PUBLIC MONITORING GUIDELINES
Delivery, Availability and Use of Medicines at the Local Level
These Guidelines were produced as a result of the United Nations Development Programme (UNDP) small grants project ‘Public Monitoring of the Delivery, Availability and Use of Medicines at the Local Level’ undertaken in 2017 and 2018. They reflect input from project implementing partners and a wide range of stakeholders.

This is a hands-on advisory paper explaining how patient organizations, non-governmental organizations (NGOs) etc. can publicly monitor the availability of medicines in any country.

These Guidelines aim to contribute to the fair and transparent provision of free medicines to patients, in particular by helping civil society organizations (CSOs) promote necessary change, take advocacy steps to protect patients’ rights and prevent discrimination.

These Guidelines are designed primarily for non-government organizations (NGOs), patient organizations and communities. In addition, they may be useful for representatives of the Ministry of Health (MoH), health care departments of regional administrations, health care facilities, decision makers, logistics partners, international donors, the media and students.

The Guidelines outline the basic concepts and definitions related to public monitoring of medicine availability, suggest best practices of public monitoring projects conducted in Ukraine, and provide step-by-step instructions on how to publicly monitor the availability of medicines.
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## Glossary

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<tr>
<td><strong>ANALYSIS</strong></td>
<td>A certain stage of assessment that entails the interpretation and comparison of data using the appropriate techniques. Analysis is a process of decomposing the whole into parts, to investigate the causes of a situation under review.</td>
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<td><strong>ASSESSMENT</strong></td>
<td>The process of collecting and analysing information and drawing conclusions from it. It can be non-systematic. The term ‘assessment’ is somewhat different from the term ‘evaluation’: the latter is used as a specific term within project management (for the evaluation of projects and programmes), while assessment is more commonly used.</td>
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<tr>
<td><strong>BENEFICIARIES</strong></td>
<td>Individuals, groups or organizations that directly or indirectly benefit from a programme/project.</td>
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<td><strong>BEST PRACTICES</strong></td>
<td>The experience of using methods, approaches and tools in management and planning that have proven their effectiveness and success over time and can be applied to address similar problems in similar circumstances.</td>
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<td><strong>CAPACITY-BUILDING</strong></td>
<td>A process by which individuals, groups, organizations and countries develop, increase and organize their resources, knowledge and management procedures, which in combination translates into their ability to meet specific objectives, formulate goals and achieve them, both individually and collectively.</td>
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<tr>
<td><strong>CIVIL SOCIETY</strong></td>
<td>A field of social relations outside the family, the government and business where people come together to satisfy and/or promote common interests and uphold common values.</td>
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<td><strong>CIVIL SOCIETY ORGANIZATIONS</strong></td>
<td>NGOs, professional and creative unions, employers' organizations, charitable and religious organizations, bodies of self-organization of the population, private mass media and other non-profit associations and institutions whose activities are regulated by the legislation of Ukraine, and political parties not represented in the Parliament of Ukraine.</td>
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**EVALUATION**  
A systematic and objective study that can be carried out at different stages (design, implementation, finalization) of a programme/project. The goal of evaluation is to determine and quantify the programme/project’s achievements against objectives, progress, effectiveness, efficiency, impact and sustainability of results. Evaluation provides reliable and useful information that integrates lessons learned and engages both decision makers and donors in the decision-making process, serves as the basis for managerial decisions, and improves the programme/project. Evaluation is also part of the process of determining the programme/project’s added value or sense.

**GENDER EQUALITY**  
Equal legal status of women and men and equal opportunities for its implementation that allow persons of both sexes to participate equally in all areas of social life.\(^4\)

**LESSONS LEARNED**  
Conclusions based on findings from programme/project evaluations that allow decision makers to obtain a more strategic vision from a specific situation. Normally the lessons learned highlight the strengths and weaknesses of a programme/project’s development and implementation that affect its performance and future outcomes. Lessons learned should be taken into account during the subsequent programme/project planning cycle or during the development of similar programmes/projects.

**MONITORING**  
The process of regularly collecting and analysing quantitative and qualitative data against predefined indicators to facilitate timely decision-making, accountability and the creation of a framework for training activities within the framework of the programme/project. Monitoring enables the accumulation of information that is necessary for evaluation.

**ORPHANE DISEASE**  
A disease that threatens a person’s life, or the chronic progress of which leads to a reduction in his or her life expectancy or to his or her disability, with a prevalence of no more than 1:2,000 people.\(^5\)

**STAKEHOLDERS**\(^6\)  
Organizations, groups or individuals that are interested in the results of a strategy/programme/project and may impact project development and implementation, as well as those who may be affected by the strategy/programme/project, both positively and negatively.

**SUSTAINABILITY**  
The probability of maintaining positive effects and political and financial support for the programme/project after the inputs (funding, materials, training) from donors/organizations that have implemented the programme/project are no longer provided, and of the achievement of long-term benefits from the programme/project. Depending on the context, the term can be used to mean sustainability of results, effects etc., including the sustainability of commodities, and should cover both environmental and social sustainability, taking into consideration the whole life cycle of the product.

**TARGET GROUP**  
Social groups, organizations or individuals that benefit from a programme/project. The target group includes all individuals affected by the programme/project, while specific individuals, organizations or social groups that benefit from the programme/project are its beneficiaries.

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<table>
<thead>
<tr>
<th>Abbreviation</th>
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<tr>
<td>CF</td>
<td>Charitable fund</td>
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<tr>
<td>CO</td>
<td>Charitable organization</td>
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<tr>
<td>CSO</td>
<td>Civil society organization</td>
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<tr>
<td>MoH</td>
<td>Ministry of Health</td>
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<td>NGO</td>
<td>Non-governmental organization</td>
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<tr>
<td>SDG</td>
<td>Sustainable Development Goal</td>
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<tr>
<td>SOA</td>
<td>State Oblast Administration</td>
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<td>UNDP</td>
<td>United Nations Development Programme</td>
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Section 1. Key notions of monitoring in general and public monitoring in particular. Public monitoring of availability of medicines and medical products

WHAT IS MONITORING, HOW IS IT CONDUCTED, AND HOW DOES IT RELATE TO PLANNING AND EVALUATION?

MONITORING is a process of regular collection and analysis of key data (indicators) to determine what progress has been achieved in a process or development.

Key components of monitoring are:
- indicators, targets and actual progress against them;
- regular collection of data to compare actual progress against indicators; and
- matching targets to actual progress, to determine success or deviations.

STAGES OF MONITORING

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
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<tr>
<td>Planning</td>
<td>Determining needs for information (indicators of the implementation of measures, achievement of goals etc.) and who requires the information. Determining how often information should be collected. Identifying sources and methods for obtaining information. Determining the person responsible for collecting information. Determining the costs of monitoring and collecting information.</td>
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<tr>
<td>Preparation</td>
<td>Development and testing of documents for collecting and recording data. Producing job descriptions (terms of reference) that specify the functions of those responsible for the monitoring process. Providing training to the staff responsible for monitoring. Training programme staff to use the monitoring system.</td>
</tr>
<tr>
<td>Data collection</td>
<td>Permanent collection of identified data. Oversight over how the monitoring is conducted.</td>
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INTERCONNECTION AND INTERDEPENDENCE BETWEEN PLANNING, MONITORING AND EVALUATION

PLANNING is a process of setting goals and developing strategies, programmes, projects or mechanisms for the provision and use of resources to achieve those goals.

MONITORING is a process by which stakeholders regularly receive information on the progress to achieve the goals and objectives of the strategy/programme/project in terms of its results.

EVALUATION is a thorough and independent measurement of an already completed or ongoing activity, to determine the level of achievement of the goals and facilitate appropriate management decisions.

1.1. Fundamentals of monitoring

1.2. Public monitoring

Monitoring — the regular collection and analysis of key data/indicators — is actively used to observe general trends and changes in society.

Public monitoring is a particular form of social oversight made possible under a democratic rule of law and with a developed civil society. When public monitoring takes place, it is a confirmation of the democracy of the State and the government’s accountability to its citizens. In turn, social (or public) oversight is envisaged as a tool for the public to assess the extent to which the authorities and other entities are achieving their social objectives. Thus, the difference between public oversight and any other type of monitoring concerns the entity/subject that performs the oversight and its scope. First, public oversight is exercised precisely by the public (organized and unorganized). Second, the process of public oversight monitors the fulfilment of social objectives directly related to the protection and fulfilment of citizens’ rights and freedoms, ensuring and harmonizing the social needs and interests of the people.
Therefore, the **scope** of public monitoring covers the processes and phenomena of the social and political sectors that are important to the public. For example, the scope of public monitoring of the availability of medicines covers the delivery, availability and use of medicines procured from the state budget at the local level. The subjects involved are civil society institutions, individual citizens and informal associations of citizens, as well as representatives of other States with the appropriate powers.

The **goal** of public monitoring is to obtain **information** (data). Thus, it is practical rather than theoretical. It normally addresses a specific problem and can help identify and take specific action that can solve the problem or in some way improve the situation. Since public monitoring is a necessary part of establishing a dialogue between the authorities and the public, it enables the authorities to provide timely and open responses to citizens' proposals, taking into account **public opinion** on important state decisions, and establishing an **effective mechanism for public oversight**.  

**Why do we need public monitoring?**

**TO:**
- strengthen the role, visibility and impact of the public;
- offer an objective assessment of the performance of the authorities; and
- communicate the public’s needs to the authorities.

**TO PREVENT:**
- abuses of power and corruption; and
- restrictions on access to socially important information.

It is important to understand that public monitoring is not only about **obtaining** information, but also about its **processing** and **use** – namely:

- learning public and expert opinion on the decisions taken by the authorities on socially important matters;
- systematizing and summarizing various information at all levels of governance;
- analysing public opinion on the current situation and key challenges of various aspects of social life from different perspectives;
- analysing expert opinion on the current situation and key challenges of policymaking and implementation in various aspects of social life;
- learning the level of awareness and the dynamics of support for the implementation of managerial decisions in various aspects of social life among different population groups in Ukraine;
- learning the level of awareness among national experts on the current situation and key challenges of implementing managerial decisions in various aspects of social life;
- supporting the development of analytical papers to assess proposed decisions/solutions and inform decision-making in line with national policies in various aspects of social life; and
- improving the interaction between legislative and executive authorities in managerial decision-making.  

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In addition, public monitoring can be conducted at various levels:

- **national** — at the country level, it normally focuses on the activities of national authorities;
- **regional** — at oblast level or the level of several neighbouring oblasts that make up an economic or geographical region; or
- **local** — at the level of a district or a locality.

LIMITATIONS, RISKS AND BOTTLENECKS WHILE CONDUCTING PUBLIC MONITORING

It is necessary to identify possible limitations, risks and bottlenecks in the process of planning and conducting public monitoring. Some of these can be summarized as follows:

1. **Resistance from authorities.** This is the most serious bottleneck. As public monitoring aims to improve government policymaking and the quality of public services, its success depends largely on the commitment of the authorities to consider proposals from the public. It is possible to either demonstrate to the government the benefits of public monitoring or set up a powerful advocacy group to overcome resistance from the authorities.

2. **Lack of a strong and active civil society.** When the government is ready for public monitoring but there is no active civil society sector to mediate the process, monitoring becomes an issue. In this situation, citizens may have a negative attitude towards initiatives that come directly from the government.

3. **Lack of open information and/or limited access to information.** Information about monitoring should be publicized through the use of presentations, newsletters, publications, the media etc. It is also important that all stakeholders and the public are informed throughout the process. This ensures its transparency and facilitates public feedback, which in turn helps avoid many problems and mistakes.

4. **Absence of a qualified implementor.** Even if the authorities are committed to the public monitoring of their policies, in some cases there may not be any local organization that can carry out the monitoring. In this case, the most effective solution is to invite external experts that provide services at a higher rate. Another possible solution is to set up a local monitoring organization. Local government, together with the private sector, can set up such an organization by providing it with seed funding and committing to maintain its relative independence.

During the monitoring, organizations may encounter other obstacles (for example, a lack of information about the monitoring progress and the results; loss of confidence in the authorities and the public; loss of independence; attacks by the authorities etc.). Therefore, before starting the monitoring, it is important to understand which obstacles and problems may arise and take appropriate steps, such as: making a back-up plan for receiving and collecting information, preparing arguments in favour of public monitoring, finding allies in the media, authorities and civil society organizations, ensuring the independence of the organization to secure its reputation, and seeking legal protection.

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Given the decentralization reform currently taking place in Ukraine and the transfer of decision-making to the local level, public monitoring at the local level has never been more significant.

To sum up, public monitoring as a form of public/social oversight is a key indicator of public activism and the level of development of civil society, which is extremely relevant for Ukraine. On the one hand, public monitoring helps citizens fulfil their constitutional right to participate in social and political processes (according to the provisions of Article 5 – the people are the only source of power in Ukraine — and Article 38 – on the right of citizens to take part in public administration). On the other hand, it creates an efficient feedback mechanism to improve the performance of public and local authorities and ensure that social and political processes in Ukraine are in line with the legislation in effect.

1.3. Ethical standards of public monitoring

One of the prerequisites of successful public monitoring is to comply with professional and ethical standards. Ethical issues are some of the most vulnerable and thus require the most attention. Entities that conduct public monitoring should abide by the ethical standards of international organizations in the field of monitoring and surveys, such as the Code of Ethics of the World Association of Public Opinion Research.13

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**CODE OF ETHICS OF THE WORLD ASSOCIATION OF PUBLIC OPINION RESEARCH**

**EXCERPTS**

5. The objective study of facts and data, conducted as accurately as permitted by the available resources and techniques, is a guiding principle of all research.

7. The researcher shall in every report and other presentation of the findings distinguish her/his actual data from observations or judgments that may be based on other evidence.

10. Without prior authorization of the sponsor/client, no findings from commissioned research shall be disclosed by the researcher.

**III. Rules of practice between researcher and respondents**

*D. Responsibility to informants*

21. No informant, respondent or other research participant must be adversely affected as a result of his/her answers or of the research process. The researcher shall respect respondents’ decisions about their participation in the research and use no methods or techniques by which the informant is put in the position where they cannot exercise their right to withdraw or refuse their answers at any stage of the research.

22. No response in a survey or other research finding shall be linked in any way to an identifiable respondent. Respondents must remain unidentified, except in rare cases, with the respondent’s specific permission. The interview method or any other method employed by the researcher must never be used as a guise for other purposes such as marketing, sales solicitation, etc.

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23. For field interviews:
   a) The interviewer should not disclose the research objectives and materials, as well as the information received from the respondents to anyone other than the research organization that conducts the research;
   b) No information obtained through research should be used, directly or indirectly, for the personal benefit of the interviewer in his/her relations with the respondents.

Entities conducting public monitoring within a certain project should also comply with the ethical requirements of the donor. For example, entities monitoring the availability of medicines within the framework of UNDP projects should adhere to the fundamental ethical values of the United Nations, including:

- independence;
- loyalty;
- impartiality;
- integrity;
- accountability; and
- respect for human rights.

Therefore, irrespective of the scope of analysis, key ethical guidelines for entities conducting public monitoring should be: maximum impartiality and avoiding biased judgements; confidentiality; and a respectful attitude towards respondents.

1.4. The role of public monitoring of the availability of medicines: Who? What? Why?

1.4.1. WHY DOES THE STATE PROCURE MEDICINES?

The world community envisages the health care system as a global social good. Social (or public) means something that is used by all members of society. While health is of particular importance to everyone, its protection is not limited to individual efforts. It also requires the involvement of the State, as it relates to the level of economic development, quality of human capital, social expenditures, etc. Global means that this good is universal for all countries, people and generations.

Every country has developed its own policy on providing health care to its citizens. In Ukraine, the right to health care and the protection of health is enshrined in the Constitution (Article 49). According to the Constitution, the State shall provide conditions for health care that is effective and accessible for all citizens; health care in state and community-owned health facilities is provided free of charge.

The State guarantees to fulfil all citizens’ rights to health care, including “providing funding for the guaranteed amount of health care services and medicines to all citizens of Ukraine and other persons specified by law according to the procedure established by law”.

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16 Ibid., p. 86.
The list of health care services and medicines that shall be provided out of the State Budget of Ukraine is specified by the Programme of Medical Guarantees approved by the Verkhovna Rada of Ukraine as part of the State Budget of Ukraine for the respective year.\(^\text{18}\)

### 1.4.2. WHY SHOULD PUBLIC PROCUREMENT OF MEDICINES BE SUBJECT TO PUBLIC MONITORING?

There is a risk in low- and middle-income countries — such as Ukraine — that the government ignores the normative needs of society, which entails reducing funding for the health care system and shifting the burden onto patients, leaving them hostage to an imperfect institutional system.\(^\text{19}\) In such circumstances, the health care system loses its status as a public good.

Furthermore, as found in research,\(^\text{20}\) the health care sector is vulnerable to corruption, even in developed countries. In Ukraine, the unacceptable level of corruption was one of the key drivers of the Revolution of Dignity of late 2013 and early 2014, and the rationale for the international procurement of medicines.\(^\text{21}\)

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.\(^\text{22}\)

Therefore, CSOs play a key role in public oversight and ensuring the accountability of government and its agencies, including health care. Public monitoring of the availability of medicines is a significant way of ensuring that the State fulfils its obligations to uphold its citizens’ rights to quality health care.

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**ACCESSIBILITY OF MEDICINES**

Accessibility of medicines means:

- **Affordability**: medicines are provided by the government rather than bought at the patient’s expense. The process of providing medicines to a patient is free from corruption.

- **Geographical accessibility**: the medicines are available in the health care facility at which a patient receives treatment.

- **Information accessibility**: a patient is informed about his/her rights to receive medicines free of charge, the ways to protect his/her rights, and the availability of medicines at a health care facility.

- **Timeliness**: a patient receives medicines and starts treatment without delay.

WHO?  Implementing entities: civil society institutions, individual citizens, informal associations of citizens, and representatives of other States that have the appropriate authority.

Stakeholders: representatives of public authorities, health care facilities, patients and their legal representatives, representatives of communities of people living with diseases, media representatives, international organizations.

WHAT?
- Data on the terms and quantities of delivery of medicines procured by UNDP out of the state budget to the warehouses and health care facilities in the regions
- Information on the availability of medicines for patients.

WHY?  Why is it necessary for civil society, the State, patients, regional health care departments, health care facilities, the media (stakeholders)?
- It provides reliable information on the current situation (gaps, needs, perspectives).
- It facilitates communication between the stakeholders.

For the State
- Improved reputation, greater trust in the government (MoH)
- More effective use of funds by the MoH
- Developing recommendations for amending the legal framework
- Raising international technical aid.

For patients
- Awareness of opportunities to access medicines and medical products
- Reduced burden on family budgets
- Improved access to quality treatment
- Patients change from passive into active stakeholders
- Patients have a voice
- Communities of patients improve access to information, including on their rights and advocacy opportunities, expand networks and invite new members.

For health care departments/facilities
- Improved communications and logistics
- Improved competence of health care workers
- Improved transparency and accountability of medical processes
- Reduced corruption in health care sector.

For mass media
- Reliable socially important information for producing media stories
- Improved reputation, ratings, greater trust among the public.
1.4.3. THE ROLE OF NGOS IN PUBLIC MONITORING OF THE AVAILABILITY OF MEDICINES

Key functions of CSOs – including NGOs – encompass both ‘ethical’ (or ‘invisible’) functions, such as the protection of public values and building of social capital (trust, mutual support) among the members of society or a community, and ‘visible’ functions – service provision and public representation/public monitoring and oversight. In public monitoring of the availability of medicines, NGOs are both initiating and implementing agencies. Namely, they:

- represent the interests of a particular patient community;
- establish cooperation with partners and stakeholders;
- identify and highlight problems related to the delivery, availability and use of medicines in their regions;
- receive and provide strategically important information for decision-making by stakeholders; and
- offer solutions to identified problems and conduct advocacy activities, thus contributing to improving the procurement system and the process of delivery and use of medicines, increasing funding and improving the quality of health care and medicines.

1.4.4. WHY ARE PATIENT ORGANIZATIONS BEST SUITED FOR CONDUCTING PUBLIC MONITORING OF THE AVAILABILITY OF MEDICINES?

NGOs are very different in terms of their status, geographical coverage, objectives and activities, the sectors in which they operate etc.

Patient communities are interested like no other in ensuring that the process of procurement and provision of medicines meets the highest standards, because:

- they are the ultimate beneficiaries of health reform;
- they have a deep understanding of the specificity of their nosology, are familiar with treatment protocols and medicines, and are the most aware of the availability or absence of medicines and the quality of health care;
- they are not affiliated with other entities, which reduces the likelihood of conflicts of interest and corruption;
- they act as a bridge between the medical community (doctors, administrators), public authorities and patients; and
- patient associations concerned with specific diseases can talk to respondent patients on an equal footing.

As UNDP was able to see over the implementation of small grants projects on public monitoring of the availability of medicines in 2017 and 2018, patient organizations are best suited for carrying out monitoring. In addition, the voice of the patient community must be heard. It is important for patients to monitor the availability, management and use of procured medicines to improve ongoing issues.

Experience in implementing monitoring projects on medicine availability in Ukraine demonstrates that, ideally, patient organizations with an interest in a specific nosology should be engaged in the respective monitoring project. However, the experience of monitoring conducted in previous years also shows that if there is no specialized patient organization in certain regions, monitoring may be performed by an experienced NGO specialized in a different nosology, especially if the monitoring involves a small group of patients and/or their legal representatives and the range of medicines is small in scope.

1.4.5. PARTICIPATION OF STAKEHOLDERS IN MONITORING THE AVAILABILITY OF MEDICINES

The stakeholders involved in monitoring the availability of medicines include:

- civil society;
- patients and their legal representatives;
- representatives of communities of patients living with specific diseases;
- health care facilities;
- public authorities (health care departments);
- the mass media; and
- international organizations.

These stakeholders can play the following roles:

- **Customers of monitoring of medicine availability** – if your organization has not initiated the monitoring (grantees – Ukrainian CSOs or international organizations);
- **Informants** – survey participants, providers of information following paper-based requests (patients and/or their legal representatives; representatives of communities living with diseases; representatives of health care facilities and health care departments; representatives of logistics companies delivering medicines to warehouses in the regions);
- **Partners** – organizations or entities that will, if necessary, provide letters of support or otherwise help establish contact with informants (CSOs; international organizations; health care departments; representatives of communities living with diseases) or help organize advocacy activities following the results of public monitoring (CSOs, communities of people living with diseases), including:
  - **Information partners** – organizations or individuals that will help publish the results of monitoring through their information resources or groups/pages on social networks (media representatives; CSOs; international organizations; representatives of communities living with diseases); and
  - **Hidden opponents** – information providers that either refuse to provide the requested information or provide it in a distorted or incomplete form (often representatives of health care departments).

In addition, stakeholders operate at different levels:

- **International/external** – international organizations and MoHs that enable you to gain international public monitoring experience and can disseminate the results of your monitoring project internationally;
- **National** – the MoH, logistics partners that deliver medicines (which are a source of information on dates/terms of procurement and supply of medicines), as well as CSOs, communities of people living with diseases, and the media as information partners;
- **Regional/local** – health care departments, health care facilities, CSOs, patients and their legal representatives, communities of people living with diseases, and local media.
Also, by type of interaction, stakeholders can be divided into:

- those with which you will communicate directly – customers/donors; survey participants (representatives of health care facilities, patients or their legal representatives); potential mediators for the survey (representatives of health care facilities, representatives of communities of people living with diseases);
- those with which you will communicate indirectly (for example, through written information requests) – health care facilities, health care departments or information partners (media, CSOs);
- those whose information resources you will use – for example, the websites of the MoH, health care departments, logistics partners for medicine delivery; and
- those that may be targeted by your advocacy – the MoH, health care departments, health care facilities, communities of people living with diseases.

All these aspects have to be taken into account in planning and in undertaking direct interaction with the stakeholders. It is important to bear in mind that every stakeholder has its own values and mission. All stakeholders together are involved in the value chain of your public monitoring project. The situation is usually complicated by the fact that the stakeholders of one value chain are parties to many other value chains. Therefore, stakeholder planning should also include identifying and minimizing the risks of your collaboration.

In 2015, the AccountAbility Institute for Social and Ethical Reporting (London, UK) developed a Stakeholder Engagement Standard (AA 1000) that is recommended for general use when planning, conducting, evaluating, informing and performing non-financial audits of the quality of stakeholder engagement that can be used in public monitoring of medicine availability.

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Section 2. UNDP’s role in public monitoring of the availability of medicines

UNDP applies a multidimensional approach to support health care reform in Ukraine, drawing on key United Nations concepts such as the human rights-based approach, leaving no one behind, gender equality, women's empowerment, sustainability and resilience, and accountability.

UNDP’s work on health is based on the 2030 Agenda for Sustainable Development, the UN–Ukraine Partnership Programme (2018–2022) and the UNDP Strategic Plan (2018–2021). It is aligned with the strategies of its partners such as the UNAIDS Strategy (2016–2021), the Global Fund Strategy (2017–2022), the World Health Organization Global Plan for the Prevention and Control of Noncommunicable Diseases (2013–2020), and others.

In addition, UNDP’s work in the health sector relies on the belief that health is both a driving force and a result of development, and that actions across a wide range of development sectors have a significant impact on health outcomes. Therefore, to promote development efforts, UNDP focuses on addressing social, economic and environmental health issues, which primarily affect health inequalities. By investing in work on health, UNDP and its partners seek to achieve other Sustainable Development Goals (SDGs). Health is a major contributor to sustainable development, but many economic, social and environmental determinants of health are outside the health sector itself, requiring decisive coordinated cross-sectoral action, particularly in the areas of poverty (SDG 1), gender equality (SDG 5), decent work and economic growth (SDG 8), reducing inequalities (SDG 10), sustainable urban and community development (SDG 11), responsible consumption and production (SDG 12), and peace, justice and strong institutions (SDG 16).
2.1. UNDP in Ukraine’s activities to promote health and transparency

In 2015, the MoH of Ukraine asked UNDP in Ukraine and other international partners (including UNICEF and Crown Agents) to support the public procurement of medicines. According to the agreement signed between the Ministry and UNDP, Ukraine should procure medicines through international organizations, including UNDP, as a temporary solution. Meanwhile, the state-owned enterprise Medychni Zakupivli Ukrainy (Medical Procurement of Ukraine), which will ultimately become the central procurement agency, will accumulate experience in procurement and adopt best practices from UNDP.

Since the beginning of cooperation, UNDP has saved about UAH1.7 billion of state funds, and the share of goods purchased directly from producers has increased to 51 percent. Ukraine’s medical procurement experience has been scaled up to five other countries (Bosnia and Herzegovina, Kazakhstan, Moldova, Turkmenistan and Uzbekistan).

2.2. UNDP in Ukraine’s anti-corruption activities

2.2.1. ANTI-CORRUPTION AS ONE OF THE PRIORITIES OF THE UNITED NATIONS AND UNDP

Sustainable development is impossible without adequate efforts to combat corruption. Corruption prevents access to public services in both quantitative and qualitative terms, especially when it comes to health and education, by diverting public resources for private gain. It takes away resources and opportunities to improve the lives of the most vulnerable citizens, impedes economic development, erodes the rule of law and democratic institutions, and disrupts public trust in governments and leaders.

UNDP is a long-standing partner of the Government of Ukraine’s reform programmes. It has been supporting anti-corruption reform in Ukraine since 2014, focusing on innovation to ensure transparency and integrity.
In 2016, UNDP supported the launch of a comprehensive and innovative asset declaration system for individuals authorized to perform state or local self-government functions and provides support to ensure automatic verification of electronic declarations.

2.2.2. THE NEED TO COMBAT CORRUPTION IN THE HEALTH SECTOR IN UKRAINE

Corruption in the health sector is not limited to a bottle of brandy in exchange for quality health care; it is a far greater threat affecting the procurement of medicines, charitable foundations at hospitals, diagnostic centres, the privatization of premises and ‘money-back’ offers to health care professionals for better and faster treatment.26

In Ukraine, the systemic nature of corruption has hit the pharmaceutical sector, as several key players have been able to dominate the market and influence the regulatory system to their personal benefit for years. It has led to the possibility of influencing regulatory institutions or even a more severe form of corruption — the ‘capture’ of public offices — from important positions in the pharmaceutical industry to positions in government agencies responsible for the definition, procurement and distribution of pharmaceuticals.27

UNDP actively promotes anti-corruption measures in health procurement, which include support for the development of the concept of a central procurement agency and procurement system, supported by the government in September 2018; drafting the action plan for public procurement reform in accordance with the reform agenda for the health sector; support for annual MoH anti-corruption action plans; conducting training for MoH employees regarding conflicts of interest; communication support to boost the effectiveness of public procurement reform; research, such as a Sector Integrity Vulnerability Assessment (SIVA), a Public Expenditure Tracking Survey (PETS), a Legal Environment Assessment for Tuberculosis (TB LEA) etc.; and public monitoring of the delivery, availability and use of medicines at the local level.

To reduce the risk of corruption at the local level, the MoH assessed the vulnerability of the sector and conducted a public health expenditure survey (PETS) in collaboration with the World Bank in Donetsk and Luhansk oblasts. These assessments made it possible to identify and highlight gaps in the health care system that need to be addressed in policy and planning.

The UNDP-led Health Care Resources Tracking study, in partnership with the World Bank and the Kyiv School of Economics, provided an assessment of the sector’s inefficiencies and suggested recommendations for improving the allocation and use of public-sector resources.

2.3. What is the scope of public monitoring of the availability of medicines within the framework of UNDP projects?

Public procurement of medicines is a long-term process, which is carried out in stages – from a needs assessment in the regions and the formation of the nomenclature to the direct distribution of the procured medicines and their delivery.

As one of the organizations that procures medicines out of the state budget, UNDP is interested in tracking what happens to the medicines once they have been procured: when they get to the central warehouse, how and when they are distributed and when they are delivered to the regions. In addition, even if medicines are delivered on time and in full, it is important to ensure that they are actually available to patients, by monitoring the availability and use of medicines in health care facilities.

To ensure access to effective medicines of guaranteed quality, the Global Fund has developed a series of policy measures and principles for procurement and supply management aimed at:

- supporting the timely procurement of medical products of guaranteed quality and quantity;
- achieving cost-effectiveness in procurement and supply management activities;
- ensuring the reliability and stability of distribution systems;

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Public Monitoring Guidelines

- encouraging the appropriate use of medical supplies; and
- monitoring all procurement and supply management activities.\(^{29}\)

Adapted to Ukrainian realities, these principles serve as a benchmark for analysing the delivery, availability and use of medicines locally.

### 2.4. The role of civil society in monitoring medicine availability within the framework of the UNDP programme

As noted above, UNDP is helping the MoH of Ukraine to reform its public procurement system. Within the framework of the project ‘Procurement Support Services to the Ministry of Health of Ukraine throughout 2015–2019’ UNDP procured a number of medicines and medical products through selected national programmes, making them available to patients at grass-roots level. The programme had a particular focus on the cost-effectiveness, transparency and timeliness of procurement, as well as on developing the structural and human capacity to plan, forecast, control and evaluate deliveries to ensure transparent and cost-effective procurement at the MoH.

To monitor the supply and distribution of medicines procured through UNDP nationally, local NGOs in four selected regions (Lviv, Poltava, Kharkiv and Cherkasy) implemented the first round of the project ‘Public Monitoring of Delivery, Availability and Use of Medicines at the Local Level’. Specifically, they assessed whether medicines are available for adult patients with oncological and oncohaematological diseases, as well as for children suffering from chronic viral hepatitis.

In 2018, the project aimed to monitor the availability of medicines procured by UNDP from the MoH budget for adult patients with haemophilia and children with oncohaematological diseases in four other regions (Dnipro, Zaporizhia, Vinnitsia and Chernihiv). A report with the findings of the public monitoring is available in Annex 5.

It was important that patient organizations became the implementing partners of the public monitoring project as a result of the open competition. In addition to relevant project implementation experience, direct contractors had personal experience of living with diseases, which gave them a deeper understanding and greater ability to analyse the situation.

Figure 3. Project geography, target groups and implementing partners.
To assist the implementing partners, UNDP developed a step-by-step guide on which data should be collected and how, including separate questionnaires for physicians and patients (or their parents/guardians), with a list of data sources, indicating the required sample; how data should be processed; and a description of the expected results of data collection (see more information on methodology in the next section).

Local project partners undertook thorough, high-quality work on data collection and situation analysis, despite the difficulty of reaching out to patients (those who were not in hospital at the time of the survey) and the unwillingness of individual doctors to communicate and provide information.

A consolidated report for each round of the project summarized the difficulties encountered during the polling, communication problems, the findings (regarding planning/needs of regions, distribution of medicines, amount of medicines received/available at health care facilities, patient satisfaction/availability of treatment, difficulties encountered by patients, transparency of the supply and use of medicines, and conditions under which patients received medicines), recommendations (to the MoH, State Oblast Administrations (SOAs), health care facilities, health care departments, international partners), successes and lessons learned.

The monitoring organizations disseminated the results of their work on this project to the communities in their regions (through online resources and social networks, and at special events), and they are using the knowledge they have acquired to further advocate for the rights of patients to free-of-charge medicines (see Section 4. Use of collected data and monitoring to advocate for change).

Proposals made by implementing partners and other stakeholders to improve the methodology and processes of public monitoring of the availability of medicines were considered when these technical guidelines were drafted.
Section 3. Methodology. Selecting tools and collecting information

The goal of public monitoring of medicine availability is to obtain data on the timing and quantitative indicators of the delivery of medicines procured from the state budget to warehouses and medical institutions in the regions and to collect information on the availability of medicines for patients.

Every such project has preparatory (planning) and implementation and post-implementation (dissemination of project results, conducting advocacy actions) stages.

In this section, we will briefly elaborate on the first stage and look at the second stage in more detail, including the methodology for implementing public monitoring projects based on the example of the methodology developed by UNDP in Ukraine, which implemented two rounds of small grants projects in 2017 and 2018, taking into account proposals from the implementing partners of these projects and a wider range of stakeholders.30

3.1. What comes before the start of public monitoring?

If the organization is a direct implementer rather than an initiator of the monitoring, the main planning activities are performed by the customer (donor). Namely, the latter:

- defines the purpose, goals and objectives of the specific monitoring project;
- chooses nosologies and regions;
- determines the size of the sample to be surveyed, taking into account factors such as whether the selected disease is rare (orphan), the features of the treatment process (whether there will be a sufficient number of respondents in a health care facility at the time of monitoring), how open and accessible the patient community is etc.; and
- selects implementing partners.

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30In May 2019, UNDP in Ukraine held a stakeholder meeting to discuss the methodology of public monitoring of medicine availability. The proceedings of the meeting are reflected in this publication. A full list of participating organizations is provided in the Acknowledgments section at the end of the Guidelines.
As a rule, the contracting authority/initiator provides **technical support** to the contractors. It can include:

- the *research methodology*, including the necessary tools (questionnaires, templates), technical guidelines, online resources etc.;
- practical/training sessions for the implementers to learn the methodology and features of working with certain tools and to get to know other executive partners (counterparts) if the project is designed for several regions and/or nosologies; and
- letters of support to state health authorities at different levels (MoH and regional, district and city health departments).

Public monitoring in each case will have its own characteristics, given the selected nosology, sample size, patient age (adults or children), region etc., but in general, the **practical part** of the monitoring will consist of the steps described below.

### 3.2. Step-by-step guide to public monitoring

1. **ESTABLISHING A CONTACT**
   - Doctors/decision makers
   - Patients/their representatives

2. **COLLECTING INFORMATION**
   - Entering information in SurveyMonkey, Google Forms, Survio, Typeform, Simpoll etc.
   - Automatic data processing
   - Survey
   - Websites of MoH, health care departments, facilities, e-liky etc.
   - Info. boards in facilities
   - Doctors/decision makers
   - Decision makers
   - Patients/their representatives

3. **Off. data monitoring**
   - Orders on distribution
   - Surplus medicines
   - Medicine availability
   - Q-re 1 of Block A
   - Q-re 2 of Block A
   - Q-re 1 of Block B
   - Q-re 2 of Block B

4. **Analysis of information**
Let us have a closer look at each step.

3.2.1. STEP 1. ESTABLISHING A CONTACT

As an implementing partner, you evaluate your prospects and scope of work on the project, especially with regard to the immediate target group – the people you will need to interview, including doctors, decision makers (representatives of health care departments, executives) and patients (or their legal representatives).

Your organization may already have experience working with a specific health care facility, probably even with the relevant doctors and decision makers. Your organization may be working with and/or representing the patient community in a project on a specific nosology. Communication will then take place through standard means — via telephone, official/friendly correspondence, in private meetings.

If you need to start communicating with your target audience for the first time, you may have to leverage your organization’s reputation, by telling them about your organization and its activities and accomplishments, and the benefits of the project for both the health care facility and the public. Perhaps your partners which are familiar with your work and have established contacts with health care facilities, and your donors/monitoring customers will help you do this.

Communicating with representatives of health care facilities (doctors and decision makers) through public access monitoring projects is about ensuring citizens’ right to access public information — the information they create and obtain in the course of their duties and responsibilities as employees of state or community-run facilities. With the development of civil society in Ukraine and the expansion of cooperation between the government and non-governmental sectors, NGOs see partnerships with doctors and decision makers as mutually beneficial. Therefore, the latter may not only agree to interviews but may also often promote communication with patients.

When it comes to health care professionals, it is at least evident where to look for them. But as far as patients are concerned, monitoring implementers may have no physical access to them in health facilities.

WHY?

On the one hand, the law on the protection of personal data forbids doctors to share information about patients’ names and contact details. On the other hand, because of the small number of patients in a department, there may only be between one and three or four patients there at a time, whereas usually several dozen people need to be interviewed.

Sometimes patients refuse to communicate. They will have various reasons for doing so, such as not trusting the person collecting the data; not considering the reason for the request to be sufficiently meaningful; being scared of a potential negative impact of the survey on their further treatment; or feeling unwell or not wanting to mention being in a hospital.

PRACTICAL TIP

WHAT IF A DOCTOR/DECISION MAKER STILL AVOIDS COMMUNICATION?

Here is a tip from one of the monitoring implementers: “Chief physicians at health care facilities often complain that they are already tired of all sorts of verification activities. But this is only half true ... The fiscal authorities will check them purely in a digital format. An NGO that focuses on a specific nosology can identify some root issues that only patients know. Persistence overcomes obstacles in communication with doctors and accustoms them to being constantly monitored by NGOs.”

An effective way to encourage doctors to cooperate is for international (donor) organizations to submit official letters to health care executives at different levels (MoH, health care departments and facilities), as well as to representatives of the authorities and decision makers.
First, you should treat any refusal with understanding and respect. Showing consideration for patients and their feelings should remain a top priority.

In most cases, patients can be persuaded to answer if they receive support from people they trust and respect, such as a doctor, a social worker, family members, or friends from the patient community.

3.2.2. STEP 2. COLLECTING INFORMATION

Information on the availability of medicines under public monitoring is collected in two blocks:

- Block A. Supply of medicines
- Block B. Use of medicines.

Data are collected in two ways:

- monitoring of official information (official web resources, information requests to health care facilities/departments, information stands in health care facilities); and
- surveys of doctors, decision makers, patients (or their legal representatives).

3.2.2.1. DATA SOURCES

Information for Block A. Supply of medicines is collected from:

- official sources, such as the MoH website (‘MoH Orders’ (http://moz.gov.ua/nakazi-moz) and ‘Procurement of Medicines’ (http://moz.gov.ua/zakupivli-likiv) sections;

PRACTICAL TIP

WHAT SHOULD I DO IF I HAVE NO ACCESS TO PATIENTS?

The most effective way is to reach out to the patients themselves. Ask for contact information from those with whom they are communicating, or communities of people living with the disease (as a rule, they have closed groups on social networks through which you can find respondents for monitoring).

In cases where the patients are children, the monitoring implementers do not communicate directly with them, but with their legal representatives (parents or guardians), including so as not to harm them psychologically.

If you think you can help the patient in some way (for example, you want to engage him/her in self-help group meetings or a closed group on a social network to communicate with other patients or access important information), be sure to do so in a friendly way, respecting the patient’s right to refuse.

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COMMUNICATION WITH DIFFERENT TARGET GROUPS DURING PUBLIC MONITORING

According to professional standards, monitoring implementers should respect human dignity and try to act in such a way that survey participants do not feel threatened. Given that monitoring results may adversely affect the interests of individual stakeholders (e.g. decision makers, doctors), monitoring implementers should collect and disseminate information about the project’s goal and results in a way that clearly demonstrates respect for stakeholders’ dignity and importance. Monitoring implementers should also ensure that interviews are timely, take as little time as possible and respect respondents’ right to privacy.
- websites of health care departments of SOAs;
- the websites http://eliky.in.ua and http://liky.ua;
- consolidated requests for medical supplies from regional authorities;
- official written requests to the health care department of the respective SOAs or to the heads of relevant units of health care facilities; and
- interviews with health care providers (doctors, decision makers).

All information collected under **Block A** is entered into a **separate table**, which may later be necessary for analysis.

Information for **Block B. Use of medicines** is collected from:

- a specialist doctor;
- a decision maker (head of a health care facility/unit);
- a patient (or a child patient’s parents/guardians); and
- information on the list of medicines provided in a health care facility free of charge should be available at:
  - information stands in health care facilities;
  - official websites of health care facilities, regional departments;
  - the website https://eliky.in.ua/;
  - the free medicines website, https://liky.ua/; and

### 3.2.2.2. MONITORING OF OFFICIAL INFORMATION

Information on the supply of medicines is collected for each medicine procured under central government procurement (the list of medicines is usually provided by the monitoring customer). In particular, you need to determine the following:

<table>
<thead>
<tr>
<th>Block A. Supply</th>
<th>Documents</th>
<th>Where to look</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1.1</strong> When was the MoH order for the distribution of medicines issued?</td>
<td>MoH orders on regional distribution of medicines</td>
<td>MoH website (‘MoH Orders’ section (<a href="http://moz.gov.ua/nakazi-moz">http://moz.gov.ua/nakazi-moz</a>))</td>
</tr>
<tr>
<td><strong>1.2</strong> When did the medicines arrive at the regional warehouse?</td>
<td>Responses from health care departments of SOAs, Schedule of medicine supply</td>
<td>Submit information requests to health care departments of SOAs, MoH website (‘Medicine Procurement’ section (<a href="http://moz.gov.ua/zakupivli-likiv">http://moz.gov.ua/zakupivli-likiv</a>))</td>
</tr>
<tr>
<td><strong>1.3</strong> When did the medicines arrive at the hospital?</td>
<td>Responses from health care departments of SOAs, Orders from health care departments for the distribution of medicines</td>
<td>Submit information requests to health care departments of SOAs, Websites of health care departments of SOAs</td>
</tr>
</tbody>
</table>
1.4 How many units of each medicine were requested?
- Responses from regional statistics units on disease prevalence (by nosology)
- Consolidated requests for centralized medicine procurement
- Submit information requests to health care departments of SOAs
- Websites of health care departments of SOAs

1.5 How many units of each medicine were received?
- Responses from health care departments of SOAs
- Submit information requests to health care departments of SOAs

Information on medicines procured from savings from previous years may also be collected.

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WHAT TO DO WHEN THE INFORMATION YOU NEED IS MISSING OR CANNOT BE OBTAINED

GENERAL RECOMMENDATIONS:
- Consult with partner organizations that conduct monitoring within the same project, possibly in the same nosology, but in a different region.
- Elevate this issue to the donor and jointly seek a solution.
- If information cannot be obtained in any way, the reasons for this situation should be described in the report.

WHAT TO DO WHEN ACCESS TO INFORMATION IS RESTRICTED

Every citizen has the right to access public information that has been created or obtained in the course of the exercise of power. There are simple steps to requesting information: contact an authority rather than an official; use concise and understandable wording; refer to the Law on Access to Public Information; and specify your contacts and how you would like to receive a response.  

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3.2.2.3. SURVEYS (QUESTIONNAIRES)

A survey is conducted using a questionnaire (through a telephone survey, a poll in a closed group on a social network or completed by respondents themselves). All data collected (questionnaires and paper-based and electronic databases) should be kept confidential and should not contain patients’ first or last names. The minimum required number of interviewed patients depends on the total number of patients of this nosology in Ukraine as a whole.

Questionnaires for each nosology differ due to differences in the treatment process (protocols, regimen, standards). A respondent should answer the questionnaire. A respondent or an interviewer (often patients are ready to answer questions while refusing to fill in a template) fills in a questionnaire immediately during the survey. At the request of a respondent, a questionnaire can be sent to his/her email address. In this case, the respondent fills in the questionnaire at his/her convenience and sends back the completed version. The implementer enters data from the questionnaires into the online database ‘Use of medicines’ (prepared through SurveyMonkey, Google Forms, Survio, Typeform, Simpoll or another web-based service).

Questions to be included in a questionnaire may be drawn from the examples developed for UNDP public monitoring projects in Ukraine.

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For **Block A. Supply of medicines**, two questionnaires were drafted:

- **Questionnaire 1. Receiving medicines** (you can interview a specialist doctor or a decision maker) aims to identify problematic issues related to requesting and receiving medicines, including how much need was covered.

<table>
<thead>
<tr>
<th>Block A. Questionnaire 1. Receiving medicines</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Date of survey</td>
</tr>
<tr>
<td>2. Name of facility</td>
</tr>
<tr>
<td>3. Number of patients with a specific nosology registered at the hospital</td>
</tr>
<tr>
<td>4. Does the amount of medicines requested by the hospital for patients meet 100% of the need? If not, what percentage of the need was requested?</td>
</tr>
<tr>
<td>5. What problems did the hospital management have when requesting medicines?</td>
</tr>
<tr>
<td>6. What problems did the hospital management have with obtaining medicines?</td>
</tr>
<tr>
<td>7. Other problems</td>
</tr>
</tbody>
</table>

- **Questionnaire 2. Communication and up-to-date information** are necessary to interview decision makers. These are the people who know where the medicines are, when they will be delivered etc. These are executives who have information about the budget, balances and funds, and who communicate with the relevant public authorities (the MoH, health care departments).

<table>
<thead>
<tr>
<th>Block A. Questionnaire 2. Communication and up-to-date information</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Date of survey</td>
</tr>
<tr>
<td>2. Name of facility</td>
</tr>
<tr>
<td>3. How do the health care facilities determine the need for medicines?</td>
</tr>
<tr>
<td>4. Are there communication problems between the MoH, health care departments and facilities?</td>
</tr>
<tr>
<td>5. What are they?</td>
</tr>
<tr>
<td>6. Is there an open source where the supply nomenclature for the coordinated use of medicines is formed? Which one?</td>
</tr>
<tr>
<td>7. How often do you update information on the availability of medicines in official sources? Which ones?</td>
</tr>
<tr>
<td>8. Which are the most requested medicines for patients?</td>
</tr>
<tr>
<td>9. Are there enough funds (100% coverage needed)?</td>
</tr>
<tr>
<td>10. Are the necessary medicines distributed on time? If not, why not? (Is this a problem solely with delivery delays, or is it important for them to receive medicines every month?)</td>
</tr>
<tr>
<td>11. Do health care facilities have the physical capacity to store medicines? How many medicines can be stored? Is it enough?</td>
</tr>
<tr>
<td>12. Are the MoH, health care departments and facilities able to transfer surplus medicines to other regions?</td>
</tr>
<tr>
<td>13. How often does the facility check the surplus?</td>
</tr>
<tr>
<td>14. When was the last redistribution of the surplus?</td>
</tr>
</tbody>
</table>
For **Block B. Use of medicines**, two questionnaires were also developed:

⚠️ **Questionnaire 1. Use of medicines** aims to interview patients (or their legal representatives — parents of child patients, or caregivers — usually family members — of adult patients) regarding the aspects of their treatment associated with the use of medicines procured from public funds.

<table>
<thead>
<tr>
<th>Block B. Questionnaire 1. Use of medicines (survey of patients)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Date of survey</td>
</tr>
<tr>
<td>2 Age of patient/child (full years)</td>
</tr>
<tr>
<td>3 Sex of patient/child</td>
</tr>
<tr>
<td>4 Place of treatment</td>
</tr>
<tr>
<td>5 When did you start treatment?</td>
</tr>
<tr>
<td>6 Which medicines do you take? (select from the suggested list)</td>
</tr>
<tr>
<td>7 Have you received medicines for free?</td>
</tr>
<tr>
<td>If yes, which medicines have you received in the unit for free? (select from the suggested list).</td>
</tr>
<tr>
<td>If yes, when did you receive them? (At the beginning of treatment/in the course of treatment/preventive/to take at home/urgent)</td>
</tr>
<tr>
<td>8 Have you been asked to make a donation to receive free medicines?</td>
</tr>
<tr>
<td>9 Have you refused any free medicines that you have been offered?</td>
</tr>
<tr>
<td>10 If so, why did you refuse the free medicines offered?</td>
</tr>
<tr>
<td>11 Where did you buy medicines? (from a health practitioner in a unit, from a pharmaceutical company representative, from a pharmacy at a hospital, from another pharmacy, via the Internet etc.)?</td>
</tr>
<tr>
<td>12 What problems did you face while receiving your treatment? (unaffordable cost of medicines, lack of medicines in pharmacies, delay in delivery of promised free medicines, other)</td>
</tr>
<tr>
<td>13 Other problems and comments</td>
</tr>
</tbody>
</table>

⚠️ **Questionnaire 2. Communication and up-to-date information** are also necessary to interview patients (or their legal representatives — parents of child patients, or caregivers — usually family members — of adult patients), but for the purpose of empowering them. This concerns patient awareness, their access to reliable information, strengthening their role in decision-making regarding their treatment, and their active participation in the treatment and recovery process.

<table>
<thead>
<tr>
<th>Block B. Questionnaire 2. Communication and up-to-date information</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Are you familiar with the materials, orders, nomenclature, protocols for your nosology?</td>
</tr>
<tr>
<td>2 What kind of information are you missing?</td>
</tr>
<tr>
<td>3 Do you know the open source where the nomenclature of supplies for the coordinated use of medicines is formed? Which one?</td>
</tr>
<tr>
<td>4 How often do you track up-to-date information on the availability of medicines in official sources? Which ones?</td>
</tr>
</tbody>
</table>
5 Which medicines do you need most?
6 Are there enough medicines (100% coverage needed)?
7 Are the necessary medicines distributed on time?
8 Are you able to store the medicines properly (if you can have them to take at home)?

3.2.3. STEP 3. ENTERING INFORMATION INTO SURVEYMONKEY/GOOGLE FORMS/SURVIO ETC.

To facilitate further analysis of responses, modern and accessible online services (such as SurveyMonkey, Google Forms, Survio, Typeform, Simpoll etc.), which have several advantages, can be used. These services are helpful for both simple and small surveys, as well as for mass mailing of questionnaires or for identifying certain trends. Possible distribution channels are websites, social networks and mailings. Surveys using these web services are conducted in three stages:

PREPARE A SURVEY
COLLECT RESPONSES
ANALYSE FINDINGS

Survey results are reported as automatically generated information based on the responses. Aggregated data are displayed in graphs and tables. Settings can be applied to charts (choice of chart type, display options, colours, labels etc.), and data in tables can be sorted.

3.2.4. STEP 4. ANALYSIS OF INFORMATION

The information gathered from both blocks will help you understand the current situation of and trends in the supply of medicines procured from budget funds, and determine the next steps.

To draw conclusions and recommendations based on the findings of public monitoring of medicine availability, the following guiding questions should be answered:

Block A, findings from official information and Questionnaire 1.

<table>
<thead>
<tr>
<th>Guiding questions for analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1-1 How long does it take to deliver medicines from central to regional and hospital locations?</td>
</tr>
<tr>
<td>A1-2 Were there any delays in the delivery of medicines from the central warehouse to the regional warehouses and hospitals? What are the reasons?</td>
</tr>
<tr>
<td>A1-3 Does the amount of medicines received match the request?</td>
</tr>
<tr>
<td>A1-4 Does the amount of medicines received match the hospital’s actual need based on the number of patients?</td>
</tr>
<tr>
<td>A1-5 Did the hospital management face any issues with obtaining medicines procured centrally?</td>
</tr>
<tr>
<td>A1-6 To what extent was the information requested by the NGO available?</td>
</tr>
<tr>
<td>A1-7 Did the project implementers face any issues with communication with hospital executives and health practitioners?</td>
</tr>
</tbody>
</table>
### Block A, data from Questionnaire 2

<table>
<thead>
<tr>
<th>Guiding questions</th>
<th>Relevance</th>
</tr>
</thead>
<tbody>
<tr>
<td>A2-1 Are there communication problems between the MoH, health care departments and</td>
<td>Addressing communication problems, further fruitful cooperation</td>
</tr>
<tr>
<td>facilities?</td>
<td></td>
</tr>
<tr>
<td>A2-2 What are the problems?</td>
<td></td>
</tr>
<tr>
<td>A2-3 Is there an open source where the supply nomenclature for the coordinated use</td>
<td>Access of patients to reliable information, improving the quality of</td>
</tr>
<tr>
<td>of medicines is formed? Which one?</td>
<td>treatment/prevention</td>
</tr>
<tr>
<td>A2-4 How often do you update information on the availability of medicines in</td>
<td>Implementation of MoH orders, possibility of public oversight of medicine</td>
</tr>
<tr>
<td>official sources? Which ones?</td>
<td>availability</td>
</tr>
<tr>
<td>A2-5 Which are the most requested medicines for patients?</td>
<td>Developing further requests to the MoH</td>
</tr>
<tr>
<td>A2-6 Are there enough funds (100% coverage needed)?</td>
<td>Public oversight (overcoming the inaccuracy of information provided by</td>
</tr>
<tr>
<td></td>
<td>doctors)</td>
</tr>
<tr>
<td>A2-7 Are the necessary medicines adequately distributed on time?</td>
<td>Opportunity to prevent interruptions to treatment, stock-outs and surpluses</td>
</tr>
<tr>
<td></td>
<td>of medicines</td>
</tr>
<tr>
<td>A2-8 Do health care facilities have the specific physical capacity to store</td>
<td>Addressing problems of shelf life and claimed efficacy of medicines</td>
</tr>
<tr>
<td>medicines? How many medicines can be stored? Is it enough?</td>
<td></td>
</tr>
<tr>
<td>A2-9 Are the MoH, health care departments and facilities able to transfer surplus</td>
<td>Addressing problems of timely distribution of medicines</td>
</tr>
<tr>
<td>medicines to other regions?</td>
<td></td>
</tr>
<tr>
<td>A2-10 How often does the facility check the surplus?</td>
<td></td>
</tr>
<tr>
<td>A2-11 Was a surplus identified (at the time of monitoring)?</td>
<td></td>
</tr>
</tbody>
</table>

### Block B, data from Questionnaire 1

<table>
<thead>
<tr>
<th>Guiding questions for analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>B1-1 Percentage of patients surveyed who received free medicines procured from the national</td>
</tr>
<tr>
<td>budget</td>
</tr>
<tr>
<td>B1-2 Percentage of patients who received one, two, three or more medicines for free</td>
</tr>
<tr>
<td>B1-3 Percentage of patients who refused free medicines, and why</td>
</tr>
<tr>
<td>B1-4 What problems did patients face when being provided with their medicines?</td>
</tr>
</tbody>
</table>
**Block B**, data from Questionnaire 2

<table>
<thead>
<tr>
<th>Guiding questions</th>
<th>Relevance</th>
</tr>
</thead>
<tbody>
<tr>
<td>B2-1  Are you familiar with the materials, orders, nomenclature and protocols for your nosology?</td>
<td>Access of patients to reliable information, improving the quality of treatment/prevention</td>
</tr>
<tr>
<td>B2-2  What kind of information are you missing?</td>
<td>Public request</td>
</tr>
<tr>
<td>B2-3  Do you know the open source where the nomenclature of supplies for the coordinated use of medicines is formed? Which one?</td>
<td>Public oversight</td>
</tr>
<tr>
<td>B2-4  How often do you track up-to-date information on the availability of medicines in official sources? Which ones?</td>
<td>Implementation of MoH orders, possibility of public oversight of medicine availability</td>
</tr>
<tr>
<td>B2-5  Which medicines do patients need most?</td>
<td>Developing further requests to the MoH, comparing the real and the desired situation of medicine procurement</td>
</tr>
<tr>
<td>B2-6  Are there enough medicines (% of coverage needed)?</td>
<td>Public oversight (overcoming the inaccuracy of information provided by doctors)</td>
</tr>
<tr>
<td>B2-7  Are the necessary medicines adequately distributed on time?</td>
<td>Opportunity to prevent interruptions to treatment, stock-outs and surpluses of medicines</td>
</tr>
<tr>
<td>B2-8  Are you able to store the medicines properly (if you can have them to take at home)?</td>
<td>Addressing problems of shelf life and claimed efficacy of medicines</td>
</tr>
</tbody>
</table>

Analysis of the responses will help assess:

- **Availability of centrally procured medicines for patients in the regions**
  - A1-3; A1-4; B1-1, B1-2

- **Covering the need for quality medicines**
  - A1-4
  - B1-2; B1-3

- **Timeliness of provision of medicines to patients**
  - A1-1
  - A1-2; A1-5

- **Transparency of distribution of medicines in the regions and readiness to communicate with the public**
  - A1-6
  - A1-7

- **Effective communication and availability of up-to-date information**
  - A2-1 – A2-11
  - B2-1 – B2-8

Based on these guiding questions, implementing partners prepare their narrative programme/analytical reports and – more important – plan follow-up steps, update the public and conduct advocacy (at the post-implementation stage of the project).
3.3. Reporting on the public monitoring project

If public monitoring of the availability of medicines is carried out in the framework of a specific project, at the end of the project, the implementers should submit a report on the work performed. The requirements of the report are normally set by the customer/initiator of the monitoring (see the template for a narrative report in Annex 4).

Please also see the contents of the 2016–2017 Public Monitoring of Supply and Use of Medicines report which was used during the implementation of the 2018 UNDP project as an indicative example of a report on public monitoring of the availability of medicines.

REPORT OUTLINE (2018)

About the Public Monitoring of the Delivery, Availability and Use of Medicines at the Local Level project

Methodology

Report structure

SECTION 1. PAEDIATRIC ONCOHAEMATOLOGY PROGRAMME
   I. Analysis of the supply of requested medicines
      ■ Situation analysis (number of patients, regional quotas)
      ■ Correlation between the request submitted to the MoH (2016 and 2017) and the actual amount of medicines received (%)
      ■ Timeliness of medicine delivery
   II. Analysis of the use of requested medicines
      ■ Survey of doctors
      ■ Survey of patients/their parents or guardians
   III. Analysis of the availability and cost of medicines from the MoH list in a hospital pharmacy and the pharmacy closest to the hospital

SECTION 2. ADULT HAEMOPHILIA PROGRAMME
   I. Analysis of the supply of requested medicines
      ■ Situation analysis (number of patients, regional quotas)
      ■ Correlation between the request submitted to the MoH (2016 and 2017) and the actual amount of medicines received (%)
      ■ Timeliness of medicine delivery
   II. Analysis of the use of requested medicines
      ■ Survey of doctors
      ■ Survey of patients
   III. Problem analysis and recommendations from an NGO for launching a system for home treatment

Conclusions

Recommendations

Annexes
Section 4. Using the evidence and findings of monitoring in advocacy for change

4.1. How does public monitoring contribute to building the capacities of NGOs?

CAPACITY-BUILDING OF ORGANIZATIONS

CAPACITY is the ability of people, institutions and societies to perform functions, solve problems, set goals and achieve them in a sustainable way.

CAPACITY-BUILDING is the process through which people, organizations and societies receive, enhance and retain the ability to set and achieve their own development goals over time.

In other words, it is a process of growth and positive change that is constantly evolving.

The transformation that drives this process is based on a set of skills known as ‘functional abilities’ (capacities).

UNDP identified five functional abilities that are important to determine 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.

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. It fully applies to public monitoring projects.

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Therefore, how exactly does a public monitoring project contribute to building the capacities of NGOs that directly implement it? As a rule, growth and positive change take place at three levels:

**Environment:**
- **Establishing contacts** (visibility, recognition, reputation, recognition of expertise) with stakeholders and the patient community
- Expanding opportunities to **have an impact** (advocacy), including by collaborating with other NGOs
- Creating opportunities to **share experience** of performing public monitoring or providing technical assistance to other NGOs
- Creating opportunities to improve the quality of life of the patients interviewed (by working directly with them in the future, expanding the **client base** or referring them to relevant NGOs or patient communities).

**Organization:**
- Receiving **up-to-date first-hand information** on the availability of medicines
- **Improving expertise** on the availability of medicines and the features of treatment for a particular nosology
- The results of the monitoring offer an understanding of the necessary direction of **advocacy** in the future
- Experience of **cooperation with international organizations** (systems of programme and financial reporting, monitoring and evaluation, learning new tools and working approaches)
- Building the organization’s **financial capacity**
- Enhancing the organization’s **human capital** (by building employees’ skills, experience and knowledge) and strengthening loyalty to an organization
- Ability to plan/implement **similar public monitoring activities** independently or with support from other donor organizations
- Improving the organization’s understanding of its **own strengths and areas for development**.

**People:**
- Improving the **skills, experience and knowledge** of staff who were directly involved in the project
- Empowering staff, especially those living with diseases (understanding that they can be **agents of change** and have a real impact on the procurement, delivery and use of vital medicines).
Changes in the context of capacity-building mostly take place in the following four major areas: 34

I. **Institutional arrangements** — policies, practices and systems that enable an organization to function effectively. Public monitoring makes an organization review/adjust its own policies, practices and systems related to project management, human resources management, decision-making, accounting, financial analysis, client interaction, stakeholder engagement etc.

II. **Leadership** is the ability to influence, inspire and motivate others to achieve or even go beyond their goals; it is also the ability to anticipate and respond to change. Leadership is not necessarily synonymous with power; it may also be informal. Public monitoring gives an organization the opportunity to prove itself as a leader that is capable of both promoting improvements to the delivery system for medicines procured out of the state budget and inspiring patient communities to protect their rights.

III. **Knowledge** — or literally ‘what people know’ — is the basis of their capabilities and, therefore, of capacity-building. From the three levels defined above, knowledge is traditionally formed at the individual level, mainly through education. But it can also be created and disseminated within an organization — for example, through on-the-job training. As already mentioned, it is about the skills, experience and knowledge of the employees directly involved in the public monitoring project.

IV. **Accountability** evolves when rights-holders are able to make duty-bearers fulfil their obligations. In terms of capacity-building, interaction between providers and customers of public services or service providers and supervisors is key. More specifically, it is about the willingness and capacity of public institutions to create systems and mechanisms to engage, receive and use feedback from groups of citizens, and the ability of citizens to use such platforms. In fact, public monitoring projects are an opportunity for interaction between service providers (the MoH, health care departments and facilities) and the public (NGOs representing the communities). This is an opportunity to oversee service providers’ performance and — by providing feedback — influence the situation when needed.

To sum up, by conducting public monitoring of the availability of medicines, an NGO becomes a catalyst for positive change at the environment level, at its own organizational level and at the level of specific individuals (its employees and clients). The organization’s policies, practices and systems evolve, and its leadership and expertise in its sector grow. It becomes capable of producing and sharing important public knowledge. It is able to carry out a high-quality social oversight role and objectively assess the activities of the public authorities it is overseeing.

### 4.2. Examples of successful/standard advocacy activities

**WHAT IS ADVOCACY?**

**Advocacy** is the activity of individuals or organized groups that seeks to influence public policy and decisions of political, economic and social institutions to represent and protect the rights and interests of those individuals or groups.

**Advocacy** is always an action aimed at making a managerial decision. Advocacy efforts should result in a change in your community or country as a whole. 35
The results of public monitoring of medicine availability (summarized in conclusions and recommendations to stakeholders at different levels; see example in Annex 5) are the basis for your further advocacy efforts.

According to recommendations from Round I and Round II of the project, NGOs involved in public monitoring can:
- raise patients’ awareness of the possibility of receiving medicines for free, develop patients’ ability to stand up for their rights to free treatment and an active, conscious (rather than passive) attitude to their treatment;
- publish all their materials on their websites, on forums and on their pages on social networks;
- disseminate the experience and successful practices of the project among the patient community at national and regional levels, among doctors and representatives of national and regional authorities; and
- use the project results to further advocate for access to quality timely treatment and prevention services.

Advocacy will mainly be undertaken at the post-implementation stage of a public monitoring project. However, in some cases, it may be possible to assert patients’ rights during project implementation, as described in Examples 1 and 2 below.

Issues identified during public monitoring can relate to different levels:
- the individual level – when it is necessary to work with patients to raise their awareness of their rights or empower them; when you have a lot of patients facing the same problem, it means that there is a trend that should be changed through advocacy;
- the level of health care facilities – for example, a lack of qualified staff or the need to keep patient records on a specific nosology;
- the level of health care departments – regulating the issue of transparent data collection and reporting on the use of charitable funds in health care facilities to ensure that regional specialists produce objective requests for medicines that comply with patients’ real needs; or
- the MoH level – for example, updating the National List of Medicines and including vital medicines that are not listed yet, or providing doctors with information on expected terms of medicine delivery that will allow for better planning of patients’ treatment.

These may be issues that can be addressed in the short term (as in the case of a lack of information on surplus medicines in facilities), the medium term (the need to create a permanent expert council consisting of specialized doctors, economists and statisticians to develop the necessary list of medicines for each year, taking into account not only medical but also economic factors for the formation of a regional quota for medicines) or the long term (important systemic changes – for example, a full-scale change in the approach to the management of haemophilia, in particular the transition from urgent to preventive/home treatment, the consolidation of certain concepts in the legislation, the adaptation of international standards and recommendations, increased funding to change the approach to calculating the number of required medicines, work with health care departments at the regional level and with facilities at the local level etc.).

Certain advocacy activities can be carried out by NGOs, while others will require close cooperation with the stakeholders.
EXAMPLE 1. ADVOCATING FOR OPENNESS OF INFORMATION ON THE AVAILABILITY OF MEDICINES IN HEALTH CARE FACILITIES (ROUND II OF THE PROJECT, 2018)

According to the Order of the Ministry of Health of Ukraine #509 of 2 June 2016 “On Implementation of Measures to Control the Use of Medicines and Medical Products Procured from Budget Funds”, the heads of health care facilities subordinated to the MoH of Ukraine that receive medicines and medical devices procured from state budget funds should ensure that information is available on their official websites about the need, availability and surplus of medicines and medical devices procured from budget funds. Not every health care facility, however, has its own website. In this case, they can join the E liky initiative (https://eliky.in.ua), which automatically meets the requirements of this Order for them.

Also, according to the Order of the Ministry of Health of Ukraine #459 of 26 April 2017 “On Approval of the Procedure for Placement of Information on Medicines, Supplies, Medical Devices and Food for Special Dietary Consumption Procured from State and Local Budgets, Charitable Donations and Humanitarian Aid on Information Stands”, health care facilities should publish such information to ensure that citizens have access to it.

According to public monitoring of medicine availability conducted with the support of UNDP in 2018 in four regions (Vinnytsia, Dnipro, Zaporizhia, Chernihiv), not all facilities that were subject to monitoring have their own websites or pages on an eliky.in.ua or liky.ua affiliate website (for example, Zaporizhia Oblast Children’s Clinical Hospital and Chernihiv Oblast Children’s Hospital). Those facilities that do have a website do not necessarily update the information (e.g. Dnipro General Clinical Hospital #4 only updates data on medicine availability on information stands in the facility, not on its website, due to the heavy workload involved for a pharmacist). At the same time, information on the availability of medicines for haemophilia patients in Vinnytsia and Chernihiv oblasts is updated regularly.

There are also differences in terms of the availability and accuracy of information on special stands. For example, in Vinnytsia oblast, the list of medicines for cancer patients is placed in the hospital (and on the facility’s website), while in Chernihiv oblast, no such list is available in the facility, and the facility has no website.

However, it turns out that the availability of information is not enough; patients also need to know about its existence and purpose. Therefore, during a survey of parents/guardians of cancer patients in Vinnytsia oblast (where information is available) and Chernihiv oblast (where information is not available), it was found that none of the respondents knew that they could ask a doctor for a list of medicines procured from the state budget that are currently available in the hospital.

On the one hand, patients (or their legal representatives) are often unaware of any such information or where it can be found; on the other hand, health care facilities do not provide such information, which is a violation of patients’ rights. What can the monitoring organization do in this situation?

In the first case, an NGO that conducts monitoring can update the patients or their legal representatives on their rights when communicating with them.

In the second case, an NGO can ask responsible persons to remedy the situation. This activity is advocacy. According to an example from one of the health care facilities in Dnipro oblast, “Before the project started, up-to-date information on surplus medicines was not available on the hospital’s official website or information stands. At the end of the project, after we contacted the chief doctor, information was placed on the stands.”

The most effective way in this case is to send a formal written request to a decision maker (for example, the chief doctor of a health care facility), with references to legislative and regulatory documents that have not been complied with.

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37 See https://zakon5.rada.gov.ua/laws/show/z0841-17.
EXAMPLE 2. ADVOCACY TO LAUNCH A SYSTEM FOR HOME TREATMENT OF HAEMOPHILIA AT THE REGIONAL LEVEL (PROJECT ROUND II, 2018)

The haemophilia treatment system in Ukraine focuses on treating the effects of the disease rather than effectively providing timely care to patients. The vast majority of patients with haemophilia in Dnipro oblast (94 percent) and Zaporizhia oblast (88 percent) only receive urgent treatment (during the survey they indicated that they would also like to receive preventive and home treatment). Other patients (6 percent in Dnipro and 12 percent in Zaporizhia) did not contact the health care facility at all during the previous year. In both oblasts, patients seek inpatient treatment only in 10 percent of cases of bleeding when they need help (factor input).

Patients in Vinnytsia and Chernihiv oblasts — especially those living in district centres — report that they contact hospitals in less than 50 percent of cases of bleeding requiring factor input. Medicines are more affordable for patients who live in oblast centres. Most patients are unable to receive treatment in certain facilities (either due to their health condition or because it is difficult for them to get there).

The possibility of only urgent treatment in a hospital setting and a lack of home treatment creates an excessive burden on the health care system and leads to an unnecessary social burden of disease (calling an ambulance, additional tests, a prolonged stay in hospital, increased factor consumption, treatment of the consequences of lack of care, need for rehabilitation etc.). It is also the main cause of low patient satisfaction with the haemophilia management system in Ukraine. This issue is even more important than the medicine shortages and supply disruptions in the past (in 2015—2017).

The lack of a home treatment model that enables patients to receive medicines to take at home for both treatment and prevention — rather than attending a hospital each time — causes haemophilia patients to seek alternative ways of looking for blood-clotting factors. According to the results of public monitoring, the introduction of home treatment for haemophilia would improve the quality of the disease management system and patient satisfaction without additional budgetary funds.

Within the framework of the public monitoring project, the implementing partners working on adult haemophilia discussed the launch of a home treatment system with representatives of local authorities in selected oblasts (Vinnytsia, Dnipro and Chernihiv).

In particular, discussions were held with Dnipro SOA about launching a home treatment system, the timing for the order to be signed, and the mechanism for transferring blood coagulation factors to grass-roots level under the responsibility of family doctors. Attention was also paid to the development of the mechanism (for example, the paediatric haematology department in Dnipro oblast), the introduction of the home treatment system, and the problems of the existing system relating to the transfer of blood coagulation factors to district hospitals and primary health care centres.

In addition, a discussion was conducted with Vinnytsia SOA about launching a home treatment system, the timing for the order to be signed, and the mechanism for transferring blood coagulation factors to grass-roots level under the responsibility of family doctors.

The monitoring implementers also conducted discussions about the development of a mechanism (based on the example of Vinnytsia oblast), launching a home treatment system and the problems of the existing system relating to the transfer of blood coagulation factors at the regional hospitals in Chernihiv oblast with the head of the Department of Oncohaematology of Chernihiv Oblast Oncological Clinic.

The home treatment system will commence in Vinnytsia oblast in December 2018 to December 2019, after the start of deliveries of medicines procured from the 2018 budget. The signed order specifying the mechanism of transferring medicines to the grass-roots level under the responsibility of family doctors in Vinnytsia oblast will become a model for the home treatment system in Chernihiv oblast.

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38 Prophylactic treatment is the only treatment for haemophilia that helps avoid complications of the disease; it is used for adults (secondary prevention) to improve patients’ quality of life.

39 Home treatment is a haemophilia treatment model that allows patients to receive medicines to take at home for both treatment and prevention rather than going to a hospital each time.
Based on the analysis of data obtained, **standard advocacy actions** can aim at the following:

**DEVELOPMENT OF A METHODOLOGY FOR CALCULATING 100 PERCENT OF THE NEED FOR MEDICINES FOR THE REGIONS:**
- requesting medicines for a maximum of six months rather than for a year, for more effective treatment and provision of medicines; and
- organizing and constantly updating the registers of patients with rare/orphan diseases.

**CHANGING THE APPROACH TO DETERMINING THE QUOTA FOR MEDICINES FOR THE NEXT YEAR:**
- establishing a central commission composed of specialized doctors, economists and statisticians to assist in drawing up the required list of medicines for the coming year;
- establishing a conditional central warehouse to store products that can be transferred to regional offices/health care facilities if needed;
- health care departments and facilities redistribute medicines between regions and between various facilities in one region;
- budget allocation among regions, taking into account the number of inhibitory patients (haemophilia) in the region and the severity of each patient’s condition rather than only on the number of patients; and
- ensuring accurate diagnosis of various types of haemorrhagic conditions (haemophilia) for optimal planning of regional needs.

**QUALITY ASSURANCE OF MEDICINES AND TREATMENT:**
- launching quality control mechanisms in the activities of the National Procurement Agency to continue preventing cases when patients refuse medicines due to their poor quality; and
- ensuring that there are sufficient skilled health professionals, in particular by improving the motivation and training of doctors.

**ENSURING TRANSPARENCY OF MEDICINE DELIVERY OR ESTABLISHING A CONSISTENT PATIENT MONITORING SYSTEM:**
- development and implementation of a national electronic system of accounting for medicines procured from public funds that will capture all movements of medicines from the MoH to patients.

**IMPROVING THE LOGISTICS OF MEDICINE DELIVERY TO THE REGIONS:**
- within the framework of the National Procurement Agency’s activities, organizing careful planning of time intervals in the tendering and supply of medicines to the regions, taking into account the specifics of each nosology, to ensure the uninterrupted supply of medicines throughout the process;
- setting clear terms and schedules for medicine deliveries to the regions; and
- revision of the National List of Medicines to include medicines that are currently missing from it.

**IDENTIFICATION AND DISCLOSURE OF CASES OF CORRUPTION:**
- counteracting extortion of patients at health care facilities through the introduction of transparent donation mechanisms.

**DEVELOPMENT OF LEGISLATION:**
- consolidating the concept of preventive treatment of haemophilia patients at the legislative level.

**DISSEMINATION OF SUCCESSFUL EXPERIENCES TO OTHER REGIONS OF UKRAINE:**
- extending the experience of the haemophilia treatment system in primary care facilities from Dnipro oblast to other regions.
Section 5. Gender aspects of public monitoring

**SUSTAINABLE DEVELOPMENT GOAL 5 ON GENDER EQUALITY**

Eliminating all forms of discrimination against women and girls is not only a fundamental human right, it is also crucial for accelerating sustainable development. It has been repeatedly proven that women’s and girls’ empowerment has a significant positive impact in all areas and promotes economic growth and development.

Labour market inequalities, sexual abuse and exploitation, unequal distribution of unpaid childcare and domestic work still remain major obstacles. Granting women equal rights to access economic resources, such as land and property, is a vital task in the context of achieving this goal. Ensuring universal **access to sexual and reproductive health care** is equally important. More women currently occupy public office than ever before, but encouraging women leaders will help strengthen policies and legislation to enhance gender equality.

**The link between SDG 3 and SDG 5:** SDG 5 on gender equality requires women’s empowerment, which can lead to better health. Mothers make most medical decisions for their families, which in turn improves their children’s health.

*More information on UNDP’s work on promoting gender equality and women’s empowerment can be found at: http://www.ua.undp.org/content/ukraine/en/home/gender-equality.html.*

Gender equality and non-discrimination should apply to all areas of society. A gendered approach ensures fairness and equality, increases the level of trust in the authorities, improves the efficiency and sustainability of development, encourages support from international organizations and promotes a chain reaction to improve the quality of life of the community.⁴⁰ Public monitoring should be planned and conducted with due respect for human rights, in particular those relating to gender equality.

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5.1. Survey process

The survey process should take gender into account. First, it is important to record who is conducting the survey, how, and in what setting. If possible, organize patient interviews with an interviewer of the same sex or ask the interviewees whether it is important for them, and consider their response in the future. Second, the sex and age of respondent doctors/decision makers should also be considered for specific cultural characteristics (this information should also be juxtaposed with the distribution of his/her patients by sex and age).

5.2. Gender profile

During public monitoring, it is important to obtain a so-called gender demographic profile/portrait, including information on the respondents’ sex, age, place of residence (village/city), occupation and marital status.

Figures 1 and 2. Examples of data collected (sex and age of patients, 2017)

The goal of creating a gender profile of respondents is to identify and respond to social and gender-related issues of patients and their parents/caregivers by making decisions from a gender perspective.

The gender profile can include data both about the patients/their caregivers and about the staff of the health care facilities where they receive treatment, including the staff of units dealing with specific nosologies. For patients, information is collected from the patients/caregivers interviewed; for health practitioners, from the decision makers or patients (obviously, in this case information will be limited by the age, sex and position of medical staff).
1. The gender profile of patients (and their caregivers) with a specific nosology should ideally cover the previous two years. This helps identify trends in the data (if regular monitoring of medicine availability is possible).

**TEMPLATE FOR THE GENDER PROFILE OF PATIENTS/CAREGIVERS INTERVIEWED**

<table>
<thead>
<tr>
<th>Primary data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nosology</td>
</tr>
<tr>
<td>Children/adults</td>
</tr>
<tr>
<td>Date of creation</td>
</tr>
<tr>
<td>Name of health care facility</td>
</tr>
<tr>
<td>Localities/region whose residents were interviewed</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Demographics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distribution of respondents, by sex</td>
</tr>
<tr>
<td>Distribution of respondents, by age</td>
</tr>
<tr>
<td>Marital status of respondents</td>
</tr>
<tr>
<td>Number of family members of respondents</td>
</tr>
<tr>
<td>Are there children or family members in need of care (number)?</td>
</tr>
<tr>
<td>Number of those on maternity leave</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Geographical and economic indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Location of a health care facility in an oblast</td>
</tr>
<tr>
<td>Do the interviewees live close to a facility?</td>
</tr>
<tr>
<td>Number of employed people, by sex</td>
</tr>
<tr>
<td>Sectors of professional activity</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Population migration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Internally Displaced Persons, by sex and age</td>
</tr>
<tr>
<td>Change of place of residence due to disease (climate; better availability of medicines in the region; family members who can provide care they need), by sex and age</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Social structure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of persons with disabilities, by sex</td>
</tr>
<tr>
<td>Number of people of pension age, by sex</td>
</tr>
</tbody>
</table>
2. The gender profile of staff of units of health care facilities in which patients receive treatment for a certain nosology should also be monitored over time (if the monitoring is regular). Analysis of these data facilitates decision-making to improve patients’ satisfaction with the services they receive in the facility.

**TEMPLATE FOR THE GENDER PROFILE OF STAFF IN A HEALTH CARE FACILITY/UNIT**

<table>
<thead>
<tr>
<th>Primary data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nosology</td>
</tr>
<tr>
<td>Date of creation</td>
</tr>
<tr>
<td>Name of health care facility, name of unit</td>
</tr>
<tr>
<td>Oblast</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Demographics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distribution of employees, by sex</td>
</tr>
<tr>
<td>Distribution of employees, by age</td>
</tr>
<tr>
<td>Marital status of employees</td>
</tr>
<tr>
<td>Are there children or family members in need of care (number)?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Geographical and economic indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Location of a health care facility in an oblast</td>
</tr>
<tr>
<td>Do the employees live close to a facility?</td>
</tr>
<tr>
<td>Position and length of service in a facility</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Population migration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Internally Displaced Persons among employees, by sex and age</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Social structure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of persons with disabilities, by sex</td>
</tr>
<tr>
<td>Number of people of pension age, by sex</td>
</tr>
</tbody>
</table>

Patients may also be asked whether the sex of their doctor matters to them.

Analysis of the patient data may, for example, reveal a significantly larger number of patients of a certain sex. If this is the case, the reasons are worth exploring. For example, is this a general picture of the country (say, in Ukraine there is a general trend of greater concern for women’s health than for men’s, and a greater need for hospital treatment and rehabilitation of men). Or is it evidence that certain diseases are more acute in men or women and require more serious and prolonged inpatient treatment (such as Willebrand disease), or are associated with a higher life expectancy among women than men (if there is a clear correlation between the nosology and the patient’s age), or there is a high level of migration in the region?

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It is also important to consider who in the family cares for the patient and the children, and who fills in the questionnaire for a child. In Ukrainian legislation, it is the mother of a child who is first mentioned in connection with a child’s stay in hospital.\(^ {42}\) Usually, mothers make many decisions related to the treatment of their children. There are cases where a father leaves a family precisely because of a child’s disease, and this imposes an additional burden on the woman (financial, time-related, physical and psycho-emotional resources).

To interpret the information obtained in a broader context, it is possible to compare it to regional or national-level data, reports and conclusions of public institutions, other NGOs and international organizations on the status of men’s and women’s rights.

For example, by analysing the sex and age profile of the respondents, the location of the facilities in the region and the proximity of the respondents’ residence to these facilities, and comparing these data with the conclusions of the Alternative Report on Ukraine’s Implementation of the Convention on the Elimination of All Forms of Discrimination against Women: VIII Periodic Report, it is necessary to take into account the risks that the amalgamation of secondary health care facilities under the current health care reform creates for rural women, especially women of pre-retirement and retirement age who comprise the majority of the rural population, as well as young women with young children.\(^ {43}\)

### 5.3. Survey of LGBT patients

IN THE SURVEY OF DOCTORS, it is necessary to identify their attitude towards patients of different sexual orientation.

WHEN INTERVIEWING LESBIAN, GAY, BISEXUAL OR TRANSGENDER (LGBT) PATIENTS, it is important to try to find out whether their rights are being violated or whether they feel discriminated against.

To access LGBT people and other communities, you should contact the NGOs that represent them or that provide services to them.

### 5.4. Detecting discrimination

- The direct questions to be asked are: Was there discrimination? Did you manage to overcome it to access treatment? (How? Who helped?)

- In the summary report, it is important to indicate whether discrimination is taking place.

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5.5. Access to information

It is important to analyse what kind of access to information about their rights men and women have. Who is more interested in it, and why? Which channels of communication are more convenient for them?

5.6. Language

During public monitoring, it is recommended to use gender-balanced language. Ukraine took a decision to use more gender-specific words. Therefore, using female versions of the words for doctor and patient (лікарка, пацієнтка) becomes normal. In addition, official male names were introduced for medical positions for which only female versions were used for a long time (nurse, hospital attendant, obstetrician – брат медичний, санітар, акушер). It is also necessary to avoid hate speech.

Particular attention should be paid to the wording of questions:
- whether they contain discriminatory statements;
- whether gender-neutral wording is used;
- people tend to give an answer that is prompted by the question (this should be avoided). 44

5.7. Avoiding gender stereotypes

It is advised to avoid using judgements, conclusions and actions based on stereotypes, such as: “Being able to communicate, being friendly and having a pleasant atmosphere in NGOs is more important for women than for men” (a stereotype voiced by a social worker in the field of harm reduction). 45 Everyone who communicates with the target audience in the context of public monitoring — such as a social worker in the example above — should be clearly aware that everyone has the right to a friendly attitude, regardless of their sex. It is important, wherever possible, to identify such stereotypes and to highlight their potential negative effects on the target groups.

Acknowledgments

UNDP in Ukraine would like to thank the implementing partners of the ‘Public Monitoring of Medicine Delivery, Availability and Use at the Local Level’ project in 2017 and 2018, as well as all representatives of organizations and stakeholders who participated in the discussion of these Guidelines, namely:

**NGO OF HEPATITIS PATIENTS “ISKRA NADII (SPARK OF HOPE)”**

**CF “STOPRAK (STOP CANCER)”**

**CO “KRAPLIA KROVI (DROP OF BLOOD)”**

**CF “CHILDREN WITH HAEMOPHILIA”**

**NGO UKRAINIAN ASSOCIATION OF HAEMOPHILIA AND HAEMOSTASIS “FACTOR D”**

**CF “PATIENTS OF UKRAINE”**

**NGO “DERMATOLOGISTS TO CHILDREN”**

**CF “PODARUI DYTNY SVIT (PRESENT THE WORLD TO A CHILD)”**

**CO “CHAS ZHYTTIA PLUS (TIME OF LIFE PLUS)”**

**CO “NETWORK OF 100 PERCENT LIFE. KHARKIV”**

**NGO ASSOCIATION OF HELP TO PEOPLE WITH DISABILITIES AND PATIENTS WITH CHRONIC LYMPHOPROLIFERATIVE DISEASES**

**NGO “RARE IMMUNE DISEASES”**

**NGO “RADIIST RUKHU (JOY OF MOVEMENT)”**
Authored by

HANNA SHEVCHENKO

NATALIA LUKIANOVA

VITALIY KUCHYNSKY

ANNA PYLYPCUK
Bibliography


Public Monitoring Guidelines


METHODOLOGY OF THE PROJECT ‘PUBLIC MONITORING OF THE
DELIVERY, AVAILABILITY AND USE OF MEDICINES AT THE LOCAL LEVEL’

THE PROJECT GOAL is to obtain data on the timing and quantitative indicators of the delivery of medicines
procured from the state budget to warehouses and medical institutions in the regions and to collect information on
the availability of medicines for patients.

The project will collect information in two blocks:
Block A. Supply of medicines (2 questionnaires)
Block B. Use of medicines (2 questionnaires)

DATA FOR MONITORING

BLOCK A. SUPPLY OF MEDICINES

This Block will collect information on the following:

<table>
<thead>
<tr>
<th>Block A. Supply of medicines (monitoring of official sources)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1  When was the MoH Order on the distribution of medicines issued?</td>
</tr>
<tr>
<td>2  When did the medicines arrive at the regional warehouse?</td>
</tr>
<tr>
<td>3  When did the medicines arrive at the hospital?</td>
</tr>
<tr>
<td>4  How many units of each medicine were requested?</td>
</tr>
<tr>
<td>5  How many units of each medicine were received?</td>
</tr>
</tbody>
</table>

Block A. Questionnaire 1, survey of doctors (or decision makers)

<table>
<thead>
<tr>
<th>Block A. Questionnaire 1. Receiving medicines</th>
</tr>
</thead>
<tbody>
<tr>
<td>1  Date of survey</td>
</tr>
<tr>
<td>2  Name of facility</td>
</tr>
<tr>
<td>3  Number of patients with a specific nosology registered at the hospital</td>
</tr>
<tr>
<td>4  Does the amount of medicines requested by the hospital for patients meet 100% of the need? If not, what percentage of the need was requested?</td>
</tr>
<tr>
<td>5  What problems did the hospital management have when requesting medicines?</td>
</tr>
<tr>
<td>6  What problems did the hospital management have with obtaining medicines?</td>
</tr>
<tr>
<td>7  Other problems</td>
</tr>
</tbody>
</table>
**Block A. Questionnaire 2, survey of decision makers**

<table>
<thead>
<tr>
<th>Question</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Date of survey</td>
<td></td>
</tr>
<tr>
<td>2. Name of facility</td>
<td></td>
</tr>
<tr>
<td>3. How do the health care facilities determine the need for medicines?</td>
<td></td>
</tr>
<tr>
<td>4. Are there communication problems between the MoH, health care departments and facilities?</td>
<td></td>
</tr>
<tr>
<td>5. What are they?</td>
<td></td>
</tr>
<tr>
<td>6. Is there an open source where the supply nomenclature for the coordinated use of medicines is formed? Which one?</td>
<td></td>
</tr>
<tr>
<td>7. How often do you update information on the availability of medicines in official sources? Which ones?</td>
<td></td>
</tr>
<tr>
<td>8. Which are the most requested medicines for patients?</td>
<td></td>
</tr>
<tr>
<td>9. Are there enough funds (100% coverage needed)?</td>
<td></td>
</tr>
<tr>
<td>10. Are the necessary medicines distributed on time? If not, why not? (Is this a problem solely with delivery delays, or is it important for them to receive medicines every month?)</td>
<td></td>
</tr>
<tr>
<td>11. Do health care facilities have the physical capacity to store medicines? How many medicines can be stored? Is it enough?</td>
<td></td>
</tr>
<tr>
<td>12. Are the MoH, health care departments and facilities able to transfer surplus medicines to other regions?</td>
<td></td>
</tr>
<tr>
<td>13. How often does the facility check the surplus?</td>
<td></td>
</tr>
<tr>
<td>14. Is there an open source where the supply nomenclature for the coordinated use of medicines is formed? Which one?</td>
<td></td>
</tr>
</tbody>
</table>

**BLOCK B. USE OF MEDICINES – QUESTIONNAIRE 1**

This Block will collect information on patients receiving free medicines.
- Information should be collected from the patients themselves or their family members who take care of them.
- For children, information should be collected from their parents.
- In addition to the patient survey, information on the availability and cost of medicines from the MoH list at a hospital pharmacy and the pharmacy closest to the hospital should be collected.

<table>
<thead>
<tr>
<th>Question</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Date of survey</td>
<td></td>
</tr>
<tr>
<td>2. Age of patient/child (full years)</td>
<td></td>
</tr>
<tr>
<td>3. Sex of patient/child</td>
<td></td>
</tr>
<tr>
<td>4. Place of treatment</td>
<td></td>
</tr>
<tr>
<td>5. When did you start treatment?</td>
<td></td>
</tr>
<tr>
<td>6. Which medicines do you take? (select from the suggested list)</td>
<td></td>
</tr>
</tbody>
</table>
Have you received medicines for free?

If yes, which medicines did you receive in the unit for free? (select from the suggested list). If yes, when did you receive them? (At the beginning of treatment/in the course of treatment/preventive/to take at home/urgent)

Have you been asked to make a donation to receive free medicines?

Have you refused any free medicines that you have been offered?

If so, why did you refuse the free medicines offered?

Where did you buy medicines? (from a health practitioner in a unit, from a pharmaceutical company representative, at a pharmacy in a hospital, at another pharmacy, via the Internet etc.)?

What problems did you face while receiving your treatment? (unaffordable cost of medicines, a lack of medicines in pharmacies, delay in delivery of promised free medicines, other)

Other problems and comments

Block B. Patient survey – Questionnaire 2

Block B. Communication and up-to-date information

1 Are you familiar with the materials, orders, nomenclature and protocols for your nosology?

2 What kind of information are you missing?

3 Do you know the open source where the nomenclature of supplies for the coordinated use of medicines is formed? Which one?

4 How often do you track up-to-date information on the availability of medicines in official sources? Which ones?

5 Which medicines do you need most?

6 Are there enough medicines (100% coverage needed)?

7 Are the necessary medicines distributed on time?

8 Are you able to store the medicines properly (if you can have them to take at home)?

DATA SOURCES

Information for Block A. Supply of medicines may be collected from official sources, including:

- the MoH website (the ‘MoH Orders’ (http://moz.gov.ua/nakazi-moz) and ‘Procurement of Medicines’ (http://moz.gov.ua/zakupivli-likiv) sections;
- websites of health care departments of State Oblast Administrations;
- the websites http://eliky.in.ua and http://liky.ua;
- consolidated requests for medical supplies from regions;
- official written requests to the health care department of the respective State Oblast Administration or to the heads of relevant units of health care facilities; and
- interviews with health care providers (doctors, decision makers).
Information for Block B. Use of medicines is collected from:

- a specialist doctor;
- a decision maker (head of health care facility/unit);
- a patient (or a child patient’s parents/guardians); and
- information on the list of medicines that are provided in a health care facility for free should be available at:
  - information stands in health care facilities;
  - official websites of health care facilities and regional departments;
  - the website https://eliky.in.ua/;
  - the free medicines website, https://liky.ua/; and

DATA SAMPLE
Information on the supply of medicines is collected for each medicine procured under central government procurement from the state budget.

The minimum required number of interviewed patients depends on the total number of patients of this nosology in Ukraine as a whole.

ETHICAL CONSIDERATIONS
All data collected (questionnaires and paper-based and electronic databases) must be confidential and must not contain patients’ first or last names.

EXPECTED RESULTS
The information collected will provide answers to the following questions:

Block A – monitoring of official data and Questionnaire 1
A1-1. How long does it take to deliver medicines from central to regional and hospital locations?
A1-2. Were there any delays in the delivery of medicines from the central warehouse to the regional warehouses and hospitals? What are the reasons?
A1-3. Does the amount of medicines received match the request?
A1-4. Does the amount of medicines received match the hospital’s actual need based on the number of patients?
A1-5. Did the hospital management face any issues with obtaining medicines procured centrally?
A1-6. To what extent was the information requested by the NGO available?
A1-7. Did the project implementers face any issues with communication with hospital executives and health practitioners?
**Block A – Questionnaire 2**

A2-1. Are there communication problems between the MoH, health care departments and facilities? Addressing communication problems, further fruitful cooperation

A2-2. Which communication problems are these? Addressing communication problems, further fruitful cooperation

A2-3. Is there an open source where the supply nomenclature for the coordinated use of medicines is formed? Which one? Access of patients to reliable information, improving the quality of treatment/prevention


A2-5. Which are the most requested medicines for patients? Developing further requests to the MoH

A2-6. Are there enough funds (100% coverage needed)? Public oversight (overcoming the inaccuracy of information provided by doctors)

A2-7. Are the necessary medicines adequately distributed on time? Opportunity to prevent interruptions to treatment, stock-outs and surpluses of medicines

A2-8. Do health care facilities have the specific physical capacity to store medicines? Addressing problems of shelf life and claimed efficacy of medicines

A2-9. Are the MoH, health care departments and facilities able to transfer surplus medicines to other regions? Addressing problems of timely distribution of medicines

A2-10. How often does the facility check the surplus? Addressing problems of timely distribution of medicines

A2-11. Was a surplus identified (at the time of monitoring)? Addressing problems of timely distribution of medicines.

**Block B – Questionnaire 1**

B1-1. Percentage of patients surveyed who received free medicines procured from the national budget

B1-2. Percentage of patients who received one, two, three or more medicines for free

B1-3. Percentage of patients who refused free medicines, and why

B1-4. What problems did patients face when being provided with their medicines?

**Block B – Questionnaire 2**

B2-1. Are you familiar with the materials, orders, nomenclature and protocols for your nosology? Access of patients to reliable information, improving the quality of treatment/prevention

B2-2. What kind of information are you missing? Public request

B2-3. Do you know the open source where the nomenclature of supplies for the coordinated use of medicines is formed? Which one? Public oversight

B2-4. How often do you track up-to-date information on the availability of medicines in official sources? Which ones? Implementation of MoH orders, possibility of public oversight of medicine availability
B2-5. Which medicines do patients need most?
   Developing further requests to the MoH, comparing the real with the desired situation of medicine procurement

B2-6. Are there enough medicines (% of coverage needed)?
   Public oversight (overcoming the inaccuracy of information provided by doctors)

B2-7. Are the necessary medicines adequately distributed on time?
   Opportunity to prevent interruptions to treatment, stock-outs and surpluses of medicines

B2-8. Are you able to store the medicines properly (if you can have them to take at home)?
   Addressing problems of shelf life and claimed efficacy of medicines.

ANALYSIS OF RESPONSES WILL HELP ASSESS:

- **Availability** of centrally procured medicines for patients in the regions (A1-3; A1-4; B1-1, B1-2)
- **Covering** the need for quality medicines (A1-4; B1-2; B1-3)
- **Timeliness** of provision of medicines to patients (A1-1; A1-2; A1-5)
- **Transparency** of the distribution of medicines in the regions and readiness to communicate with the public (A1-6; A1-7)
- **Effective communication and up-to-date information** (A2-1–A2-11; B2-1 – B2-8).
## Annex 2

### QUESTIONNAIRE TO INTERVIEW A CHILD WITH ONCOHAEMATOLOGICAL DISEASES

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Date of survey</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>Age of patient/child (full years)</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>Sex of patient</td>
<td>□ Female □ Male</td>
</tr>
<tr>
<td>4.</td>
<td>Place of treatment</td>
<td>Name of facility</td>
</tr>
<tr>
<td>5.</td>
<td>When did the treatment start?</td>
<td>Month Year</td>
</tr>
<tr>
<td>7.</td>
<td>Did you receive medicines for free?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>9.</td>
<td>If so, when did you receive them?</td>
<td>□ At the beginning of treatment □ In the course of treatment</td>
</tr>
</tbody>
</table>
10. Have you been asked to make a donation to receive free medicines?  
- [ ] Yes  
- [ ] No

11. Have you refused any free medicines that you have been offered?  
- [ ] Yes  
- [ ] No

12. If so, why did you refuse the free medicines?

13. Where did you buy medicines?  
- [ ] Pharmacy at a hospital  
- [ ] Another pharmacy  
- [ ] Internet  
- [ ] A health practitioner in a unit  
- [ ] Representative of a company  
- [ ] Other

14. What problems did you face while receiving your medicines?  
- [ ] Unaffordable cost of medicines  
- [ ] Lack of medicines in pharmacies  
- [ ] Delay in delivery of promised free medicines

15. Other problems
### QUESTIONS ON MEDICINE SUPPLY

1. Date of survey

2. Name of hospital

3. How many children with cancer are currently registered with your hospital?

4. Does the amount of medicines requested by the hospital for patients meet 100% of the need?  
   - [ ] Yes  
   - [ ] No  
   If NO, why were you unable to request 100% of the medicines necessary?

5. What problems did the hospital management have when requesting medicines?

6. What problems did the hospital management have with obtaining medicines for the hospital?

7. Other problems
# NARRATIVE REPORT

## Project ID:

## Project title:

## Date of report:

## Name of CSO:

## Location:

## Reporting period:

### 1.

<table>
<thead>
<tr>
<th>#</th>
<th>Planned activities</th>
<th>Completed activities and results</th>
<th>Confirmation materials / comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Monitoring the formation of the need for medicines</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Monitoring the delivery of medicines from the Ministry of Health to a hospital</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Monitoring of updating patients about available medicines in a hospital</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Interviewing patients who received/did not receive free medicines</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Problem analysis (stage by stage), other aspects of medicine delivery and distribution</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Creating information materials</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. Please describe the main steps in monitoring and collecting information (name, location and number of health care facilities, number of doctors/patients), results, problems, lessons learned, recommendations for improving the monitoring of medicine use in the future.

3. Please list from three to five key project results and describe the follow-up steps (if you are going to follow up the project after it is over).

In the Planned activities column, the implementing partners should specify the planned activities in more detail than shown in the table above, providing specific details about their project — for example, the region being monitored, specific names of activities/programmes, additional activities related to the selected nosology etc. The Completed activities and results column should describe what you did and what you achieved/accomplished.
Examples of activities completed:

- An information request (§) was sent to the Department of Health of the State Oblast Administration […] on…
- Requests from health care facilities for centralized procurement of medicines analysed…
- Interview with the head of unit of a health care facility conducted…
- A survey of patients was conducted between October and November of the year…

Examples of results:

- Based on the responses to information requests and open sources of the Ministry of Health of Ukraine, the process of formation of the need for free medicines under programme […] in […] region for the year […] was analysed…
- A discrepancy between the state funds allocated for the procurement of medicines and the funds available was identified; the deficit is…
- Significant differences in the management system for [nosology] between regions A and B have been identified. They are due to the total centralization of medicine storage in the regional clinical hospital in region A. This results in a statistically lower level of patient satisfaction with the availability of medicines in region B. Patients only contact the hospital in 10 percent of the cases when they need medicines.
- As the project created information materials, the experience of patient monitoring of access to free medicines under the programme […] has become available to patients, doctors, NGOs and charitable foundations working in the field of access to free treatment for patients at all levels…

To confirm the implementation of project activities, the implementing partners should supplement their programme reports with relevant documents/attachments. These may be:

- copies of information requests to public authorities, as well as copies of responses to them;
- consolidated regional requests for centralized medicine procurement;
- the completed table ‘Medicine Supply Data’ (to be filled in based on information collected under Block A using the list of medicines that were subject to monitoring (the list is provided by the customer), as well as the questions provided in the sections ‘Monitoring of Official Information’ and ‘Surveys/questionnaires’ of the Guidelines); or
- completed questionnaires (with online data entry on one of the services such as SurveyMonkey, Google Forms, Survio, Typeform, Simpoll etc.), and others.

The list of annexes is indicated in the Confirmation materials/comments column. Where appropriate, clarification/explanation of activities completed/not completed and the results is also provided.

In addition to the programme report, a narrative project report may also be submitted. To draft it, the implementing partners may use guiding questions from the subsection ‘Step 4. Analysis of Information’ of the Guidelines.
SUMMARY REPORT OF THE RESULTS OF PUBLIC MONITORING OF THE DELIVERY AND USE OF MEDICINES IN 2016–2017

Executive Summary

The United Nations Development Programme (UNDP) assists the Ministry of Health (MoH) of Ukraine in reforming the state medical procurement system. From 2015 to 2019, in the framework of the project ‘Procurement Support Services to the Ministry of Health of Ukraine’, UNDP has been procuring a range of medicines and related medical products to ensure patients have access to them locally.

In 2018 a short-term, small grants project ‘Public Monitoring of the Delivery, Availability and Use of Medicines at the Local Level’ was implemented in four regions (Dnipro, Zaporizhzhia, Vinnytsia and Chernihiv) to monitor the actual situation regarding the availability of medicines procured by UNDP from the MoH budget for adult patients with haemophilia and children with oncohaematology, as well as to obtain data on the timeliness and quantity of medicines delivered to warehouses and health care facilities in the regions.

Four selected organizations monitored the situation – each in two regions under one of two directions:

<table>
<thead>
<tr>
<th>Direction/Region</th>
<th>Dnipro</th>
<th>Zaporizhzhia</th>
<th>Vinnytsia</th>
<th>Chernihiv</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child oncohaematology</td>
<td>CFP ‘Drop of blood’</td>
<td>CFP ‘Drop of blood’</td>
<td>CF ‘STOP Cancer’</td>
<td>CF ‘STOP Cancer’</td>
</tr>
<tr>
<td>Adult haemophilia</td>
<td>Ukrainian Association for Haemophilia and Haemostasis ‘Factor D’</td>
<td>Ukrainian Association for Haemophilia and Haemostasis ‘Factor D’</td>
<td>CF ‘Children with haemophilia’</td>
<td>CF ‘Children with haemophilia’</td>
</tr>
</tbody>
</table>

The implementing partners gathered information using the methodology developed by UNDP with two sections: Section A. Delivery of medicines and Section B. Use of medicines.

Health care facilities in the regions that received medicines under the ‘Child oncohaematology’ programme:

<table>
<thead>
<tr>
<th>Region</th>
<th>Health care facility</th>
<th>Web page on eliky.in.ua or liky.ua</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dnipro</td>
<td>Dnipropetrovsk Oblast Children’s Clinical Hospital</td>
<td><a href="http://dnipro.liky.ua/#/medicationInHospital/499">http://dnipro.liky.ua/#/medicationInHospital/499</a></td>
</tr>
<tr>
<td>Zaporizhzhia</td>
<td>Zaporizhzhia Oblast Children’s Clinical Hospital</td>
<td>-</td>
</tr>
<tr>
<td>Vinnytsia</td>
<td>Vinnytsia Oblast Children’s Clinical Hospital</td>
<td><a href="https://eliky.in.ua/hospital/776">https://eliky.in.ua/hospital/776</a></td>
</tr>
<tr>
<td>Chernihiv</td>
<td>Chernihiv Oblast Children’s Hospital</td>
<td>-</td>
</tr>
</tbody>
</table>

Health care facilities in the regions that received medicines under the ‘Adult haemophilia’ programme:

<table>
<thead>
<tr>
<th>Region</th>
<th>Health care facility</th>
<th>Web page on eliky.in.ua or liky.ua</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dnipro</td>
<td>Dnipropetrovsk Multi-field Clinical Hospital No. 4. From here, medicines are distributed to other health care facilities in the oblast, such as the oblast blood transfusion station, haematology divisions in Kryvyi Rih and Kamianske, as well as primary health care centres and some rayon hospitals, to improve access to treatment.</td>
<td><a href="http://dnipro.liky.ua/#/medicationInHospital/448">http://dnipro.liky.ua/#/medicationInHospital/448</a> due to the pharmacist’s workload, information on medicine stocks is updated on the printouts displayed in the hospital, but not on the website</td>
</tr>
<tr>
<td>Zaporizhzhia</td>
<td>Zaporizhzhia Oblast Clinical Hospital</td>
<td><a href="https://eliky.in.ua/hospital/420">https://eliky.in.ua/hospital/420</a> information is not updated</td>
</tr>
</tbody>
</table>
Vinnytsia: The Mykola Pyrohov Vinnytsia Oblast Clinical Hospital

Chernihiv: Chernihiv Oblast Oncological Hospital, oncohaematology division

Information on medicine stocks is updated regularly.

Total number of children interviewed: 203 (children’s parents or guardians were interviewed).

Total number of adults with haemophilia interviewed: 101. Some patients were interviewed by phone, and some filled in the questionnaires themselves.

**FINDINGS**

1) PLANNING/REGIONS’ NEEDS

According to the implementing partners, the regions’ needs for medicines for child oncology patients are difficult to quantify accurately due to the lack of an effective methodology. At present, regional quotas are formed, as a rule, according to the average number of patients per year, and in Chernihiv, for example, for the last five years. The monetary quota is sufficient for about 90–110 percent of the need. In addition, some medicines are not included in the nomenclature of the MoH of Ukraine; medicines that are not listed in it cannot be procured locally. When calculating their needs, doctors follow an informal rule and include the most expensive medicines in their application for funds, as cheaper ones can be purchased later from local budgets or by patients.

Regional quotas for the procurement of medicines and medical products for adults with haemophilia are calculated according to the actual or average number of patients (depending on the region), regardless of the severity of the disease. However, the complexity of the calculation is caused by an unknown exact number of patients for each nosology; as a rule, a certain possible range is indicated, since there is no register of patients and the lists are not updated.

Some patients buy medicines themselves and do not attend a hospital for years; therefore, their needs are not taken into account when calculating the quota. Typically, only a certain percentage of the patients with serious cases attend hospitals regularly, and the calculation is mainly based on their needs, approximately, with no consideration for home treatment and prevention.

However, civil society organizations, referring to international documents, in particular the relevant Resolution of the Committee of Ministers of the Council of Europe,¹ insist that the calculation should be based on the total population of the country/region, rather than on the basis of an officially registered number of patients. The actual provision of medicines for patients with haemophilia (25 percent of the minimum requirement in accordance with the recommendations of the Council of Europe) currently corresponds only to the ‘minimum survival level’ (the term used by the World Federation of Hemophilia and the World Health Organization, which is FVIII 1 international unit (IU) per capita), which is typical of the poorest countries in the world.

In addition, when calculating the quota for the region, the number of patients with the inhibitory form of haemophilia should also be taken into account (the high cost of medicines for such patients may result in a budget deficit, as, for example, in Vinnytsia oblast).

Also, the comparison of orders for medicines for the ‘Adult haemophilia’ programme in different regions showed that there was a certain looseness in choosing the quantity and nomenclature of medicines. In particular, this can be seen in the proportions between shunting anti-inhibitor medicines (eptacog-alpha and anti-inhibitory coagulant complex), the quantity of desmopressin (not included in the requests from Zaporizhzhia, Vinnytsia and Chernihiv oblasts), the proportions of medicines for treatment of the same nosology (plasma ones, recombinant ones, different brands) etc.

2) DISTRIBUTION OF MEDICINES

According to the executive partners, the system for distributing medicines at present is not a ‘weak link’ in the management system of the ‘Child oncohaematology’ and ‘Adult haemophilia’ programmes in Ukraine. Medicines are delivered to the MoH warehouses stably and regularly, but the intervals between the arrival of medicines and the issuance of orders by the MoH may vary from two weeks to two months. The oblast health departments prepare their orders quite promptly, even taking into account the larger ‘logistical leg’ in Dnipropetrovsk oblast, as the medicines for the treatment of haemophilia there need to be distributed among several health facilities. Usually medicines reach hospitals from the central warehouse in Kyiv within one day.

At the same time, the oncologists interviewed pointed out the unsystematic and unplanned character of deliveries of medicines. Doctors in both programmes mentioned the lack of information on delivery dates under previous requests (2016 and 2017).

3) THE QUANTITY OF MEDICINES OBTAINED BY AND AVAILABLE IN MEDICAL FACILITIES

The quantity of medicines received was mainly in line with the requests submitted to the MoH, except for between one and three positions in each region (the reasons included the replacement of dosage forms, as well as the absence of an MoH distribution order). The hospitals where children with oncohaematology receive treatment had some remaining stocks of medicines in several positions at the time of preparing requests. The hospitals where patients with haemophilia are treated did not have any remaining stocks of medicines at the time. Also, a certain amount of medicines was received due to savings made in 2016 (the quantity of medicines was determined by the MoH).

Patients with haemophilia A indicated an increase in the number of medicines in hospitals. Patients with an inhibitory form of haemophilia A – haemophilia B – indicated an insufficient quantity of medicines for urgent treatment.

4) LEVEL OF PATIENTS’ SATISFACTION/AVAILABILITY OF TREATMENT

The system of procurement through international organizations has made it possible to minimize the number of cases of refusals among patients by ensuring the appropriate quality of medicines procured. For the most part, the parents/guardians of child oncology patients did not have any complaints regarding the quality of medicines they received at the medical facilities during treatment.

Since 2016 there has been only one known case of a complete refusal due to parents’ lack of confidence in the procurement by the MoH, in particular in the quality of the medicines purchased, and a few cases of refusal of certain generic forms of medicines (three patients in Dnipro and four in Zaporizhzhia), as parents preferred the branded forms of the medicines. A significant proportion of respondents with haemophilia refused to use the BioKlot A medicine produced in Ukraine (29 percent of those interviewed in Dnipropetrovsk oblast, 19 percent in Zaporizhzhia oblast and 6 percent in Vinnytsia oblast) because of its side effects and its lack of therapeutic effect (UNDP refused to procure this medicine in 2017–2018).

The system for the treatment of haemophilia in Ukraine targets the treatment of consequences, rather than the effective provision of timely assistance. The vast majority of patients with haemophilia in Dnipro (94 percent) and Zaporizhzhia (88 percent) oblasts receive only urgent treatment (during the interview they indicated that they would also like to receive preventive and home-based treatment). Other patients (6 percent in Dnipropetrovsk oblast and 12 percent in Zaporizhzhia oblast) did not attend a hospital during the previous year. In both oblasts, patients use inpatient care in only 10 percent of cases of bleeding when they need help (factor infusion).

\[\text{Preventive treatment is the only treatment for haemophilia that enables complications to be avoided. When used in adulthood (as secondary prevention), it helps improve the patient's quality of life.}\]
Patients in Vinnytsia and Chernihiv oblasts, especially those living in rayon centres, pointed out that they attend a hospital in less than 50 percent of cases requiring factor infusion. Medicines are more accessible for patients living directly in oblast centres. Most patients are unable to receive treatment in the assigned health facilities (either due to their health condition or because it is difficult to get there).

The possibility of receiving only urgent treatment in a hospital setting and the lack of home treatment create, on the one hand, an excessive burden on the health care system and leads to an unnecessary social burden (calling an ambulance, additional tests, long stays in hospital, increased consumption of the factor, treatment of the consequences of the absence of assistance, the need for rehabilitation etc.); on the other hand, they are the main reasons for patients’ low level of satisfaction with the haemophilia management system in Ukraine, surpassing the medicine shortages and supply disruptions in the past (2015–2017).

At the same time, according to oncologists, the situation regarding the provision of medicines for the treatment of children with oncological and oncohaematological diseases is not catastrophic. What is not procured by the State or what is delayed is covered by local budgets and charitable foundations. Haematologists in Dnipropetrovsk and Zaporizhzhia oblasts are satisfied with the level of supply of blood-clotting factors, pointing out that in 2017–2018 the MoH quotas assigned for each region met 100 percent of the need. According to the haematologist at the Mykola Pyrohov Vinnytsia Oblast Clinical Hospital, in Vinnytsia oblast the budget deficit is 50 percent of the quota allocated by the MoH for the procurement of clotting factors. However, Chernihiv oblast is better supplied with blood-clotting factors with a lower budget, since in Vinnytsia oblast there are eight patients with an inhibitory haemophilia who need very expensive medicines for treatment.

5) DIFFICULTIES FACED BY PATIENTS

Among the difficulties they faced, the parents/guardians of child oncology patients named the following: delayed delivery of promised free medicines; too high prices for medicines in pharmacies; a lack of medicines in pharmacies in the city; low professional standards of nursing staff; insufficient number of doctors and medical staff; partial compensation for the cost of medicines from charitable foundations and volunteers (it should be noted that during the interviews patients refused to give specific examples); and the provision of generic forms of medicines when parents prefer originals.

Patients with haemophilia indicate that there are no diagnostics available to identify the level of factor and the presence of inhibitors, and there is no preventive treatment that helps avoid complications of haemophilia and in adulthood (as secondary prevention) can improve the patient’s quality of life. In addition, they mention the lack of a home-based model for patients to receive medicines at home, rather than attending a hospital each time; the absence of medicines at the health care facilities in their place of residence (as has been possible in Dnipropetrovsk oblast since 2018); and the absence of clotting factors across the pharmacy network, mainly due to the high cost and specifics of procurement (none of the patients interviewed could afford to buy these medicines regularly from pharmacies at the official price, but the possibility of distributing the medicines purchased through tender procedures through the pharmacy network, similar to many countries in Europe, is welcomed by patients).

Also, in 2015–2017 there were delays in the delivery of medicines procured by the MoH (during the transition period of transferring the procurement from the Ministry). In 2018 the delivery of factors became stable and systematic. Also, patients are worried about insufficient quantities of medicines, even for effective urgent care (the dose is often reduced to a minimum, and patients who are suffering from haemophilia complicated by inhibitors do not receive enough medicines because the hospital cannot order the quantity needed, due to their very high cost). The impossibility of infusing the factor in an emergency, at night or at weekends is also a serious problem. In addition, there are no medicines for rehabilitation and endoprosthetics, and hospitals are poorly supplied with medical products (syringes, cotton wool, bandages, reagents for tests) and accompanying medicines for the treatment of patients with haemophilia (such as tranexamic acid, haemostatic sponge, anaesthetic).
6) TRANSPARENCY OF DELIVERY AND USE OF MEDICINES

The delivery of medicines and medical products from the central warehouse of the MoH to the warehouse of the health care facility is usually carried out without delays, within one day. Before the medicines are despatched, SE Ukrmepostach of the MoH notifies the regional department of health of the delivery. However, neither the MoH nor Ukrmepostach informs the regions about delivery dates in advance. For instance, the medicine Dacarbazine was delivered to Ukrmepostach by 31 October 2018, but close to the end of the year there had still been no distribution orders.

Not all the health facilities that have been monitored within the project have pages on the eliky.in.ua or liky.ua websites (in particular, Zaporizhzhia Oblast Children's Clinical Hospital and Chernihiv Oblast Children's Hospital). Those that do have pages, however, do not necessarily update the information on them (for example, Dnipropetrovsk Multi-field Clinical Hospital No. 4 updates the data on medicines only on printouts on display in the hospital but not on the website, due to the workload of its pharmacist). The interviews with the parents/guardians of child oncology patients in Vinnytsia and Chernihiv oblasts revealed that none of the respondents knew that they could ask a doctor for the list of medicines procured from the state budget and currently available in the hospital. In Vinnytsia oblast, such a list is placed on the hospital's premises and on its website; in Chernihiv oblast, there is no such list in the hospital, and the hospital does not have a website. In contrast, information on the availability of medicines for patients with haemophilia in Vinnytsia and Chernihiv oblasts is regularly updated on the websites of the respective health care facilities.

7) HOW PATIENTS RECEIVED MEDICINES

In all the regions covered by the project, the patients interviewed received medicines for free, except for one child in Dnipropetrovsk Oblast Children's Clinical Hospital; the parents bought drugs from the hospital pharmacy due to a delayed delivery.

A significant number of patients in Dnipropetrovsk (37 percent) and Zaporizhzhia (38 percent) oblasts reported that they were asked to make a charitable donation to a hospital fund. According to medical staff, money from this fund is used for laboratory tests and detergents. In contrast, none of the patients in Vinnytsia and Chernihiv oblasts indicated they had been asked for charitable contributions.

8) IMPLEMENTING PARTNERS

The local project partners (Charitable Fund of Patients ‘Drop of Blood’, Charitable Foundation ‘STOP Cancer’, Ukrainian Association for Haemophilia and Haemostasis ‘Factor D’, Charitable Foundation ‘Children with Haemophilia’) carried out diligent, quality data collection and situation analyses, despite difficulties in accessing patients (those who were not in hospitals at the time of the interviews) and the lack of willingness of individual haematologists to communicate and provide information. The organizations plan to disseminate the results of their work on this project among the communities in their regions (through the Internet, on social networks and at special events) and use the knowledge gained for further, better advocacy for the right of oncology and haemophilia patients to free medicines.
RECOMMENDATIONS

MoH

- The Central Procurement Agency needs to carefully plan the timing of procurement tenders and delivery of medicines to the regions, taking into account the specifics of each nosology, to ensure the uninterrupted delivery of medicines throughout the whole process.

- Ensure that quality control mechanisms are in place in the work of the Central Procurement Agency, to avoid patients’ refusals of medicines due to their inadequate quality.

- To calculate a regional quota for medicines, create a permanent expert council consisting of oncologists, haematologists, economists and statisticians who would develop a list of the medicines needed for the next year considering not only medical but also economic factors.

- Develop a methodology for calculating 100 percent of the need for medicines for the regions, to ensure more effective treatment and provision of medicines; medicines should not be ordered for a year, but for a maximum of six months.

- Adopt international standards and recommendations for the treatment of haemophilia (in particular, those set out in the Resolution of the Committee of Ministers of the Council of Europe),\(^3\) to improve the quality of treatment and provision of necessary medicines.

- Improve communication between the MoH and health facilities, and make the information about expected delivery times available to doctors, which will allow better planning of treatment for patients. Establish clear timelines and schedules for the delivery of medicines to the regions.

- Develop and introduce the All-Ukrainian electronic system for the accounting of medicines procured from state funds, to record the entire movement of medicines from the MoH warehouse to the patient’s hands.

- Develop the nomenclature of the MoH, and include medicines that are not listed in it.

- At the legislative level, introduce the concept of preventive treatment for patients with haemophilia.

- Set up a kind of central warehouse that will store medicines that can be transferred to the regional oncohaematology divisions in case of urgent need.

- Continue the implementation of the haemophilia treatment system at the primary health care level in Dnipropetrovsk oblast, and consider the possibility of extending this experience to other oblasts.

- Distribute the budget among the regions based on the number of patients with the inhibitory form of haemophilia and also the severity of the disease of each patient, not only based on the quantitative indicators of the number of patients.

- Optimally plan the needs of the regions to ensure accurate diagnosis of various types of haemorrhagic conditions.

- Bring the supply of medicines for patients with haemophilia up to at least the minimum recommended by the Committee of Ministers of the Council of Europe for participating countries: FVIII 4 IU per capita; FIX 0.5 IU per capita.

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**OBLAST STATE ADMINISTRATIONS**

- At the stage when oblast specialists plan the requests for medicines, ensure the objectivity of this process and correspondence to the actual needs of patients.

- Introduce home treatment of haemophilia at the regional level, which would reduce the burden on health care facilities, allow multiple complications of the disease to be avoided and improve patients' quality of life at minimal additional cost to the state budget.

**HOSPITALS**

- Systematize and keep up-to-date registers of patients with haemophilia.

- Take steps to employ a sufficient number of medical staff, and improve the system for motivating and training doctors.

**NGOs**

- Place all information materials on their websites, forums and social network pages.

- Share the experience and successful project practices among the patient community at the national and regional levels, as well as among doctors and representatives of national and regional authorities.

- Use the project findings to further advocate for citizens’ right to access quality and timely treatment and prevention services.