figure 1. Dynamics of implementation of the report's recommendations**

According to the grantees' responses, the reasons which prevented the implementation of the recommendations to the fullest extent possible include:

* conflict between the MoH and the SoE ‘Medical Procurement of Ukraine’;
* lack of control by the MoH over the timely distribution of medicines;
* lack of responsibility for non-observance of delivery timelines;
* COVID-19 and related expenses;
* problems in communication between the MoH and HDs;
* insufficient funding of the health care system;
* lack of desire to cooperate on the part of HD representatives;
* bureaucracy;
* impossibility to make accurate calculations of 100% of the need for medicines.

Despite the fact that the recommendations were not implemented to the fullest extent possible, some of them were implemented through the advocacy efforts exerted by grantees.

Thus, for instance, in Rivnenska oblast a regional program of combating TB was approved for the first time in many years.

Another example of positive moves towards the improvement of the situation with medicine supply is an increase in state funding for existing programs to cover the needs of patients with orphan diseases. In addition, through a consolidated advocacy effort of civil society organizations, the 'Concept of Development of the system of medical care for citizens suffering from rare (orphan) diseases' for 2021-2026 was approved by the Cabinet of Ministers of Ukraine on 28 April 2021.

On a separate note, it should be noted that grantees note an increase in the level of patients’ satisfaction of their needs for medicines for treatment of oncology in adults.

The system of ‘home’ treatment of haemophilia and preventive treatment in adult patients are gradually being introduced.

Through advocacy activities within the framework Programme, the attention of HDs was drawn to the problem of proper preparation of orders for free-of-charge medicines and accurate calculation of needs for them.

# Conclusions

The system of medical procurements through international organizations, including UNDP, has reduced patient's refusal to accept free medicines, by ensuring the proper quality of medicines that are purchased. The high requirements and standards that UNDP establishes for its tenders means that the medicines procured are of exceptional quality and effectiveness, as unscrupulous producers cannot participate in the process.

Since 2017, UNDP has provided Low-Value Grants to selected executing organizations (patients’ organizations) to allow them to monitor the availability, monitoring and use of medicines procured. This would allow the patient community to become one of the driving forces behind the project and, simultaneously, a beneficiary of changes in the health care system. UNDP has been working with the patient community and civil society to help build a system of ‘checks and balances’ that will ensure public control over the agency’s future activities.

Due to the results of public monitoring of medicines, certain similar problems were identified for the whole monitoring period:

* insufficient funding allocated to each of the diseases;
* delays in supplies of medicines and medical products to HCF warehouses (and thus to patients). The core delay is in the issuance of orders by the MoH and HDs;
* lack of a notice system for deliveries from the MoH and SoE ‘Ukrmedpostach’;
* lack of stable delivery schedules throughout the year;
* lack of national (and local) patient registries as a tool for planning and decision-making;
* significant differences in the methods of calculating each region's 100% need of medicines;
* impossibility to procure from local budgets additional medicines not included in the National List;
* limited ways of checking the availability of free medicines. Not all of the HCFs included in the public monitoring under the project have webpages on [www.eliky.in.ua](http://www.eliky.in.ua) or [www.liky.ua](http://www.liky.ua), and those HCFs that do have web-pages do not necessarily update the information on them;
* lack of qualified specialists for the treatment of certain diseases;
* lack of specialized equipment for diagnostic services;
* weak level of communication between key parties of public monitoring (MoH, HDs, HCFs, NGOs, patients);
* lack of or limited home treatment in case of certain diseases;
* lack of retail sales of medicines for certain diseases;
* many respondents, both patients and physicians, do not have information about the existence of local treatment programmes;
* the level of satisfaction of physicians and patients with the organization of the procurement process and the stability of supplies indicates that the supply process was constantly improving in the period from 2015 to 2019;
* in most cases patients were not asked to make a charitable donation to receive medicines.

**Limitations**

* The study was carried out by six different NGOs, with different levels of research expertise.
* The grantees had a certain expertise in dealing with specific categories of patients, but the diseases monitored might not be relevant to the organisation's previous experience.
* COVID-related restrictions led to some delays in data collection and reporting by the grantees.
* The data collected in certain years of monitoring were analysed differently from the other studies due to the specificity of monitoring conducted in that particular year. Therefore, the results are not comparable to the results related to other years of monitoring.
* Finally, the participating organisations collected a considerable volume of material which could not be included in the final report in its entirety.

# Recommendations

**Recommendations for the MoH:**

* increase funding for the procurement of certain medicines;
* improve planning and implementation of procurement stages;
* setting and monitoring annual deadlines for decision-making at each stage of the order, purchase, distribution and use of medicines;
* ensure unimpeded communication and interaction between all stakeholders at each stage of decision-making;
* introduce an effective system of internal control over the use of medicines and medical products for the diagnosis and treatment of patients purchased with the state budget;
* analyse the need of changes to the National List in accordance with regional applications;
* develop a unified methodology for calculating the total need of medicines;
* review and, if necessary, update treatment protocols;
* ensure robust communication with the regions;
* create and ensure systematic updates of patients’ registers;
* develop methods and formulae for the case-management (observation) of patients;
* optimize the supply chain of medicine delivery;
* optimize the procedure for the issuance of orders for the distribution of medicines to regions;
* ensure availability of open-source information on the schedule of upcoming deliveries;
* organise an ongoing information campaign on disease prevention;
* consider the introduction of home treatment for patients;
* introduce a series of training courses for medical staff;
* introduce the practice of holding joint meetings and round tables with the participation of representatives of the MoH and NGOs;
* create a permanent Expert Council consisting of oncologists, haematologists, economists and statisticians to develop a regional quota for drugs, which would develop the necessary list of drugs for the following year, considering not only medical but also economic factors;
* develop a methodology for calculating 100% of the need for medicines at the regional level;
* improve communication between the MoH and the HCFs and make information available for physicians on the expected delivery times of medicines, which will allow better planning of patients' treatment;
* develop and implement an all-Ukrainian electronic system of accounting for medicines purchased at public expense, which will record the entire movement of the medicines from the MoH to the patient;
* legislate for the concept of ‘preventive treatment’ for patients with haemophilia;
* create a central warehouse where medicines will be stored and from where they can be transferred to regional oncohaematology departments in case of urgent need;
* continue to implement a system of treatment for haemophilia in primary care;
* allocate the budget among the regions taking account not only of the number of available patients, but also of the presence of inhibitory patients and the severity of the disease of each patient.

**Recommendations for HDs:**

* ensure free diagnostic services;
* introduction of home treatment;
* ensure unimpeded communication and interaction between all stakeholders at each stage of decision-making on the order and purchase of medicines;
* ensure referral of the patient, when necessary, to facilities that provide medical and social rehabilitation;
* involve a wide range of medical practitioners in determining the needs for medicines;
* organize training events for medical staff;
* monitor the side-effects of medicines;
* constantly conduct appropriate media and outreach campaigns among the population to increase knowledge of and motivation for prevention and treatment;
* create services for the provision of outpatient service to patients;
* initiate the development and approval of regional and local programmes to provide medicines to patients.

**Recommendations for HCFs/physicians:**

* ensure calculation of the individualized 100% need for each patient considering the severity of the disease, the need for preventive treatment and planned surgical interventions;
* strengthen interaction and cooperation with patients;
* intensify the processes of training (retraining) of medical specialists;
* create services for the provision of outpatient service to patients;
* involve representatives of patient communities in the process of adjusting the National List and creating applications for delivery of medicines;
* intensify joint educational campaigns to strengthen adherence to treatment;
* publish and update information on the availability of medicines and their delivery schedule;
* take measures to implement a patient-centred approach in patient care and treatment schedules.

**Recommendations for NGOs:**

* disseminate the experience and successful practices of this monitoring among the patient community at national and regional level, doctors and representatives of national and regional authorities;
* use the results of this monitoring to further advocate for access to timely treatment and prevention;
* conduct information campaigns with the involvement of media, meetings, training events for patients (patient associations) to raise awareness about the free treatment programme;
* together with representatives of the professional medical community, initiate the creation of a register of patients;
* information materials for patients should be in the public domain;
* ensure robust communication between HCFs and patients;
* participate in the formation of regional policy development;
* mobilize resources and implement education programmes, monitor the procurement and distribution of medicines;
* intensify awareness-raising campaigns on the rights of patients;
* participate in the development of methods and formulae for the case-management of patients;
* conduct constant monitoring of services provided to patients;
* disseminate the experience and best practices of the Project among the patient community at national and regional levels, doctors and representatives of national and regional authorities;
* use the results of the Project to further advocate for access to quality timely treatment and prevention of medicines.

# Annexes

1. UNDP, ‘Capacity Development: a UNDP Primer’, New York, 2009, p. 46. [↑](#footnote-ref-1)
2. By ‘timescale for deliveries of medicines’ is meant the time from the date the order is issued by the MoH for the distribution of medicines among regions to the date that medicines are received at the warehouse of the HCF. [↑](#footnote-ref-2)
3. UNDP refused to purchase this medicine in 2017-2018. [↑](#footnote-ref-3)
4. Council of Europe, ‘Resolution CM/Res (2017) 43 on principles concerning haemophilia therapies (replacing Resolution CM/Res(2015)3)’, Brussels, 2017,
https://www.edqm.eu/sites/default/files/resolution\_cm\_res\_2017\_43\_on\_principles\_concerning\_haemophilia\_ther apies.pdf. [↑](#footnote-ref-4)
5. Official responses received from relevant HDs in the regions. [↑](#footnote-ref-5)
6. [Methodological](https://moz.gov.ua/article/ministry-mandates/nakaz-moz-ukraini-vid-17122019--2498-pro-zatverdzhennja-metodichnih-rekomendacij-z-planuvannja-ta-rozrahunku-potrebi-v-likarskih-zasobah-produktah-specialnogo-harchuvannja-ta-virobah-medichnogo-priznachennja) recommendations on planning and calculation of needs on medicines were approved only at the end of 2019, i.e. the development of the order and distribution of medicines during 2019 took place without taking into account these methodological recommendations, as well as without individualized collection of medicine needs. [↑](#footnote-ref-6)
7. Order of the MoH No. 643 ‘On Amendments to the Order of the Ministry of Health of Ukraine No. 829 of 25 September 2013’ dated 22 March 2019. [↑](#footnote-ref-7)
8. Source: <https://moz.gov.ua/article/news/ukraina-zakupila-visokoefektivni-liki-proti-rozsijanogo-sklerozu>. [↑](#footnote-ref-8)
9. Order of the MoH No.1062 ‘On approval of the Methodology for calculating the need for anti-tuberculosis medicines’ dated 12 October 2016 and the order of the MOH No.530 ‘On approval of health care standards for tuberculosis’ dated 25 February 2020. [↑](#footnote-ref-9)
10. The result of the studies may differ from year to year due to changes in the title of the surveyed disease: in 2017 – ‘children with chronic viral hepatitis’, in 2019, ‘HBV, HCV’ (no differentiation on adults and children), in 2020, ‘children with hepatitis B and C’. [↑](#footnote-ref-10)
11. UNDP, ‘UNDP and Civil Society Organizations’, New York, 2001, p. 2. [↑](#footnote-ref-11)