EASO
Ukraine
FFM report – healthcare reform and economic accessibility

Medical Country of Origin Information Report

February 2021
Acknowledgements

EASO is the drafter of this report.

The following departments and organisations have reviewed the report:

- Belgian Desk on Accessibility (BDA);
- Country of Origin Information Division, Office for Foreigners, Poland; and
- COI Information Desk, Federal Office for Migration and Refugees, Germany.

It must be noted that the review carried out by the mentioned departments, experts or organisations contributes to the overall quality of the report, but does not necessarily imply their formal endorsement of the final report, which is the full responsibility of EASO.
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Disclaimer

This report was written according to the EASO COI Report Methodology (2019). This report is based on carefully selected, publicly available sources of information as well as anonymous sources based in the country of origin. All sources used are referenced.

The information contained in this report has been researched, evaluated and analysed with utmost care. However, this document does not claim to be exhaustive. If a particular event, person or organisation is not mentioned in the report, this does not mean that the event has not taken place or that the person or organisation does not exist.

Furthermore, this report is not conclusive as to the determination or merit of any particular application for international protection. Terminology used should not be regarded as indicative of a particular legal position.

‘Refugee’, ‘risk’ and similar terminology are used as generic terminology and not in the legal sense as applied in the EU Asylum Acquis, the 1951 Refugee Convention and the 1967 Protocol relating to the Status of Refugees.

Neither EASO nor any person acting on its behalf may be held responsible for the use which may be made of the information contained in this report.

The drafting of this report was finalised in November 2020. Any event taking place after this date is not included in this report. More information on the reference period for this report can be found in the methodology section of the Introduction.

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1 The 2019 EASO COI Report Methodology can be downloaded from the EASO COI Portal [url].
# Glossary and Abbreviations

<table>
<thead>
<tr>
<th>Abbrev.</th>
<th>Explanation</th>
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<tbody>
<tr>
<td>AMP</td>
<td>Affordable Medicines Programme</td>
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<tr>
<td>ANTAC</td>
<td>Anti-Corruption Action Centre</td>
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<td>ART</td>
<td>Anti-retroviral therapy</td>
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<tr>
<td>ARV</td>
<td>Antiretroviral</td>
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<tr>
<td>CBT</td>
<td>cognitive behaviour therapy</td>
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<tr>
<td>CT</td>
<td>Computed Tomography</td>
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<tr>
<td>DOT</td>
<td>Directly Observed Therapy</td>
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<td>EMA</td>
<td>European Medicines Agency</td>
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<td>EMDR</td>
<td>Eye Movement Desensitization and Reprocessing</td>
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<td>EML</td>
<td>Essential Medicines List</td>
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<tr>
<td>FDA</td>
<td>U.S. Food and Drug Administration</td>
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<tr>
<td>GDP</td>
<td>Gross Domestic Product</td>
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<tr>
<td>GMP</td>
<td>Good Manufacturing Practice</td>
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<tr>
<td>HIV</td>
<td>human immunodeficiency virus</td>
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<tr>
<td>HTA</td>
<td>Health Technology Assessment</td>
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<tr>
<td>INN</td>
<td>International Non-proprietary Names</td>
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<tr>
<td>MDR TB</td>
<td>Multidrug resistant tuberculosis</td>
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<tr>
<td>MoH</td>
<td>Ministry of Health</td>
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<tr>
<td>MRI</td>
<td>Magnetic Resonance Imaging</td>
</tr>
<tr>
<td>MRTD</td>
<td>Measles-Rubella-Tetanus-Diphtheria</td>
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<tr>
<td>MS</td>
<td>Multiple sclerosis</td>
</tr>
<tr>
<td>NCSP Okhmatdyt</td>
<td>National Children’s Specialised Hospital “Okhmatdyt”</td>
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<tr>
<td>NHSU</td>
<td>National Health Service of Ukraine</td>
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<tr>
<td>Oblast</td>
<td>Region. There are 24 administrative units, oblasts, in Ukraine.</td>
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<tr>
<td>OOP</td>
<td>Out of pocket</td>
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<tr>
<td>OST</td>
<td>Opioid Substitution Therapy</td>
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<tr>
<td>PCR</td>
<td>Polymerase chain reaction</td>
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<tr>
<td>PET</td>
<td>Positron Emission Tomography</td>
</tr>
<tr>
<td>Raion</td>
<td>The second level of administrative division in Ukraine, below oblasts.</td>
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<tr>
<td>TB</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
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<tr>
<td>--------------------</td>
<td>------------------------------------------------</td>
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<tr>
<td>Verkhovna Rada</td>
<td>The parliament of Ukraine</td>
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<td>XDR TB</td>
<td>Extensively drug resistant tuberculosis</td>
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Introduction

This report, written by EASO, is the result of a Fact-Finding Mission (FFM) to Ukraine from 9 March 2020 to 13 March 2020 and supplemented by further desk research. The report draws on carefully selected sources that are referenced in the report. The information provided has been researched, evaluated and processed with utmost care within a limited time frame.

Methodology

This report is produced in line with the EASO COI Report Methodology (2019) and the EASO COI Writing and Referencing Style Guide (2019).

Defining the terms of reference

The main objectives of the fact-finding mission were to study the implementation of the healthcare reform and to collect information in general on the state of the healthcare sector, its limitations and its capacity, as well as finding information on the accessibility of the Ukrainian public healthcare system, especially in terms of economical access (cost to the patient to access treatments and medications), was also included in the objectives. See also Annex 2: Terms of Reference.

Collecting information

The FFM took place in Kiev between 9-13 March 2020. A mixture of interlocutors were interviewed to get multiple viewpoints on the topics included in the scope. Representatives from governmental ministries, NGOs, public healthcare facilities, private healthcare facilities, and international organisations were included in the programme. In addition, desk research took place between 28 October and 25 November 2020 to collect supplementary information. Additional interviews focused on the third phase of the reform took place via video link on 23 and 25 November 2020. Following suggestions from peer reviewers, more information on healthcare insurance coverage was collected in an interview via video link with the National Health Services of Ukraine (NHSU) on 26 January 2021.

Sources

The EASO delegation met with representatives from the following organisations (brief descriptions of each organization based on the information provided on their websites):

**NGOs:**

A joint meeting with CF Patients of Ukraine and representatives of various patient organisations, representing patients with Multiple Sclerosis (MS), Parkinson disease, mental health disorders, haemophilia, juvenile arthritis, oncologic diseases, and Crohn disease.

CF Patients of Ukraine: a Charitable Foundation launched in late 2010. It is a specialised association of patients that allows them to lobby their interests in front of the State and of pharmaceutical companies. 

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2 EASO, EASO Country of Origin Information (COI) Report Methodology, June 2019, url

3 EASO, Writing and Referencing Guide for EASO Country of Origin Information (COI) Reports, June 2019, url

4 CF Patients of Ukraine, [website], n.d., url
Anti-Corruption Action Centre (ANTAC): a civic society organisation fighting corruption in Ukraine. It also develops legislation, seeks to prosecute corrupt officials, and supports partners to make efficient systemic changes in Ukraine.  

International Renaissance Foundation: one of the largest charitable foundations in Ukraine. It works towards the protection of human rights and towards the use of positive change for the citizens’ benefit. It is part of the Open Society Foundations network.

100% Life: the largest patient-led organisation in Ukraine, working to improve access of care for patients with HIV and TB. It developed the e-health system and is the leading partner of Ukraine’s government in the implementation of the healthcare system reform.

International organisations:
UNAIDS: a Joint United Nations Programme on HIV and AIDS.

International Organization for Migration (IOM): the leading inter-governmental organisation in the field of migration; it works closely with governmental, intergovernmental and non-governmental partners. It is part of the United Nations system.

World Health Organization: its main role is to direct and coordinate international health within the United Nations system.

State actors:
National Health Service of Ukraine (NHSU): the central executive body that implements state policy in the field of state financial guarantees for healthcare services of the population. The NHSU’s activities are directed and coordinated by the Cabinet of Ministers of Ukraine through the Minister of Health.

Oleksandra Ustinova: Opposition Member of Parliament (Verkhovna Rada), member of the Verkhovna Rada Committee on the Prevention and Counteraction of Corruption.

Public Health Center: a state institution responsible for maintaining and strengthening public health through the control of infectious diseases, health promotion, and research.

State Expert Center: the main function of the State Expert Center of the Ministry of Health of Ukraine is to provide scientific and organisational support for the justification of the permit for medical use of only high-quality, effective and safe drugs. The State Expert Center functions as the national registration authority of medication.

HTA Department of the State Expert Center: this department performs Health Technology Assessments (HTA). An HTA reviews the medical, economic, organisational, social and ethical issues related to the use of a certain health technology in a systematic and multidisciplinary way. This includes the impact and the cost-effectiveness of medicines, medical devices, and treatment regimens for state coverage.

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5 ANTAC (Anticorruption Action Centre), [website], n.d., url
6 IRF (International Renaissance Foundation), [website], n.d., url
7 100% Life, [website], n.d., url
8 UNAIDS, [website], n.d., url
9 IOM (International Organization for Migration), [website], n.d., url
10 WHO (World Health Organization), [website], n.d., url
11 NHSU (National Health Service of Ukraine), [website], n.d., url
12 Public Health Center, [website], n.d., url
13 State Expert Center, [website], n.d., url
Healthcare facilities:
Specialised Hospital for Children Okhmatdyt: a diversified diagnostic medical institution that provides specialised high-quality medical care for children.\(^{14}\)

A pharmacist working at a private hospital pharmacy.

Clinic Boris, Andrey Raschupkin (Head of clinic): Clinic Boris is a private healthcare clinic in Kiev delivering a wide range of medical services.\(^{15}\)

National Cancer Institute: a clinically and research-accredited oncology centre.\(^{16}\)

The first draft of the report or the notes were sent to the interviewed sources. All suggested changes from the sources were implemented in the report.

In addition, desk research was conducted and its findings were included in the report. Desk research was conducted using open source and publicly available information. Desk research was used to either cover any gaps in the information provided after the interviewing process or to include more up to date, if available, information, following the FFM. Desk research was not the primary method of information collection for this report.

Quality control

In order to ensure that the EASO COI Report Methodology and the EASO Writing and Referencing Guide were respected, a review was carried out by COI specialists from Belgium, Poland and Germany, and by EASO staff. Additionally, the first draft of the report and/or interview notes were sent to the interlocutors in Ukraine for comments. All comments made by the reviewers and interlocutors were taken into consideration.

Structure and use of the report

The report is divided into five main chapters, covering the reform and general information of the healthcare system in the first chapter, and the National Health Insurance Services (NHSU) of Ukraine and health insurance aspects in the second. In the third chapter the focus is on out of pocket payments, and in the fourth the pharmaceutical sector is described. Lastly, the accessibility for specific groups are examined. The selection of these groups was based on the information needs of users of the MedCOI services as well as what information was provided during the FFM: discriminated groups; IDPs and the population in the non-government-controlled areas of Ukraine; patients with mental health disorders, patients with HIV/AIDS, patients with Tuberculosis (TB), patients with oncologic diseases, and paediatric patients.

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\(^{14}\) NCSP Okhmatdyt, [website], n.d., url

\(^{15}\) Clinic Boris, [website], n.d., url

\(^{16}\) National Cancer Institute, [website], n.d., url
Map 1: Ukraine © United Nations.¹⁷

¹⁷ United Nations, Ukraine, Map. No. 3773 Rev. 6, March 2014, url
1. Healthcare system and reform

1.1. Background to the reform

Ukraine inherited the Soviet centralised healthcare system, which in theory meant free healthcare for all. In practice, according to the Ministry of Health, this meant the ‘budget deficits, economic crises, and a lack of reform resulted in a “parallel world” where one had to solve healthcare problems through out-of-pocket informal payments and bribes’ and nevertheless received ‘rather disappointing’ medical treatment results. 18 A 2018 article published by the Friedrich Ebert Foundation noted that the postponement of the healthcare sector reform resulted in crises in the healthcare sector, with people having to pay themselves for over 50% of medical services. 19 Similarly, the Ministry of Health of Ukraine (MoH) has stated that, under the old system, individuals had to pay themselves for healthcare or even resort to bribing. 20

Therefore, in late 2017, a law was passed by the Verkhovna Rada (Ukrainian parliament) to reform the healthcare system. 21 According to a 2020 article on healthcare transformations, the main goals of the reform in Ukraine were the following: at the primary level to ‘objectify’ the procedure of medical care provision, to link the medical care provision to the financing of the medical services, and to better control the expenditure of healthcare funds. 22 In order to achieve these goals, the National Health Service of Ukraine (NHSU) was established on 1 April 2018 (see also section: Role of NHSU). The same 2020 article further pointed out that ‘[t]he transition of PHC [primary healthcare] to the principles of general practice (family medicine) is the main direction of the reform of the Ukrainian national healthcare system.’ 24

1.2. The healthcare reform implementation

The reform is to be implemented in phases. The first phase, initiated in April 2018, mainly concerned the primary healthcare system. Through an information campaign created by the NHSU, the population of Ukraine was asked to choose a family doctor. This doctor could be based anywhere, not just in the area of residence. By March 2020, 30 million people chose a family doctor (about 80% of the population) 25 and by September 2020, 610 000 more made their choice. 26

Starting in July 2018, primary healthcare facilities received financing according to the services they provide. This is according to the adoption of a so-called ‘money-follows-the-patient model,’ which replaced the old structure of state-funded facilities. The new funding is organised by the NHSU. Family

20 Ukraine, Ministry of Health of Ukraine, Key steps to transforming Ukrainian healthcare, n.d., url.
doctors are paid according to how many patients (declarations) they take on, limited to a maximum of 2,000 adult patients and 1,800 child patients for regular reimbursements. Signing on patients beyond that grants lower reimbursement. 27 Higher fees are provided for elderly and child patients. 28

The second phase was launched on 1 April 2020 and involves a reform of the secondary level of healthcare (hospital care). At the time of the FFM interview, the NHSU was in the contracting phase but stated that facilities contracted with the NHSU by that time would receive payments through the NHSU. The facilities will receive payment per treated case. 29 Judyth Twigg, a professor with experience in global health with a focus on Ukraine, 30 noted that as of April 2020, hospitals are reimbursed based on the actual conditions and diseases they treat, and it would be up to the patients to select a facility based on the care offered and the outcomes. 31 Facilities not under contract received funding from local authorities. By March 2020, some 9,000 second line proposals had been received, as well as proposals from 1,722 specialist care facilities. 32

The third phase of the reform is planned for implementation in 2021 and will involve tertiary facilities, such as NCSP Okhmatdyt Children’s Hospital and the National Cancer Institute. In 2020, these facilities still remain in the old reimbursement system (budget based on number of beds). 33 Other planned changes for 2021 include changes in medication procurement. It is currently handled by the MoH, a central state authority or local authority. A separate procurement department will take over these duties. 34

1.3. Challenges and critical outcomes of the reform

1.3.1. Phase 1: Changes in primary healthcare

Official survey results, available in the National Health Index, indicate that 87% of the population in the last few years is satisfied with primary healthcare. 35 The World Health Organization (WHO) also noted that the result of the Health Index Ukraine 2019 survey showed high satisfaction levels. 36 On 5 November 2020, the MoH of Ukraine and the WHO signed a Cooperation Agreement. This Agreement will allow the development and implementation of strategies and reforms of health financing, with the goal being universal healthcare services coverage. In addition, the Agreement will improve access to essential medications, vaccines, primary healthcare equipment and diagnostics and the country’s preparedness for emergencies. 37

The interlocutors for WHO expressed optimism for the reform of the primary healthcare system, noting that it provides a good base for developments and that the already implemented phase one works. A challenge, however, is the decentralisation aspect of the reform. Local authorities are not trained or prepared to take on the decision-making responsibility, as they have historically always

27 National Health Services of Ukraine (NHSU), interview, Kiev, 12 March 2020.
29 National Health Services of Ukraine (NHSU), interview, Kiev, 12 March 2020.
30 Virginia Commonwealth University, Judyth Twigg, Ph.D., n.d., url.
31 Twigg, J., Ukraine’s healthcare system is in critical condition again, Atlantic Council, 21 July 2020, url.
32 National Health Services of Ukraine (NHSU), interview, Kiev, 12 March 2020.
33 National Health Services of Ukraine (NHSU), interview, Kiev, 12 March 2020.
35 National Health Services of Ukraine (NHSU), interview, Kiev, 12 March 2020.
36 World Health Organization (WHO), interview, Kiev, 10 March 2020.
37 Ukraine, Government Portal, Ministry of Health of Ukraine and the WHO have signed a two-year Cooperation Agreement, 5 November 2020, url.
received instructions from central authorities. This sentiment was echoed by a representative of the Public Health Centre, who stated that as money follows the patient, facilities will have to attract patients themselves. As they are not used to being responsible, this could result in chaos. A representative of WHO noted the same risk for mental health care, where local authorities now need to take decisions but still tend to wait for ministry decisions and orders.

With the reform, one source noted that family doctors’ monthly earnings increased from USD 200 to USD 450 on average, and up to USD 1,000-1,200 in some cases. The family doctors are therefore concerned the reform will be stopped. The International Renaissance Foundation (IRF) representative estimated that salaries for family doctors have increased from USD 200 (plus USD 200 in informal payments) to USD 500-700, so there is no need to ask for additional payments from patients. There is high satisfaction from patients with the family doctors after the reform. One consequence of the reform is that patients now consider it a bribe when doctors ask for payment for home visits, as these are not reimbursed by the NHSU. Patients do not need to pay for consultations with family doctors anymore.

Interlocutors from WHO pointed out that family doctor salaries have doubled or even tripled, and a family doctor now earns around UAH 16,000, or USD 500. This has resulted in an increase in the number of family doctors. As the reform had at the time of the interview not yet been implemented at the secondary level, WHO stated that salaries there were still low.

According to Ustinova, there were early on instances of family doctors who tried to trick NHSU, but NHSU keep track and will act if any fraud is detected.

Following the reform, family doctors will be responsible for testing and treating HIV patients. The doctors are encouraged to use rapid tests, the money for which must be paid through the money assigned to the doctor for the patient. Complicated cases will be referred to the second level (e.g. hospitals) and a specialist. Previously, only infectiologists could prescribe antiretrovirals (ARVs), but with the change family doctors will be able to prescribe it as well. The family doctors are provided with a list of questions to identify patients that should be tested. There is also a law in place which specifies which people should be tested for HIV, based on their history, symptoms, behaviour, and so on. Before the reform, HIV testing was usually only offered in specialised clinics. Once this change was implemented, HIV testing is now performed at each level of the healthcare system. The system of HIV testing includes three stages: screening, which is provided in all facilities; confirmation (sometimes using rapid tests), done in all facilities; and identification, which is done in specialised facilities.

Family doctors are supposed to refer patients to the regional levels, after which they can be referred to specialist tertiary hospitals like Okhmatdyt, after consultation with the head of department whether the patient should be treated at the hospital. Paediatricians should be available in the primary care facilities. While on paper a referral is needed to be treated at a tertiary hospital, the

38 World Health Organization (WHO), interview, Kiev, 10 March 2020.
40 World Health Organization (WHO), interview, Kiev, 10 March 2020.
41 Ustinova, Oleksandra, member of parliament, interview via Skype, 26 March 2020.
42 International Renaissance Foundation (IRF), interview, Kiev, 11 March 2020.
43 World Health Organization (WHO), interview, Kiev, 10 March 2020.
44 Ustinova, Oleksandra, member of parliament, interview via Skype, 26 March 2020.
48 World Health Organization (WHO), interview, Kiev, 10 March 2020.
49 Public Health Center, e-mail, 24 December 2020.
representative from Okhmaty t explained that this is not always followed, though the aim is a strict referral system. The representative from the National Cancer Institute also stated that while patients on paper need referrals from their family doctor to a secondary facility, and then referral to the tertiary Institute, this does not work in practice and some patients come directly to the Institute on their own. One third of the patients are sent by regional oncology centres, as the cases are regarded as too complex.

1.3.2. Phase 2: Secondary care reform and COVID-19 outbreak

1.3.2.1. Brief overview of COVID-19 situation in Ukraine

In the period between 3 January 2020 and 1 January 2021 there were 1 055 047 confirmed cases and 18 680 confirmed deaths from COVID-19 in Ukraine. According to a Universal Health Coverage Partnership September 2020 article, Ukraine acted rapidly to ensure that its population would not have to pay for COVID-19 treatment and testing.

1.3.2.2. The second phase of the reform and impact of COVID-19

The second stage of the healthcare reform mainly concerned a new health financing system. Before April 1st, 2020, money was allocated to the regions based on per capita, then allocated to the local councils to purchase health services from facilities. This system was described by NHSU as fragmented and inefficient, as one city could have both a city hospital, a raion hospital and an oblast hospital, often overlapping in functions. Service delivery budget was therefore concentrated in one pool which purchased the service for the whole population.

A specification of services was introduced, where each service was defined and described. For instance, a person hospitalised for palliative care would have access to pain management, medicines for treatment of co-morbidities, etc. All services were structured in 27 packages of services, some of which are very specific and others which are more general. Each package of service is defined and selection criteria for providers are described. Before the reform, this was not regulated so for instance deliveries could be done in facilities without anaesthesiologists.

The start of the pandemic coincided with a new cabinet of ministers, and some argued that the reform needed to be stopped. However, no new financing options were introduced, so instead new packages of services were introduced. These provided support to poor performing hospitals that according to the reform should have instead received reduced funding. According to the IRF interlocutor, the biggest achievement of the NHSU and MoH was to launch the second phase of the reform in April.
2020, despite the COVID outbreak in Ukraine and the lockdown instituted in late March and in April 2020. The representative further noted that in the situation with the emerging COVID outbreak, this was probably the best consensus to be reached. The compromise gave the actors a chance to optimise their systems, although the interlocutor noted that ineffective standards and practices cannot change overnight.59

The four additional COVID-19-related packages of services were for mobile teams taking samples for PCR testing at people’s homes; additional funding for emergency care; temporary funding for hospitals that in April 2020 received COVID-19 patients but were not meant to continue doing it as they did not have enough ventilators, anaesthesiologists, infectious disease specialists, etc.; and lastly, a big package of services was provided for the COVID-designated network. The MoH selected about 400 hospitals that had enough staff, oxygen, and ventilators, and specifically contracted them for COVID-19 care. During this time it was also revealed that the country only had 18 infectious disease hospitals, ranging from small district hospitals to large, oblast-level, well-performing hospitals. All those are now designated COVID-19 hospitals.60 The IRF interlocutor pointed out that key hospitals should have been audited for their supplies earlier on. Now, Ukraine has beds for COVID-19 patients, but not sufficient oxygen concentrators in all dedicated units. There are cases of patients that are placed in beds with intravenous therapy and not with steady and uninterrupted oxygen supply.61

Additionally, the IRF interlocutor stated that in reality most patients visited their family doctors and nurses rather than specialised facilities. Primary care was not included in the service package, and personal protective equipment (PPE) was mainly distributed to specialised facilities, not primary care facilities where most cases were discovered. This resulted in many health staff getting infected, and in some cases leaving their jobs for the private sector instead. The private sector has increased their prices slightly, about 10-15%, to cover for protective measures implemented.62

The outbreak caused other issues, such as hospitals having to cancel planned treatments for chronic disease care due to the lockdown, and hence deviate from the planned treatment plan the funding was based on. During the lockdown, emergency services functioned as normal, but the rest of healthcare services struggled as they could not meet expected targets. Patients were not referred, and the government had taken a decision to minimise planned care in this period.63

There was also an initiative to in parallel give extra payment to doctors and nurses involved in COVID care, to result in a 300% salary increase. Operationally, this has proven a very weak measure, according to the IRF representative. It caused additional administrative burden, was difficult to track and could be manipulated. Payments were not issued to the healthcare staff for several months, but supposedly COVID-funds were used for this measure.64

The representative from Patients of Ukraine noted that a key part of the reform is that patients referred by their family doctor to a hospital should not need to pay. However, there is still a lot of out of pocket (OOP) payments which the representative believes is due to two reasons: patients do not understand the reform, as there have been no information campaigns from the MoH to explain this part of the reform to the general public. Secondly, doctors do not explain the new system to patients. The doctors are used to a tradition of receiving ‘thank you’-payments from patients, and it is hard to

60 National Health Services of Ukraine (NHSU), interview via Webex, 26 January 2021.
61 International Renaissance Foundation (IRF), interview via Webex, 23 November 2020.
63 International Renaissance Foundation (IRF), interview via Webex, 23 November 2020.
64 International Renaissance Foundation (IRF), interview via Webex, 23 November 2020.
change this behaviour from one day to the next. Time is needed to change behaviours, but more concrete communication from the MoH is also needed.\textsuperscript{65}

The IRF representative stated that NHSU has stood strong throughout this period, while the Minister of Health has opposed the agency. The representative explained that there is a risk that the changes on the minister post will limit the transparency of the reform. Legislation passed in response to the COVID-19 outbreak allowed the temporary and quick appointments to government positions.\textsuperscript{66} The representative of Patients of Ukraine noted that the MoH plays a less prominent role in the reform than it did during the first phase, and due to the changes in the ministry position are no longer driving the reform. NHSU is, according to the representative, the one state body committed to continue the reform. The fact that the MoH no longer plays this role contributes to the difficulty to change the behaviour of patients and doctors.\textsuperscript{67}

The system is still in late 2020 a hybrid system. The plan for the second phase of the reform was for 2020 to be a transition year where reliable data would be obtained via the newly introduced E-health system. The aim of this transition year was to reveal the real numbers and obtain accurate statistics. With the E-health system, it is possible to trace what treatments a patient has received, and which facilities they have visited.\textsuperscript{68} NHSU expected more data to become available in the E-health system in 2020, which would be used when planning new contracts. Due to the pandemic, hospitals were allowed to reduce their reporting to the E-health system, so there is now less data in the system than anticipated. The reduction of services in this period may also have had an impact.\textsuperscript{69}

Another purpose of having a transition year and of keeping a mixed system at first was to give some flexibility to hospitals, who may otherwise struggle to estimate their needs.\textsuperscript{70} Referring to the 2021-2023 NHSU strategy plan, the representative from CF Patients of Ukraine also noted that 2020 was originally planned as a transition year. Starting from 2021 the new payment system for hospitals will be implemented with a money follows the patient approach. This approach is well implemented in the primary healthcare system.\textsuperscript{71}

There are attempts to implement the same budgetary exemptions as were granted to infectious disease wards to TB and mental health care. The interlocutor for IRF noted that TB was still exempt in November 2020 from the second phase of the reform. For now, it is a debated issue and the system remains mixed. 60% of the budget comes from the historic budget.\textsuperscript{72}

In 2021, the programme of medical guarantees (further explained in section \textbf{2.2. Public healthcare insurance treatment coverage}) will continue and NHSU will elaborate on it following lessons learned in 2020.\textsuperscript{73} The interlocutor from IRF noted that the changes implemented so far cannot be easily reversed and the reform is easier, but hopes it will not remain at this stage as it is not functioning optimally. The health system is in a critical point in the middle of the transition and risks falling apart if nothing is done from this point. The reform will also deteriorate if nothing is done, and this deterioration will go fast due to the situation with the COVID-19 outbreak.\textsuperscript{74}

\begin{itemize}
  \item \textsuperscript{65} CF Patients of Ukraine, interview via Zoom, 25 November 2020.
  \item \textsuperscript{66} International Renaissance Foundation (IRF), interview via Webex, 23 November 2020.
  \item \textsuperscript{67} CF Patients of Ukraine, interview via Zoom, 25 November 2020.
  \item \textsuperscript{68} International Renaissance Foundation (IRF), interview via Webex, 23 November 2020.
  \item \textsuperscript{69} National Health Services of Ukraine (NHSU), interview via Webex, 26 January 2021.
  \item \textsuperscript{70} International Renaissance Foundation (IRF), interview via Webex, 23 November 2020.
  \item \textsuperscript{71} CF Patients of Ukraine, interview via Zoom, 25 November 2020.
  \item \textsuperscript{72} International Renaissance Foundation (IRF), interview via Webex, 23 November 2020.
  \item \textsuperscript{73} National Health Services of Ukraine (NHSU), interview via Webex, 26 January 2021.
  \item \textsuperscript{74} International Renaissance Foundation (IRF), interview via Webex, 23 November 2020.
\end{itemize}
1.3.3. Changes in health facility infrastructure

Currently, according to an interlocutor from the NHSU, there are many specialised clinics in Ukraine, but not enough money to pay for them. The reform is intended to move money away from facilities that do not work, to facilities that are more efficient.\(^{75}\) Local administrations have been tasked with the implementation of the second phase of the reform, but the IRF interlocutors pointed out that an issue is that they do not have the full national picture and instead focus on local needs. For instance, while on a larger scale it may make sense to close a particular hospital that is not highly used, this may be an inconvenience for the local residents.\(^{76}\) Oleksandra Ustinova stated that one consequence of the reform is likely to be that 30-40% of medical clinics will need to close, as there are currently huge clinics placed in small towns. In order to survive, these clinics may need to rent out space, as the government will no longer pay for the facility but only for the treatments given. This will make the system more efficient, and while it is not popular and will upset people, the current system costs too much money. 73% of the money from the government is spent on facilities and salaries, something which will change with the reform.\(^{77}\) The interlocutor with UNAIDS noted that it is likely smaller facilities may fold or merge with other small facilities. The facilities will also now have to prove they treat patients in order to get paid.\(^{78}\)

The money follows the patient principle is intended to ensure the state pays for treatments and not for empty beds. A consequence of this is according to Ustinova that the situation for the clinics will be more competitive, especially in large cities. As medications are included in the tariffs, clinics will be keener to purchase cheaper medications and in that way lessen the costs for state healthcare. The model ensures the clinics are cost efficient.\(^{79}\) The UNAIDS representative explained that facilities will now have to prove they treat patients in order to get paid.\(^{80}\) A representative from Public Health Center noted that doctors are not used to treating many patients.\(^{81}\) The interlocutor from IRF mentioned that in some maternal units, only two deliveries are done per day, only on weekdays and not on the weekends, and no complicated deliveries. As a doctor in a larger city will be paid around USD 500 in informal fees from the patient, and USD 500 will be paid to other staff, doctors can get more money through informal payments and with a lower workload, so most are against the reform.\(^{82}\) The representative of Boris Clinic believed the reform will reduce the beds in the public sector with about 30-40%.\(^{83}\)

Another issue of the current system according to Oleksandra Ustinova is that doctors in smaller clinics are sometimes not skilled enough, because they are not treating enough patients to practice all medical elements.\(^{84}\) The news agency Vox Ukraine pointed out that an additional issue that the reform is facing is the lack of doctors in the countryside. More specifically, in small towns and villages there is a very limited or no choice of doctors.\(^{85}\)

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\(^{75}\) National Health Services of Ukraine (NHSU), interview, Kiev, 12 March 2020.
\(^{76}\) International Renaissance Foundation (IRF), interview via Webex, 23 November 2020.
\(^{77}\) Ustinova, Oleksandra, member of parliament, interview via Skype, 26 March 2020.
\(^{78}\) UNAIDS and IOM, interview, Kiev, 13 March 2020.
\(^{79}\) Ustinova, Oleksandra, member of parliament, interview via Skype, 26 March 2020.
\(^{80}\) UNAIDS and IOM, interview, Kiev, 13 March 2020.
\(^{81}\) Public Health Center, interview, Kiev, 10 March 2020.
\(^{82}\) International Renaissance Foundation (IRF), interview, Kiev, 11 March 2020.
\(^{83}\) Raschupkin, Andrey, medical director, Boris Clinic, interview, Kiev, 13 March 2020.
\(^{84}\) Ustinova, Oleksandra, member of parliament, interview via Skype, 26 March 2020.
\(^{85}\) Vox Ukraine, Unchangeable? How medical reforms work and where they slow down, 13 December 2019, url.
Oleksandra Ustinova pointed out that the reform is likely to lead to longer lines. In the old system, patients could pay to receive immediate care. In the past, clinics could charge for everything. Consequently, patients who could not pay did not receive care.\textsuperscript{86}

A doctor at Boris Clinic, a private facility in Kiev, expressed some opinions that illustrated the fears some actors have for this reform. He stated that while the primary health care reform was positive, he had some reservations about the second part. In particular, he feared there may be negative consequences due to closure of clinics for psychiatric patients and clinics for TB patients. Many TB sanitoriums and psychiatric institutions are being closed during the reform, and he does not know where patients will be treated.\textsuperscript{87} A representative from WHO noted that there is a fear among the public of the closure of sanatoriums. The representative further commented that moving away from a system based on beds will have a large effect on mental health care, and there will be less need to keep patients institutionalised.\textsuperscript{88}

1.3.4. Changes to HIV and TB services

According to the Public Health Center, with the reform the NHSU will implement programmes on HIV, TB, and OST (Opioid Substitution Therapy). The government will then issue payments for each patient and for certain services. At primary level, testing and distribution of medicines to treat HIV, also called antiretrovirals (ARTs), by family doctors, as well as management of OST patients (provide drugs, adjust dosage, do screenings, and make referrals to other specialists). For the second phase of the reform, from April 1, 2020, some facilities on secondary level will handle OST, HIV testing, ART provision, and TB services. In December 2020, over 200 facilities on the secondary level implemented the OST programme. The Public Health Center noted that the laboratory package for HIV needs to be enlarged and revised, as the funds are too small. There is a belief among the representatives that quality indicators may improve through the reform.\textsuperscript{89} TB hospitals will after the reform change into something closer to infectious disease hospitals, also treating other diseases.\textsuperscript{90}

A major anticipated change within the new system relates to AIDS centres or ARV cabinets, as the provision of treatment for HIV and TB will be done differently. A possible consequence may according to UNAIDS be that some centres close permanently, as payment will be per patient. The interlocutor commented, however, that before implementation has taken place, this is only speculation.\textsuperscript{91} An interlocutor from the Public Health Centre noted that if ART centres close, patients may find themselves in a more difficult situation to find another treatment facility. The regions will be able to choose themselves if the duties should be shared over several centres or if they should be centralised in one centre, something which could overwhelm the one remaining centre.\textsuperscript{92}

1.3.5. Data collection in healthcare

Representatives of the NHSU explained that there was previously no clear overview of the number of facilities in the healthcare system, but as a side-effect of contracting individual facilities in the reform exercise, the healthcare system has been mapped simultaneously.\textsuperscript{93} The representative of 100% Life

\textsuperscript{86} Ustinova, Oleksandra, member of parliament, interview via Skype, 26 March 2020.
\textsuperscript{87} Raschupkin, Andrey, medical director, Boris Clinic, interview, Kiev, 13 March 2020.
\textsuperscript{88} World Health Organization (WHO), interview, Kiev, 10 March 2020.
\textsuperscript{89} Public Health Centre, interview, Kiev, 10 March 2020, Public Health Center, e-mail, 24 December 2020.
\textsuperscript{90} UNAIDS and IOM, interview, Kiev, 13 March 2020.
\textsuperscript{91} UNAIDS, interview, Kiev, 13 March 2020.
\textsuperscript{92} Public Health Centre, interview, Kiev, 10 March 2020.
\textsuperscript{93} National Health Services of Ukraine (NHSU), interview, Kiev, 12 March 2020.
noted that with the e-health system, information is centralised and duplication is avoided.\textsuperscript{94} However, even after the implementation of the second stage of the reform, the IRF interlocutor explained that it is likely that there is still a significant manipulation of data occurring in hospital reporting and in health statistics. For instance, there is a discrepancy in the bed occupancy rate and in the number of surgeries performed. Bed occupancy rate appears to be calculated not in relation to intensive care but in relation to extended hospital stay before and after the surgery.\textsuperscript{95}

Several interlocutors mentioned the lack of accurate data as an obstacle for planning.\textsuperscript{96} An interlocutor with WHO noted that data gaps are an issue in Ukraine.\textsuperscript{97} According to a representative of the NHSU, about 30 million people have declared their family doctor, which is about 80\% of the population. Recent official data states the population of Ukraine is 37 million.\textsuperscript{98} A representative of the State Expert Center mentioned, however, that the population number is incorrect and this means their calculations will not be correct. 15 years ago, the population was 52 million. Today, without counting the occupied territories, the population is estimated to be a bit less than 42 million.\textsuperscript{99} This was also raised by an interlocutor with the IRF, who noted that not only were the actual population statistics different from the official demographic numbers, but the patient flow in the healthcare system also differs from the official statistics. Patients do not go to the hospitals only in their own region/raion, which also impacts calculations on patient uptake for different facilities.\textsuperscript{100} The representative from 100\% Life stated that due to the uncertainty around demographics, they do not know their target numbers. In some oblasts (regions), the targets are too high compared with the actual population.\textsuperscript{101}

A representative from the Public Health Center highlighted that there are separate registers in the regions for patients with hepatitis, so the centre does not have a complete picture of the situation in the country.\textsuperscript{102} The main source is from the annual reports of health care departments.\textsuperscript{103} The Public Health Center further acknowledged that haemodialysis patients tend to ‘fall between the chairs’, so the Center does not know the incidence and prevalence of this group.\textsuperscript{104}

### 1.3.6. Opposition to the reform

According to a representative from ANTAG, many highly placed people in major hospitals have been suspected of corruption and are now in a position to criticise the reform, and people actively against the reform are now in charge of several important institutions.\textsuperscript{105} This sentiment was echoed by the interlocutor from UNAIDS who noted that the reform is in the hands of people who may not agree with all of it.\textsuperscript{106} In general, Oleksandra Ustinova noted that ‘top doctors’ are opposed to the reform because official salaries are too low. In the old system second line doctors had high wages, so they

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\textsuperscript{94} 100\% Life, interview, Kiev, 10 March 2020.
\textsuperscript{95} International Renaissance Foundation (IRF), interview via Webex, 23 November 2020.
\textsuperscript{97} World Health Organization (WHO), interview, Kiev, 10 March 2020.
\textsuperscript{98} National Health Services of Ukraine (NHSU), interview, Kiev, 12 March 2020.
\textsuperscript{100} International Renaissance Foundation (IRF), interview, Kiev, 11 March 2020.
\textsuperscript{101} 100\% Life, interview, Kiev, 10 March 2020.
\textsuperscript{102} Public Health Centre, interview, Kiev, 10 March 2020.
\textsuperscript{103} Public Health Centre, e-mail, 24 December 2020.
\textsuperscript{104} Public Health Centre, interview, Kiev, 10 March 2020.
\textsuperscript{105} Anti-Corruption Action Centre (ANTAC), interview, Kiev, 12 March 2020.
\textsuperscript{106} UNAIDS and IOM, interview, Kiev, 13 March 2020.
will see a decrease in salaries with the reform. Regional doctors are in general more positive to the reform than urban doctors.107

Other arguments against the reform is that the funds allocated are not enough for the reform and will result in health facilities down-sizing or closing due to insufficient funding - the funds would need to increase from 3.2% to 5% GDP. However, the representative from IRF stated that some health facilities are underperforming and will lose money if the funds are allocated per patient, so they are keen to keep the old system where they are paid per bed, even if the beds are empty. According to the representative, there is room to compensate and the budget is realistic.108 The interlocutor from UNAIDS explained that facilities believe the NHSU is underestimating the cost of treatments and that tariffs will have to be revised. This will not be proven until it is put in practice, however.109

1.3.7. Political changes’ impact on the reform

One challenge for the reform involves changes in government. In late March 2020, the Minister of Health was replaced, which could be a threat to the second stage of the reform.110 More specifically, in the period between August 2019 and November 2020, there were four Ministers of Health,111 with Maxim Stepanov being the fourth and current one (in November 2020).112

Minister of Health Stepanov stated in a briefing on 7 June 2020 that ‘[t]he Ministry of Health of Ukraine is conducting a detailed examination of the entire medical infrastructure for further reforming and correcting the mistakes made by previous management”.113 Professor Judyth Twigg claimed in a blog post that Health Minister Stepanov ‘seems determined to unravel most of the progress that has been made’.114

The minister appointed in September 2019, Zoriana Skaletska, was described by the interlocutor from UNAIDS as often mentioning the need to eliminate OOP payments, but the replacement minister Illya Yemets, appointed in March 2020, had a different background and had not prioritised this topic in his public messages about the health financing reform.115 The interlocutor from ANTAC mentioned that Yemets had connections to the old Yanukovych regime, and while a doctor, is unknown as a manager.116 This was echoed by member of parliament Oleksandra Ustinova, who stated that the political will from the Ministry of Health is weak. She further noted that while the first stage of the reform has been successful, there had been moves from parliamentarians to block the continuation of the reform.117 The interlocutor from ANTAC pointed out that due to the change in Minister of Health just before the initiation of phase two, it was unclear how the reform would develop. The interlocutor was also of the opinion that the greatest challenge was setting up the NHSU. As beneficiaries in charge of a lot of money and the reimbursement system, the NHSU is the driver of the reform and the only agency who can contract doctors to the new system.118 The WHO interlocutors stated that while they

107 Ustinova, Oleksandra, member of parliament, interview via Skype, 26 March 2020.
110 100% Life, interview, Kiev, 10 March 2020.
111 These Ministers were Ulana Suprun (dismissed in August 2019), Zoriana Skaletska, Illya Yemets and Maxym Stepanov.
Source: Euromaidan Press, Ukraine’s ambitious health reform now hangs by a thread, 28 May 2020, url.
112 Euromaidan Press, Ukraine’s ambitious health reform now hangs by a thread, 28 May 2020, url.
113 Ukraine, Ministry of Health of Ukraine, The Ministry of Health of Ukraine has begun developing and approving new governmental standards for medical care, 7 June 2020, url.
114 Twigg, J., Ukraine’s healthcare system is in critical condition again, Atlantic Council, 21 July 2020, url.
116 Anti-Corruption Action Centre (ANTAC), interview, Kiev, 12 March 2020.
117 Ustinova, Oleksandra, member of parliament, interview via Skype, 26 March 2020.
118 Anti-Corruption Action Centre (ANTAC), interview, Kiev, 12 March 2020.
try to keep their own programmes on track, the changes in government risk putting things off track.\textsuperscript{119} Other things in the pipeline, such as procurement of medication by an independent central procurement agency – a change which would save money – may also not be implemented.\textsuperscript{120}

The outbreak of COVID-19 in Ukraine coincided with, according to Oleksandra Ustinova, the most vital part of the reform. The reform’s second stage is by Ustinova predicted to be ‘tough’, but she fears the reform will not continue if it is halted now. With a stable government it could have been postponed for six months, but that would be too risky in the current political climate.\textsuperscript{121} See also section 1.3.2.2. \textbf{The second phase of the reform and impact of COVID-19.}

\section*{1.4. Quality practices}

The interlocutor from the HTA pointed out that the use of international practices and guidelines is an important step in the reform.\textsuperscript{122} From March 2020, health care providers should not use outdated national protocols, as they had not been updated in almost ten years and there was no practice of revision of the protocols. The representative of Boris Clinic stated that the clinic follows international treatment guidelines, as national guidelines run the risk of becoming outdated.\textsuperscript{123} The representative of the National Cancer Institute explained that treatments are provided according to international and national guidelines. The national guidelines are adapted from the ESMA/US system, while other centres only use national guidelines.\textsuperscript{124} The interlocutor at Okhmatdyt hospital explained that if existing national protocols do not cover a rare, complicated case, approved and certified international protocols are used. The hospital is also ISO9001-certified and has an internal quality control with a person responsible for the controls and a methodology to follow.\textsuperscript{125}

In terms of advanced training, doctors need to obtain 50 accredited points each year through attending conferences, giving lectures, writing articles and so on. This system is controlled by the MoH. In the public sector however, the staff need to pay for this training themselves or receive grants from a charitable organisation. This continuous medical education can be done in Ukraine or abroad.\textsuperscript{126} The representative from the National Cancer Institute explained that the Institute is underfunded, so they are not able to send staff abroad. To participate in conferences, the staff have to pay for it themselves or get sponsored by pharmacological companies.\textsuperscript{127} The representative from Boris Clinic confirmed this, and also noted that the budget is too small in the public sector for doctors to upgrade qualifications continuously. The staff at the private facility have the opportunity to study abroad, financed by the clinic.\textsuperscript{128}

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\bibitem{120} UNAIDS and IOM, interview, Kiev, 13 March 2020.
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\bibitem{122} Health Technology Assessment (HTA) Department at State Expert Center, interview, Kiev, 12 March 2020.
\bibitem{123} Raschupkin, Andrey, medical director, Boris Clinic, interview, Kiev, 13 March 2020.
\bibitem{124} National Cancer Institute, interview, Kiev, 13 March 2020.
\bibitem{125} NCSP Okhmatdyt, interview, 12 March 2020.
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\bibitem{128} Raschupkin, Andrey, medical director, Boris Clinic, interview, Kiev, 13 March 2020.
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2. Health insurance

2.1. National Health Service Ukraine (NHSU)

NHSU is funded through taxation and gives guarantees for free healthcare, and was founded on the Cabinet of Ministry Decree No 65. The idea of the NHSU was to create a strong primary healthcare sector with a referral system. The representative of ANTAC described the NHSU as the ‘drivers of the reform’, and hence a key player. Setting NHSU up was the greatest challenge of the reform according to ANTAC. NHSU is rumoured to be down-sized soon, and the architect of the reform left the NHSU in December 2019. The representative from UNAIDS observed that with the departure of the team of architects of the reform, it will be ‘painful to continue [the reform], but probably more painful to reverse [it].’ On the website of NHSU, real-time data of the implementation of the reform is continually updated (in Ukrainian: https://nszu.gov.ua/en/pro-nszu).

Oleksandra Ustinova commented that the NHSU reimbursement system works well, with payments issued each month to facilities as planned. The Covid-19 outbreak poses a problem however, as all budgets will be cut.

2.2. Public healthcare insurance treatment coverage

As explained on the NHSU website, ‘primary care, palliative care, and emergency medical care are 100% funded by the state. Besides, the state provides reimbursement for medicines for cardiovascular diseases, asthma, and type 2 diabetes.’ Further, ‘[t]he government pays for the guaranteed benefit

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129 National Health Services of Ukraine (NHSU), interview, Kiev, 12 March 2020.
130 World Health Organization (WHO), interview, Kiev, 10 March 2020
131 Anti-Corruption Action Centre (ANTAC), interview, Kiev, 12 March 2020. See also Euromaidan Press, Ukraine’s ambitious health reform now hangs by a thread, 28 May 2020, url.
133 National Health Services of Ukraine (NHSU), interview, Kiev, 12 March 2020.
134 Ustinova, Oleksandra, member of parliament, interview via Skype, 26 March 2020.
135 Ukraine, Ministry of Health of Ukraine, Key Steps To Transforming Ukrainian Healthcare, n.d., url
package of healthcare services for individuals, and healthcare providers compete for these funds. Services beyond the guaranteed package can be paid or co-paid for by patients directly or by other health insurance types.136 The Verkhovna Rada (Ukrainian parliament) each year approves a Medical Guarantee Programme, starting in 2019 with approval for the 2020 programme.137 The Medical Guarantee Programme determines the state coverage of treatments, and can differ from year to year, depending on the budget and on lessons learned. The 2021 budget only increased by 6%, which does not compensate for inflation, according to the NHSU.138

Most services are covered, except for non-urgent care without referral and some other minor services. The NHSU plan for the same number of services which were historically provided in the system. In 2019, there were 8 million hospitalisations, so the same was planned for in 2020. NHSU noted that there are many misunderstandings on what is included in the packages. For instance, providers have erroneously believed only patients in treatment are covered, and declined free treatment to new patients. These misunderstandings are communicated to patients, which then communicates them to patient organisations.139

What was included in 2020 is available (in Ukrainian) on the NHSU website,140 called the Packages of Services, and each package describes what is included. In very general terms, consultations of doctors are included in every package, diagnostic treatments, etc.141 A draft programme for 2021 is also available.142

The Medical Guarantee Programme for 2020 includes:

1. Primary medical care
2. Emergency medical care
3. Ambulatory secondary and tertiary medical assistance for adults and children, including medical rehabilitation and dental care
4. Mammography of breast
5. Hysteroscopy (diagnostic / with endoscopic manipulation)
6. Oesophago-gastro-duodenoscopy (diagnostic / with endoscopic manipulation)
7. Colonoscopy (diagnostic / with endoscopic manipulation)
8. Cystoscopy (diagnostic / with endoscopic manipulation)
9. Bronchoscopy (diagnostic / with endoscopic manipulation)
10. Haemodialysis in outpatient conditions
11. Inpatient surgical interventions for adults and children
12. Inpatient care for adults and children without surgical operations
13. Medical care for acute stroke
14. Medical care for acute myocardial infarction

136 Ukraine, Ministry of Health of Ukraine, What Services Do Patients Pay For?, n.d., url
137 Ukraine, Ministry of Health of Ukraine, Громадянам – Які медичні послуги будуть платними для пацієнтів? [To the citizens – what medical services will be paid for patients?], n.d., url
138 National Health Services of Ukraine (NHSU), interview via Webex, 26 January 2021.
139 National Health Services of Ukraine (NHSU), interview via Webex, 26 January 2021.
140 NHSU (National Health Service of Ukraine), Вимоги ПМГ 2020 [PMG 2020 Requirements], n.d., url
141 National Health Services of Ukraine (NHSU), interview via Webex, 26 January 2021.
142 NHSU (National Health Service of Ukraine), Вимоги ПМГ 2021 [PMG 2021 Requirements], n.d., url
15. Medical care for childbirth
16. Medical care for new-born in complex neonatal cases
17. Diagnosis and chemotherapeutic treatment of oncological diseases in adults and children
18. Diagnosis and radiological treatment of oncological diseases in adults and children
19. Psychiatric care for adults and children
20. Diagnosis and treatment of adults and children with TB
21. Diagnosis, treatment and maintenance of persons with HIV
22. Treatment persons with mental and behavioural disorders due to use of opioids with drugs substitution therapy
23. Inpatient palliative medical care for adults and children
24. Palliative medical care for adults and children at place of residence
25. Medical rehabilitation of infants born prematurely and/or sick, during the first three years of life
26. Medical rehabilitation of adults and children from three years old with disabilities of the musculo-skeletal system
27. Medical rehabilitation of adults and children from three years old with damaged nervous system
28. Emergency medical care of patients with suspected or established disease with acute respiratory disease COVID-19 caused by the coronavirus sars-cov-2
29. Medical care provided by mobile medical teams created to respond to COVID-19
30. Inpatient care for patients with COVID-19 in the period from 1 to 30 April 2020

2.2.1. Included population groups

NHSU representatives explained that all citizens get benefits through the NHSU, and citizens who have lived abroad get access to the benefits as soon as they move back to Ukraine. Foreigners with legal stay permits, including asylum seekers, are covered as well. IDPs access the system on the same premise as other citizens, as there are no area restrictions in terms of which facility to use. A person needs a passport in order to obtain access and prove their citizenship.

2.2.2. Coverage for oncology treatment

Much oncologic medication, including targeted therapy, is not part of the benefit package but is part of the budget for centrally procured medication. There is not sufficient medication for all patients who need it, so once the medication runs out patients need to pay. For oncology patients, full coverage with targeted therapy or innovation therapies will likely never be economically possible.

The representative from the National Cancer Institute explained that 80% of treatments are covered and patients pay the rest, usually materials. Emergencies are fully covered. 60% of chemotherapy

143 NHSU (National Health Service of Ukraine), Вимоги ПМГ 2020 [PMG 2020 Requirements], n.d., url
144 National Health Services of Ukraine (NHSU), interview, Kiev, 12 March 2020.
145 National Health Services of Ukraine (NHSU), interview via Webex, 26 January 2021.
drugs are covered by the state, and the patients buy the rest. Most targeted and immunotherapy\textsuperscript{146} provided at the National Cancer Institute are paid by the patients whereas chemotherapy is covered up to 60%. Paediatric oncologic treatments are covered completely, except for targeted therapy.\textsuperscript{147} To clarify the situation regarding targeted therapy, the representative from CF Patients of Ukraine explained that basic medications are procured via the state budget and is free for the patient, while more expensive targeted therapy in most cases would need to be covered by the patients themselves. The patient representative deemed that some treatments are still ‘affordable’ for patients. The situation is similar e.g. for MS medication, where only the more regular medication for simple cases is free for the patient while patients will have to pay for more complex medication themselves.\textsuperscript{148}

A patient representative confirmed that most aspects of the treatment are provided for free for adult oncology patients, but more expensive and efficient medication is not accessible. Oncology patients need to pay for tests to get a diagnosis, immunotherapy is not free for the patients, basic targeted therapy is provided for free and chemotherapy is mostly free. Surgery is paid by the patients. For this reason, treatments of patients could be discontinued as they cannot afford it or go abroad to get treatment. The representative specifically mentioned that melanoma patients often cannot continue their treatment due to the costs. Innovative treatments for patients with stage 3 or 4 melanoma cancer can cost up to USD 4 000. There are waiting lists for radiation therapy as the equipment is old and there are not enough machines. Palliative care is also an issue due to lack of staff. The representative also stated that there are many reports of wrong prescriptions and misdiagnosis. Staff may lack knowledge and provide the wrong treatment in local hospitals.\textsuperscript{149}

Patients for some diseases get a disabled status, and the disability pension is UAH 1 500 (about EUR 44).\textsuperscript{150} How long they remain classified as disabled can vary though. For instance, breast cancer patients retain their status as disabled, but must reapply every 2 years. Oncology patients who receive targeted therapy lose their status as disabled once the treatment continues with hormone therapy. As treatment is no longer covered, patients stop treatment. A patient who loses their disability status loses both pension and social security. Patients with mental health disorders need disabled status in order to get treatment, but the disability status does not always match the diagnosis and severity of the patient’s condition, and there are administrative barriers to sort this out. Both a diagnosis and disability status are needed to obtain treatment.\textsuperscript{151}

\textbf{2.2.3. Coverage for patients with Crohn’s disease and Parkinson disease}

A representative of patients with Crohn’s disease stated that children who are considered disabled according to the law, have right to free treatment. However, the responsibility is relegated to local authorities and as there is not enough money, there is no automatic free access for children who must struggle to get free treatment. Adult patients suffering from Crohn’s disease do not receive free treatment, and many patients discontinue treatment as they cannot afford it. Patients who do not get treatment will need surgery, which also costs money. Furthermore, the representative noted that it is difficult to get the initial diagnosis, especially in rural areas as they tend to lack colonoscopy and colon biopsy. The patients must also pay for the biopsy tests.\textsuperscript{152}

\textsuperscript{146} Targeted cancer therapies block the growth and spread of cancer and immunotherapy helps the immune system fight cancer.
\textsuperscript{147} National Cancer Institute, interview, Kiev, 13 March 2020.
\textsuperscript{149} CF Patients of Ukraine and representatives of different patient organisations, interview, Kiev, 10 March 2020.
\textsuperscript{150} Xe.com, Xe Currency Converter, 2 February 2021, url. Conversion rate at the time of writing (February 2021) is EUR 1 = UAH 33.87.
\textsuperscript{151} CF Patients of Ukraine and representatives of different patient organisations, interview, Kiev, 10 March 2020.
\textsuperscript{152} CF Patients of Ukraine and representatives of different patient organisations, interview, Kiev, 10 March 2020.
Patients with Parkinson need medication which costs UAH 7,000, 20% of which is covered by local budget. There is no state financing for the disease.\textsuperscript{153}

### 2.2.4. Coverage for patients with TB, Hepatitis and HIV

TB patients are diagnosed and receive treatment at the family doctor. Both diagnosis and medication are free, and the medication includes new drugs.\textsuperscript{154} The UNAIDS representative describes TB and MDR-TB as major concerns, as TB is the number one cause of death for people living with HIV. All TB cases are tested for HIV, and all newly discovered HIV patients get tested for TB.\textsuperscript{155}

New hepatitis B and C medication is provided for free to patients, and screening of viral hepatitis markers is also provided free of charge by family doctors. Consultation with a specialist is also free, though there are waiting lists as there are not enough infection specialists and lack of procured medications at the scale needed. However, the Public Health Center noted that other doctors can treat these patients in case no infectious disease specialists are available. The patient will have to pay for the PCR test as it is done in private laboratories.\textsuperscript{156}

Viral load laboratory tests and CD4 tests are available free of charge, and patients with HIV receive free ART treatment in Ukraine.\textsuperscript{157} Order 504 from 19 March 2018, ‘On approval of the Procedure for providing primary care’, states that family doctors have to provide free testing for HIV and viral hepatitis.\textsuperscript{158}

### 2.2.5. Coverage for paediatric patients

According to the interlocutor from the paediatric hospital Okhmatdyt, the state budget finances most medications, and charitable organisations buy some. The paediatric patients rarely need to buy medication, though sometimes the parents do co-payments. Most treatments at the hospital are free. One exception is reconstructive spinal surgery, like scoliosis, which must be paid for. There are officially no co-payments at the hospital.\textsuperscript{159}

### 2.3. Affordable Medicines Programme

The design and implementation of the Affordable Medicines Programme constitute a key aspect of the healthcare sector reform in Ukraine.\textsuperscript{160} Prior to the introduction of the Affordable Medicines Programme (AMP), there was no centralised system in place in Ukraine for public reimbursement of prescription medication in the outpatient sector, resulting in the majority of outpatient medication not being publicly subsidized.\textsuperscript{161}

The Affordable Medicines Programme started in April 2017 and includes medication for cardiovascular diseases, diabetes type II and bronchial asthma. To access it, a prescription using the International Non-proprietary Names (INN), not a trademark name, from the family doctor is needed. The patient

\textsuperscript{153} CF Patients of Ukraine and representatives of different patient organisations, interview, Kiev, 10 March 2020.

\textsuperscript{154} Public Health Center, interview, Kiev, 10 March 2020.

\textsuperscript{155} UNAIDS and IOM, interview, Kiev, 13 March 2020.

\textsuperscript{156} Public Health Center, interview, Kiev, 10 March 2020; Public Health Center, e-mail, 24 December 2020.

\textsuperscript{157} UNAIDS and IOM, interview, Kiev, 13 March 2020.

\textsuperscript{158} Public Health Center, e-mail, 24 December 2020.

\textsuperscript{159} NCSP Okhmatdyt, interview, 12 March 2020.

\textsuperscript{160} WHO, Evaluation of the Affordable Medicines Programme in Ukraine, 2019, url, p. 4.

\textsuperscript{161} WHO, Evaluation of the Affordable Medicines Programme in Ukraine, 2019, url, p. 2.
can then choose which brand to use. The medication will be free or with a co-payment.\footnote{National Health Services of Ukraine (NHSU), interview, Kiev, 12 March 2020.} The list contains 23 INNs.\footnote{Health Technology Assessment (HTA) Department at State Expert Center, interview, Kiev, 12 March 2020.} The medications have reference prices, which are approved by the Minister of Health. This list is renewed every 6 months.\footnote{State Expert Center, interview, Kiev, 11 March 2020.} The list of medication included in the Affordable Medicines Programme, including reference price, can be accessed via the NHSU’s website.\footnote{NHSU (National Health Services of Ukraine), Affordable Medicines Program, n.d., url.}

In a 2019 report, the WHO stated that the implementation of the AMP increased the affordability of the medications covered. Approximately 20% of the generic medications included are fully covered without the patients having to pay a contribution. For another 20% of the medications included, the patients have to pay a contribution smaller than 20% of the medication’s price.\footnote{WHO, Evaluation of the Affordable Medicines Programme in Ukraine, 2019, url, p. 28.}

Insulin is currently reimbursed in a similar way as the medication covered under Governmental Order number 1 303 (see below), where patients need to go on the first of every month to get the medication, before the money runs out. The plan is for insulins to be included in the Affordable Medicines Programme from 1 July 2021, and mental health medications from 1 October 2021. The programme will be expanded, but as only medication included in the EML can be reimbursed, this is not fully within NHSU’s control. Only pharmaceutical manufacturers can apply for expansion of the EML, and the MoH decides on expansion of the list.\footnote{National Health Services of Ukraine (NHSU), interview via Webex, 26 January 2021.}

Paper prescriptions have been replaced by e-prescriptions, which are connected to a central database which pharmacies have access to. The patients get a code to bring to any pharmacy in Ukraine with an NHSU agreement. 7 000 pharmacies are included in the system and are recognisable through an Affordable Medicines sign. According to representatives of the NHSU, there should always be an affiliated pharmacy within 1 km.\footnote{National Health Services of Ukraine (NHSU), interview, Kiev, 12 March 2020.} In addition, through the e-prescription system, personalized information is collected on prescription, provision and reimbursement of medications in the Affordable Medicines Program. The database links information on prescribed medication with patients, health providers and pharmacies and ‘should allow the introduction of the prescription and budget control systems.’\footnote{WHO and World Bank (The), Ukraine Review of health-financing reforms 2016–2019, April–July 2019, url, p. 36.}

Outpatients in private hospitals with NHSU contracts can also be reimbursed. Outpatients at private hospitals without a NHSU contract are not eligible for reimbursement.\footnote{International Renaissance Foundation (IRF), interview, Kiev, 11 March 2020.} The e-prescription system is ‘working quite well’, according to the representative of the State Expert Center.\footnote{State Expert Center, interview, Kiev, 11 March 2020.}

The representative of the State Expert Center acknowledged that it is possible in many pharmacies to buy medication without prescription. Due to this, there is a huge problem with overmedication, even though all medication is quality checked. In particular, this is a problem with antibiotics as people are developing resistance. It is hard to encourage patients to visit a doctor when they can obtain the medication directly from a pharmacy. In this regard, the new reimbursement system will encourage patients to visit a doctor as a prescription is needed for reimbursement.\footnote{According to a pharmacist, there is no shortage of stock for medication included in the list, and the}
reimbursement system is working.\textsuperscript{174} A representative of the State Expert Center noted that relatively few medications are reimbursed by the state, and more than 85\% of all medications are paid OOP.\textsuperscript{175}

Before the introduction of the AMP, reimbursements were handled via the local health departments and the money came from the local budget.\textsuperscript{176} As is still the system in some post-Soviet countries, certain population groups may receive discounts or free medications (e.g. Chernobyl victims, people with war disabilities, mothers with 5 children under 15 years of age, and so on).\textsuperscript{177} Based on the Order of the Government number 1 303 from 1998,\textsuperscript{178} local councils or the central budget should provide medicines free of charge to all patients listed in the order. However, NHSU representatives noted that the wide range of patients with different kinds of diseases included means that the central budget would never have money to cover it. Local budgets tend to provide for those considered more eligible to get the free medicines. The system is described as ‘very non-transparent’ and ‘a very locally created system,’ and the implementation differs between local councils. A patient organisation with influence on the local council may secure medication to its members, or some other council would provide cover for specific population groups. This vulnerability-based local programme still exists in some local councils, but it is underfinanced with too wide a scope. In practice, some people at the beginning of the month will get medication before the monthly budget runs out. Other issues include that some medication is not evidence-based, and others used in the system are not effective. The system only works for patients that can stand up for their rights, and more vulnerable patients may not be able to get their medication.\textsuperscript{179} The representative from IRF confirmed that the funds are too low and tend to run out at the end of the month. The process is also described as intricate by the representative, so patients need to understand the process in order to access the free medication. That means they are likely to remain in the old mindset and will give informal payments to their family doctor.\textsuperscript{180}

2.4. Private sector

Private facilities can contract with the NHSU on the same conditions as public facilities. According to representatives of the NHSU, there are only a few private specialised hospitals in Ukraine, as well as a limited number of private primary care facilities. Official figures state that 3.6\% of the population visit private healthcare facilities (not including dentists).\textsuperscript{181} The medical director of the private Boris Clinic noted that, while the facility is contracted with NHSU for primary care, this is mostly done out of charity as the facility barely makes even on it. The facility will not be involved in the second part of the reform as they would lose too much money if they participated.\textsuperscript{182}

Many private facilities have official price lists for procedures. According to the representative from IRF, the private sector respects these price lists and no informal payments are asked.\textsuperscript{183} The representative of Boris Clinic noted that the online price list is kept updated and adjusted every time prices change. There are no charities connected to the facility. The inpatient services at the clinic tend
to belong to higher income population groups, while the outpatient services are described as more affordable for all.\textsuperscript{184}

The private sector in Ukraine is growing while the public sector is shrinking. According to the representative of Boris Clinic, patients are not satisfied with the level of qualification of doctors in the public sector. However, about 50\% of doctors work in both private and public facilities.\textsuperscript{185}

According to the same source, the facility seldom has shortages of supplies of medications and medical devices. An exception are some medical devices like gastrostomy devices and naso-gastric-tubes (PEG tubes). In 2018-19 the facility experienced some problems with the availability of certain vaccines, but in general there are no medication shortages. The facility uses what is available in the domestic market.\textsuperscript{186}

### 2.5. Private insurance

Private health insurance, Voluntary Health Insurance, is available but is not relevant in the context of NHSU. The coverage concerns private facilities only. NHSU also monitors that no agreements are made between clinics in order to circumvent the system in any way.\textsuperscript{187} At the private Boris Clinic, most patients pay the treatment themselves and a small percentage, about 20\%, has private health insurance.\textsuperscript{188}

### 3. Out of pocket (OOP) payments

Co-payments for services are illegal, though the NHSU know that informal payments are still prevalent. They believe it is not just that staff salaries are too low, but that other policy measures will need to be applied in order to eliminate catastrophic expenditures for health.\textsuperscript{189}

The representative from IRF observed that while the general levels of corruption in the country decreased after the 2014 Maidan protests, it has returned under new forms. One example of this is an increase in informal payments, where about 80\% of patients are estimated to pay informal payments and there is reportedly a fear among patients of not paying enough.\textsuperscript{190} According to a Joint World Bank and WHO 2019 Report, before the reform, 54\% of per capita health spending rates originated from OOP.\textsuperscript{191} The ANTAC representative explained that people know what they are entitled to for free. Some OOP payments disappeared with the reform, but payments are still given to specialists at secondary level. The interlocutor believes the second stage of the reform will likely reduce the OOP payments. However, the mindset of people will not change, and especially old people are not used to going to the doctor without paying.\textsuperscript{192} Also the interlocutor from IOM noted that informal payments are part of the Ukrainian culture.\textsuperscript{193} The UNAIDS interlocutor stated that the

\begin{footnotesize}
\begin{enumerate}
\item Raschupkin, Andrey, medical director, Boris Clinic, interview, Kiev, 13 March 2020.
\item Raschupkin, Andrey, medical director, Boris Clinic, interview, Kiev, 13 March 2020.
\item Raschupkin, Andrey, medical director, Boris Clinic, interview, Kiev, 13 March 2020.
\item National Health Services of Ukraine (NHSU), interview, Kiev, 12 March 2020.
\item Raschupkin, Andrey, medical director, Boris Clinic, interview, Kiev, 13 March 2020.
\item National Health Services of Ukraine (NHSU), interview via Webex, 26 January 2021.
\item International Renaissance Foundation (IRF), interview, Kiev, 11 March 2020.
\item WHO and World Bank (the), Ukraine Review of health-financing reforms 2016–2019, April–July 2019, \url{url}, p. 23.
\item Anti-Corruption Action Centre (ANTAC), interview, Kiev, 12 March 2020.
\item UNAIDS and IOM, interview, Kiev, 13 March 2020.
\end{enumerate}
\end{footnotesize}
message from the government is that patients are not meant to pay, but at the same time a cultural imperative exists where patients pay to obtain better treatment. 194

According to the interlocutor of the IRF, patients may need to keep paying informal payments, if the reform is stopped. Studies show that in 2016, 32% of patients delayed care due to lack of financial means. Now the figure is at around 20-22%. People paying out of pocket may need to take bank loans, a practice which the reform is asked to reduce. 195

The ANTAC interlocutor highlighted that a hurdle to fight corruption is that it is difficult to do something against highly respected doctors in key positions. 196 Oleksandra Ustinova pointed out that currently, almost all healthcare staff are taking bribes, as salaries are too low. This is a custom dating back to the Soviet era, and patients will pay ‘thank-you-money’ even when not prompted to do so. Corruption is described as a system of its own, and the only way to change it is by changing the system (a change NHSU oversees). Because of the reform, it is believed it will be more difficult for doctors to make additional charges, as patients will know that the state has already paid for the treatment. Clinics may risk losing a patient if they ask for extra payments. Ustinova acknowledges that there are a lot of fears over the reform, but states that there are also doctors who welcome it and are relieved they no longer have to ask for bribes. 197 The representative from IRF also noted that there are a lot of doctors who are trying to change the current situation, but it is difficult as the whole system has been undermined for a long time. 198

Another form of OOP payment is when patients are ‘recommended’ to give to a charity. ANTAC research done in 2017 showed that there was a ‘black box office’ at charities, in order to bypass taxation authorities. This makes it hard to see where the money actually goes to. 199

According to studies by the IRF, 85-92% of people provide informal payments for treatments. The amount differs, especially geographically. Healthcare providers will demand higher payments in urban areas, but patients will pay more for medication in rural areas. The informal payments vary between facilities and services, and patients ask each other to find out the rate for a specific hospital. The interlocutor further explained that the informal payments do not correlate with the prices in private sector. As an example of informal payments, the IRF representative noted that a delivery in a large city would cost about USD 500 for the doctor, and USD 500 in additional fees. 200 A 2019 Joint Report by the World Bank and WHO also observed that patient OOP spending on prescription medication vary across health facilities, which results in significant inequalities for care affordability. 201 The ANTAC representative noted that there is a hierarchy of who pays whom in hospitals. 202 The representative from UNAIDS commented that inpatients in addition need to pay the nurse, materials and so on. 203 The representative of the organisation for patients with juvenile idiopathic arthritis noted that for a treatment that may cost USD 1 500 (of which the state covers 60% of the costs), paediatric patients must give several hundred USD in informal payments. The representative is not aware of what bribes an adult patient may need to pay. 204

196 Anti-Corruption Action Centre (ANTAC), interview, Kiev, 12 March 2020.
197 Ustinova, Oleksandra, member of parliament, interview via Skype, 26 March 2020.
199 Anti-Corruption Action Centre (ANTAC), interview, Kiev, 12 March 2020.
201 WHO and World Bank (the), Ukraine Review of health-financing reforms 2016–2019, April–July 2019, url, p. 47
202 Anti-Corruption Action Centre (ANTAC), interview, Kiev, 12 March 2020.
204 CF Patients of Ukraine and representatives of different patient organisations, interview, Kiev, 10 March 2020.
According to the representative from IRF, there are imposed informal payments in the healthcare system. For some patients this can be deadly, for instance for patients with oncologic disorders. The informal payment for an MRI in a public facility can be almost as much as the price to get an MRI in a private facility.\textsuperscript{205}

On the question if OOP payments change over time, the representative of haemophilia patients replied that it depends on supply and demand and will go up and down. The representative of Patients of Ukraine observed that ‘the more there are free medication, the more there are bribes.’ Furthermore, the representatives noted that corruption is institutionalised and there is little confidence in government action against bribes. Additionally, the position of patients is weak. Patient representatives of MS patients explained that there is a reasonable fear from patients that they will not receive the treatment if they do not pay bribes. In order to get the treatment, patients follow the ‘rules.’ The patient organisation for haemophilia representative explained that if patients make enough ‘noise’ they may get treatment for free, but this tactic can also backfire. In general, patients pay to ensure continuity in the treatment. The representative of the organisation for patients with juvenile idiopathic arthritis added that it is more difficult in small cities to organise patients against corruption.\textsuperscript{206} Additionally, the ANTAC representative explained that parents of sick children do not make it public if they are asked to pay.\textsuperscript{207}

According to the interlocutor from ANTAC, it is a common complaint that patients at the National Cancer Institute must pay the doctors and pay for procedures that have already been paid for, as well as pay very high prices for oncologic medication. This resulted in the two previous Directors having to resign. The ANTAC representative also noted that reports of patients having to pay had reduced significantly.\textsuperscript{208} An NHSU interlocutor stated that oncologic treatment is ‘highly corrupt,’ which was the case also before the reform.\textsuperscript{209} A representative from the National Cancer Institute explained that the institute does not receive enough budget from the state to cover all necessary treatments, so often patients need to pay part of the treatment/medication/medical device themselves.\textsuperscript{210}

A representative of an oncology patient organisation exemplifies the corruption with a story of a patient who was asked to pay UAH 100 000 (about EUR 2 950\textsuperscript{211}) for a needed surgery, twice the price of the same procedure in a private facility while the procedure should be free in public facilities. The patient was told they would be banned if they went public with the story. The representative from Patients of Ukraine noted that ‘doctors see patients as money; as long as they have money, they are treated’ and that without money, they may not receive treatment. The representative assesses that about 1-2 % of doctors are honest, and that less than 5 % do not ask for money.\textsuperscript{212}

The representative for 100% Life informed that for patients with HIV, treatment and medication is mostly free, with no additional OOP payments. Additional diagnostics are ‘mostly free’, though the representative explained that diagnostics are free at the organisation’s own facilities.\textsuperscript{213} A representative from WHO confirmed that treatment and ARVs are free though laboratory tests are not free.\textsuperscript{214} The representative from UNAIDS also claimed that there had been no reports of informal

\textsuperscript{205} International Renaissance Foundation (IRF), interview, Kiev, 11 March 2020.
\textsuperscript{206} CF Patients of Ukraine and representatives of different patient organisations, interview, Kiev, 10 March 2020.
\textsuperscript{207} Anti-Corruption Action Centre (ANTAC), interview, Kiev, 12 March 2020.
\textsuperscript{208} Anti-Corruption Action Centre (ANTAC), interview, Kiev, 12 March 2020.
\textsuperscript{209} National Health Services of Ukraine (NHSU), interview via Webex, 26 January 2021.
\textsuperscript{210} National Cancer Institute, interview, Kiev, 13 March 2020.
\textsuperscript{211} Xe.com, Xe Currency Converter, 2 February 2021, url...
\textsuperscript{212} CF Patients of Ukraine and representatives of different patient organisations, interview, Kiev, 10 March 2020.
\textsuperscript{213} 100% Life, interview, Kiev, 10 March 2020.
\textsuperscript{214} World Health Organization (WHO), interview, Kiev, 10 March 2020.
payments for anti-retroviral treatment. A representative from the Public Health Center noted that the procedure for hepatitis is problematic, as in general HIV patients have to be tested for hepatitis, but the hepatitis test must be paid for by the patients.

A representative for WHO pointed out that in mental health care, informal OOP payments exist, but also that people without resources will receive care.

4. Pharmaceutical sector

4.1. Essential Medicines List (EML)

The Essential Medicines List (EML) is the list of essential medication that should be available for inpatient care in hospitals, containing over 400 international non-proprietary name (INNs) medications. It entails central procurement of more expensive medication, which is then free for patients. The EML is under oblast responsibility, though it is controlled by a committee in the MoH (institute of pharmacology and toxicology). It is approved by a Cabinet of Ministers decree and is determined in the Law of Financial Guarantees. The list was last updated in 2017; the MoH decides when to update, though it should be updated at least once a year. There are currently over 100 applications to the EML, listed on the State Expert Center’s website. The representative from the HTA Department stated that 50% of the medication in the EML were fully available in 2018. A representative from the NHSU noted that the EML often contain older medication, and regards including more modern medication or combination drugs as a future task for the agency.

For inpatient treatments, all medications on the list should be free, and the reimbursement programme (Affordable Medicines Programme) is used for outpatients. The medications included in the Affordable Medicines Programme are based on the EML for the included disease groups. The representative of the IRF noted that 95% of inpatients would still need to pay for some medications. According to a household survey, 70% have had to borrow money to pay for medication or treatment. Representatives of the NHSU informed that there are currently informal payments for medication on the EML on the tertiary level, but the reform is intended to fix this.

The oncology patients’ representative noted that the medication on the EML list is not enough for treatments, and that doctors encourage patients to use medication off the list as the EML medications ‘are not effective.’ Patients are instead encouraged to choose other targeted therapies that are not provided for free. The representative claimed doctors push patients to buy from specific providers.

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217 World Health Organization (WHO), interview, Kiev, 10 March 2020.
218 National Health Services of Ukraine (NHSU), interview, Kiev, 12 March 2020.
220 National Health Services of Ukraine (NHSU), interview, Kiev, 12 March 2020.
222 Health Technology Assessment (HTA) Department at State Expert Center, interview, Kiev, 12 March 2020.
223 National Health Services of Ukraine (NHSU), interview via Webex, 26 January 2021.
227 National Health Services of Ukraine (NHSU), interview, Kiev, 12 March 2020.
Patients have no access to complaint mechanisms and due to a lack on oncologists, it is not possible to change doctors. While the system has gotten more transparent and there is no shortage, doctors still encourage patients to buy medication as the doctors receive a percentage of the sales.228

4.2. Accessibility of medication

The representative of the State Expert Center explained that availability of medication is not a problem in Ukraine; the affordability is. The main medications are registered and available. The GDP is less than USD 300, and the medication market is not price-regulated in general. The representative was of the opinion that too much price regulation risked taking medications off the market. The medications included in the EML are price-regulated however, and there are limitations on mark-ups.229 A 2019 WHO Report noted that the pricing mechanism was criticised by pharmaceutical manufacturers on the basis that the Affordable Medicines Programme calculates prices per defined daily dosage, and as a result combination medication are in most cases not considered eligible for the reimbursement list.230

A representative of a MS patient organisation noted that while both treatment and medication are supposed to be free, in reality patients need to pay. Both the representative of the MS organisation and the representative of Patients of Ukraine agreed that only about 10% of patients entitled to it receive medication for free.231

Another issue is that the medications procured by the state tend to be older, classic medicines. Newer medication is often not reimbursed. Some of the representatives stated that the available medication tends to be older generation drugs, and, while they are supposed to be free, in practice they are ‘absolutely not free’. For patients with mental health disorders, only first-generation medications are available for free. Newer medications must be paid for by the patients.232 According to the WHO representative, psychiatric patients will pay for newer medicines.233 The representative of a haemophilia patient organisation noted that while supplies are available, they are ‘not good’. Medication to prevent bleedings is not available; in the regions only curative injections for when a bleeding has started is available in practice. Due to budget cuts, there is not enough money available for the medication. The representative of Patients of Ukraine pointed out that while the quantity of haemophilia medication is sufficient in Kiev and in 4-5 oblasts, the quantities are too low in all other regions and only for emergency cases.234

The geographical access in the regions is another concern. A representative of a haemophilia patient organisation explained that patients in the regions may need to travel 200 km to obtain the medication. While the medication is free, in some regions medications are not handed over to the patients who have to go to the hospital which may be located far away.235 The patient representative of patients with juvenile idiopathic arthritis added that an important problem is the under-representation of specialists and medical facilities in small cities.236

Medication for 38 disease programmes are procured with the state budget. The representatives of the different patient organisations noted that the available state support differed between patient

228 CF Patients of Ukraine and representatives of different patient organisations, interview, Kiev, 10 March 2020.
231 CF Patients of Ukraine and representatives of different patient organisations, interview, Kiev, 10 March 2020.
232 CF Patients of Ukraine and representatives of different patient organisations, interview, Kiev, 10 March 2020.
233 World Health Organization (WHO), interview, Kiev, 10 March 2020.
234 CF Patients of Ukraine and representatives of different patient organisations, interview, Kiev, 10 March 2020.
235 CF Patients of Ukraine and representatives of different patient organisations, interview, Kiev, 10 March 2020.
236 CF Patients of Ukraine and representatives of different patient organisations, interview, Kiev, 10 March 2020.
groups. The representative of patients with juvenile idiopathic arthritis stated that 90% of the needed treatments are available in Ukraine, and central financing from MoH and local bodies cover 60% of treatment costs for the patients. The 20% most severe cases require a 28-day treatment course which costs USD 1 000-1 500. The state coverage does not include rehabilitation. Since 2019, treatment and medication are provided to adult patients as well, but a lot of bureaucratic and logistical efforts are necessary to obtain it. The representative of the haemophilia organisation informed that paediatric haemophilia patients receive the needed support as well.237

The representative of patients with Parkinson reported that, in general, their patients buy medication and get treatment abroad, as it is 2-3 times cheaper in other countries like Poland, Hungary, and Egypt. Prescription is provided in Ukraine and the medication is bought in another country. The representative of Patients of Ukraine further explained that there is a monopoly on the pharmaceutical market which drives up prices in Ukraine. A draft law on parallel import did not receive enough support, so was never approved for vote in the parliament. There is no legislative restriction on prices of medicines.238

According to the representative from the National Cancer Institute, patients do not pay for treatment, but as the medical system is underfunded only about 60% of chemotherapy drugs are covered by the state and the patients pay the rest. Targeted and immuno-therapy are paid by the patients. Traditional chemotherapy is covered up to 60%. Paediatric oncologic treatments are covered completely, except for targeted therapy. Targeted therapy is bought directly from the medical companies. Staff costs are low, so patients do not need to pay for surgery, though they sometimes need to pay for one use materials.239

4.3. Registration and procurement of medication

The State Expert Center prepares applications for the registration of new medication, although the final decision on registration is taken by the MoH. The State Expert Center functions as the national registration authority of medication.240

There are different procedures for registering medication, depending on the type of medication and volume of the medication:

- Standard procedures – the procedure is harmonised with EU procedures (83 EU Directive). The time frame is 110 days and the procedure costs UAH 100 000 (about EUR 2 950).241 Generic medication registration takes 90 days to process.
- Simplified procedures – international procedures, where medication has been registrated by EMA, the Swiss national registry, or FDA. The procedure takes 7 days if no expertise from the Center is needed. If expertise is needed, the procedure takes 45 days. WHO prequalified medications for oncology, hepatitis, rare diseases and TB do not require expertise.
- 2017 EBR procedure – Ministry of Health will take a decision on registration based on a report available on their website.242

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237 CF Patients of Ukraine and representatives of different patient organisations, interview, Kiev, 10 March 2020.
238 CF Patients of Ukraine and representatives of different patient organisations, interview, Kiev, 10 March 2020.
239 National Cancer Institute, interview, Kiev, 13 March 2020.
241 Xe.com, Xe Currency Converter, 2 February 2021, url.
In 2019, a total of 900 registrations were done through the standard procedure. 70 medications were registered through the simplified procedure. In general, EU manufacturers tend to be used for the Ukrainian market as FDA registered medications are quite expensive to bring to Ukraine.243

A suggestion for electronic applications was with the MoH at the time of the interview (March 2020), which, if approved, will reduce the time and logistics of the process.244

7% of registered medicines are only available through one manufacturer (for instance medication for rare diseases). Other medicines have many manufacturers, like diclofenac with over 30 brand names. There are 100 licensed manufacturers in Ukraine. Half of the medications are for external use (e.g. ointments). 10 of the manufacturers are quite big and also sell medication in other countries. In the Soviet era the focus was on Eastern Europe, which is still the case for Ukrainian manufacturers. Most of the medications are generics that are needed on the internal market.245

Importers and Ukrainian manufacturers have equal rights and they must all be Good Manufacturing Practice (GMP) certified to get the products registered. State Services of Medicines handle GMP certification. Chinese and Indian manufacturers often register in Ukraine first and then in the EU; 80% of the simplified procedure concerns medication from India. The State Expert Center has a WHO certified medicine lab, one of nine in Ukraine, where chemical and physical properties can be tested. The laboratory can also test immunobiological medication and vaccines. Vaccines have a special level of control and are controlled both before registration as well as after each import batch. There are four pharmabio laboratories/pharmacokinetics laboratories in Ukraine, three of which are private. Manufacturers can choose to be tested anywhere, also abroad.246

The representative of IRF mentioned that medication procurements tend to operate on budgets, not on needs, which means that patient groups advocate in order to assure their groups get medication. This has varying results; in some regions the input from rights groups is regarded as important while the advocacy is disliked in other regions. Hospital budgets are in general too low to procure enough medications, so the chief doctors negotiate with the MoH. The outcome depends on relations between the doctors and ministry officials.247

The interlocutor from the Children’s Hospital Okhmatdyt stated that onco-haematology drugs and expensive medicines are obtained through central procurement at the Ministry of Health. The delivery is not always well-timed, which can cause problems. Other medication is bought with the hospital’s budget. In terms of supply, the representative noted that while the supply for onco-haematology is problematic, the supply of insulin is fine.248

According to an ANTAC representative, the old procurement system was flawed; it was not transparent and favoured a few distributors. This could result in the state paying high above market price for certain medicines. After the 2014 Maidan protests, the system was reformed and the ProZorro system249 was introduced. As a result, 40-50% of the budget was saved on procurement orders. Hospitals are also now mandated to report the stock of medication each week. Through the ProZorro system, it is possible to see if the medication was purchased by the hospital.250

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244 State Expert Center, interview, Kiev, 11 March 2020.
249 The ProZorro is an online public procurement platform that ensures open access to public procurement (tenders) in Ukraine.
250 Anti-Corruption Action Centre (ANTAC), interview, Kiev, 12 March 2020.
An interlocutor at the National Cancer Institute explained that the MoH makes central purchases of chemotherapeutics (e.g., cytostatics) through the ProZorro system, the hospital buys some medication, and some foreign companies make some purchases. Later, once the new procurement department at the MoH is established, it will handle all medication purchases. The interlocutor believes the hospital needs liberty to buy from different companies to circumvent corruption, and also as the hospital knows what they need, they prefer to control some purchases themselves. Bulk medicines should be bought centrally, though. Currently they try to ensure all needed medicines are purchased in advance by the MoH, but now they get medication bought two years ago.251

The ANTAC representative stated that there were systemic problems with procurement in the field of oncology, with tenders agreed in advance and too high or too low prices.252

### 4.4. Pharmacies

There are many pharmacies in Ukraine – according to the representative of the State Expert Center, there are five times as many per inhabitant as in Denmark. In the past ten years the ownership of the pharmacies has changed, going from individually owned to chain pharmacies. The pharmacies can give rebates for customers, as can holders of the Kiev Citizen Card (the card also gives other social benefits, like rebate for public transport).253 A pharmacist in Kiev informed that pharmacies in Ukraine are climate controlled.254

Pricing on medication is free in general; it is only regulated for a few medicines. Medication on the Essential Medicine List have a limit on mark-ups.255 This was confirmed by a pharmacist who stated that while medication not on the NEDL are not regulated, medication included in state programmes have the same price everywhere. On other medication, prices will vary depending on area, as prices are affected by supply and demand.256 The price of medication is consistent within one pharmacy

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251 National Cancer Institute, interview, Kiev, 13 March 2020.
252 Anti-Corruption Action Centre (ANTAC), interview, Kiev, 12 March 2020.
chain, though. Following a direct question on online pharmacies, the pharmacist stated that online pharmacy prices can be regarded as reliable and mentioned tabletki.ua as one site where patients can order medication for delivery or pickup at a pharmacy.

A pharmacist explained that there are seldom stock issues in private pharmacies and patients can go to a private pharmacy if the hospital pharmacy is running out of the medication. The pharmacy where this interlocutor works at has a computerised programme that gives a warning when stock is running low on certain medication.

According to the pharmacist in Kiev, pharmacists in Ukraine do not have any mechanisms for detecting or preventing contra-indications of medication, as this is considered to be solely the duty of the treating physician.

Opiate medication is strictly controlled. For instance, morphine, tramadol and opioid substitution treatment are all ‘rigorously’ regulated, a legacy from the Soviet era. According to the IRF representative this can lead to accessibility problems when doctors may not prescribe the medication and some local authorities may not wish to fund this medication. This means the patient needs to pay full price. Only certain pharmacies have licences to operate such controlled medication, and in some oblasts there are only one or two with these licenses. It is regarded as not profitable, so it is not desirable for pharmacies to apply for the licence. There is no legislation to regulate the amount of controlled medication at each pharmacy. The patient will receive the address of the pharmacy together with the prescription, not before. The representative further noted that some unlicensed pharmacies sell these medicines as well, but it is done under the table. There can be consequences because of the strict opiate policy. The IRF have documented cases of oncologic patients who need to get black market alternatives, or who commit suicide because they were not able to access pain medication.

4.5. Not registered medication

Medication that is not registered can be easily obtained, according to representatives from the Public Health Center, but the problem is that the quality is not guaranteed. A representative of the State Expert Center pointed out that according to official statistics about 1-2% of medication on the market is counterfeit. Lists of medication which are suspected of being counterfeit are published on the State Service on Medicines’ website. The State Drugs and Medications Control Service issues GMP certificates, licenses pharmacies and distributors, and controls them. The agency also monitors for counterfeit drugs and is able to stop the sale of medicines if the safety is in doubt. A pharmacist interviewed in Kiev mentioned that the authorities do a lot of controls of pharmacies and patients can ask for certificates for medication. Due to all these controls, counterfeit drugs are not a problem, according to the pharmacist.

The following three procedures, which are regulated by law, set out the legal import of unregistered medications. Via a procedure in the MoH, medication can be imported as humanitarian aid. Patients can also themselves bring medication into the country, which is controlled by Customs. Lastly, medication can be brought within the scope of national and international clinical trials, approved by

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the MoH. For a doctor to prescribe not registered medication in a legal way, they must prove that the medication is only intended for an individual patient. Any other way of import is prohibited.265

5. Accessibility for specific groups

5.1. Discrimination and societal groups

On the topic of discrimination, the representative of the IRF explained that Roma are discriminated against and can be refused care or receive worse care than other patients. For LGBT patients, there is not a lot of discrimination unless they need to disclose their status, for instance in reproduction and family planning. The situation is the same for drug users, who may experience discrimination in e.g. the field of pain management. The discrimination could take the form of denial of treatment, being told to go to other facilities, etc.266 This was confirmed by the representative from UNAIDS, who explained that at risk population (LGBT, sex workers, drug users, etc.) are discriminated against in general. The interlocutor noted that rural areas differ from Kiev, where people in general are more open. HIV patients can face stigma, and among some HIV patients there is the fear that, following the reform, they will need to go to general hospitals, where their health status may become known in the community or doctors may have negative attitudes to HIV patients. There is a history of not respecting the confidentiality of medical diagnosis in the healthcare system.267 Similarly, the interlocutor from WHO explained that the population at risk of HIV transmission in Eastern Europe are drug injecting people, the incarcerated population, sex workers and LGBT communities, and a second wave of heterosexual transmissions. There is still a lot of stigma and discrimination for these groups, especially outside of Kiev.268

5.2. IDPs and the situation in the non-government-controlled areas

The reform has, according to a representative from IOM, improved access to healthcare for IDPs. In the past it could be difficult to get treatment, but as people can register with a general practitioner anywhere now, access has improved.269 This was also highlighted by the representative from 100% Life.270 For the people living in the non-government controlled areas, it may however be difficult to get the declaration signed with a general practitioner. If an IDP is not registered, they cannot get free treatment. The representative from UNAIDS noted that it is important to distinguish between IDPs settled in government-controlled areas and those remaining in the non-government-controlled areas of Ukraine. The NHSU focuses on the government-controlled areas and population living there, whereas people living in the non-government-controlled areas have no access to NHSU treatment on that side of the contact line. However, people living with HIV on the non-government-controlled territories can get anti-retroviral therapy there too, paid for from the grant to Ukraine from the Global Fund to fight HIV, TB, and malaria (and distributed by 100% Life, see below). It should be noted that, since 2014, Crimea is part of Russia and internationally considered illegally annexed. UN agencies can access the non-government-controlled areas in Donetsk and Luhansk, but not Crimea.271

266 International Renaissance Foundation (IRF), interview, Kiev, 11 March 2020.
268 World Health Organization (WHO), interview, Kiev, 10 March 2020.
271 UNAIDS and IOM, interview, Kiev, 13 March 2020; UNAIDS, email, 8 December 2020.
The representative from 100% Life explained that the organisation procures ARV medication for patients on the other side of the contact line in Donbass, as the government cannot do this. The organisation also transfers HIV medication to the territory. Reports are quite positive, though as monitoring is difficult in that area, the NGO only has estimates.\textsuperscript{272} The interlocutor from UNAIDS also confirmed that the government does not provide ARV medication in the non-government-controlled areas, though patients can pick up medication on the other side of the contact line provided they are able to cross.\textsuperscript{273}

According to WHO representatives, HIV and TB services ‘were not unduly affected’ by the conflict, but addiction services have been. As methadone is not provided in Russia, methadone substitution therapy has stopped in Donbass.\textsuperscript{274}

### 5.3. Patients with mental health disorders

A representative from WHO explained that Ukraine still has a post-Soviet mental health system, with asylum-like hospitals with many human rights violations.\textsuperscript{275} According to a 2017 World Bank Report, the mental health care system in Ukraine is centralised and the services are provided mostly through psychiatric clinics, while 90% of the funding goes towards psychiatric hospitals. There is an absence of mental healthcare on a community-level. In addition, the provision of mental health care support by non-specialised staff such as general practitioners and family physicians is very limited.\textsuperscript{276} The centralised system includes psychiatric and narcological hospitals (for addiction problems), outpatient clinics, psychiatric departments in hospitals, psychiatric agencies linked to other governmental ministries, polyclinics possibly having psychiatrists or psychologists on staff, and a few private health care facilities.\textsuperscript{277}

In the public sector, psychiatric treatment is currently provided at secondary level, even though a couple of regions have introduced it at primary level. There is a growing awareness of mental health care at primary level, according to a WHO representative. Primary mental health care includes psychosocial support, intervention, simple diagnosis, basic treatment and medicine. Recently a system of referral has been introduced, where the first contact at primary level will refer a patient to specialised care/psychiatrist. Currently, supervision of a family doctor by a psychiatrist is absent in the public sector, while in the private sector supervision is known. The idea is that when first level staff acquire the necessary skills, they can manage more psychiatric patients themselves. This is a new system for the country and is not fully implemented yet, though the development is more pronounced in the fields of mental health and HIV/TB.\textsuperscript{278}

For patients with schizophrenia, all costs were covered by a social benefit package, and both in- and outpatient care was free. Due to the decentralisation of healthcare in the reform, it is not known if this will still be the case. Local budgets should cover treatments, but the local authorities are not always prepared for this.\textsuperscript{279}

\textsuperscript{272} 100% Life, interview, Kiev, 10 March 2020.
\textsuperscript{273} UNAIDS and IOM, interview, Kiev, 13 March 2020.
\textsuperscript{274} World Health Organization (WHO), interview, Kiev, 10 March 2020.
\textsuperscript{275} World Health Organization (WHO), interview, Kiev, 10 March 2020.
\textsuperscript{276} World Bank Group (the), Mental health in transition. Assessment and Guidance for Strengthening Integration of Mental Health into Primary Health Care and Community-Based Service Platforms in Ukraine, 2017, url, p. 11.
\textsuperscript{277} World Bank Group (the), Mental health in transition. Assessment and Guidance for Strengthening Integration of Mental Health into Primary Health Care and Community-Based Service Platforms in Ukraine, 2017, url, p. 44.
\textsuperscript{278} World Health Organization (WHO), interview, Kiev, 10 March 2020.
\textsuperscript{279} World Health Organization (WHO), interview, Kiev, 10 March 2020.
A psychiatric patient representative stated that there are no facilities or specialists outside the big cities. Some mental diseases are not treated or supported in the country at all.280 Local budgets do not always provide enough funds for psychiatric treatment.281 According to the WHO representative, rehabilitation and recovery has been recently introduced and it is more about arts and crafts than real life skills. There is a general lack of understanding of what rehabilitation is, so there is not much support available on e.g. how to apply for jobs or other necessary skills.282

The treatment is medication oriented and patients are often prescribed drugs only. While psychotherapy, behavioural therapy, cognitive behavioural therapy (CBT) and EMDR exist, they are not common in the whole country. Different types of psychotherapy are available, but they are almost all paid OOP and are often only available in the private sector. Staff in the public sector cannot afford the training to specialise in e.g. EMDR. Nurses in Ukraine are not trained for medical procedures or for psychiatric cases.284

The representative from IRF explained that the psychiatric sector utilises closed facilities that may be hard to access without paying bribes. Patients can be tied to beds or badly treated.285 Article 14 of the Law of Ukraine ‘On Psychiatric Care’ states that a person suffering from a mental disorder can be hospitalised without their consent or without the consent of their legal guardian or representative if inpatient treatment is possible and if they have a severe mental disorder making them a direct danger to themselves or to others or if they cannot meet their basic needs in order to ensure their livelihood. This article was amended in 2016 and a court order is required for involuntary admission. In 2017, the government developed a mental health concept note, with a strategy to create an alternative community-based service and day institutionalisation (day care). The action plan has gotten stuck, however.287

On the question if a patient in a closed facility can experience problems getting released, the representative from IRF explained that if a patient is declared ‘incompetent’, the responsibility for a release is with the guardian, which is often the Chief Doctor. In that case, a patient may not be released when they wish. If the patient’s family want them released and declared ‘competent’, there are no issues leaving the facility. Some patients stay in facilities as they have nowhere to go; they would be homeless if released. Acute cases are normally admitted for 2-4 weeks in a facility, according to the IRF representative.288

Psychiatric patients report facing discrimination in outpatient settings, according to the representative from IRF. Not all family doctors want to sign their declaration or provide prescriptions. Some of the psychiatric medications are restricted, which requires a different prescription.289

A mental health patient spokesperson explained that patients with mental health disorders may not even be notified of their diagnosis. The information is passed between doctor and therapist, bypassing the patient, who must ‘fight’ to find out the diagnosis. Patients also avoid medical committees, as

280 CF Patients of Ukraine and representatives of different patient organisations, interview, Kiev, 10 March 2020.
282 World Health Organization (WHO), interview, Kiev, 10 March 2020.
284 World Health Organization (WHO), interview, Kiev, 10 March 2020.
287 World Health Organization (WHO), interview, Kiev, 10 March 2020.
these committees can suggest for a person to work from home, which can create problems with the patient’s employer.290

5.4. HIV patients

5.4.1. Funding for HIV services

There is a transition plan for the government to take over procurement of ARVs.291 Global Fund has funded USD 130 million for HIV treatment over 3 years in Ukraine.292 The current annual budget for TB/HIV treatments in Ukraine is USD 70 million, which has been the case for the past ten years.293 Over time, the Ukrainian state has promised to transition from donor funding to national funding for TB/HIV treatments, until in the long term no international funding will be needed.294 About half was nationally funded in 2020.295

Initially, the funding from Global Fund296 was given to the government, but later this changed and the funding was given to NGOs (Alliance for Public Health and 100% Life are equal partners). This was the first time Global Fund gave funds to NGOs.297

If the government underbudgets and treatment is missing, 100% Life steps in; something which recently happened. There is no problem currently in Ukraine with the procurement, delivery and supply of ARV’s, and most are available. The procurement of ARVs is done according to WHO protocol, and they are only able to procure what is included in the WHO protocol. WHO protocols on testing and prescription should be implemented soon.298 Innovative testing equipment would be procured by the government, as it cannot done with the international funding.299

Regarding HIV prevention, the government picks up the services, but donors are paying for condoms, needles, staff resources, etc. According to the representative from UNAIDS, it is a good understanding but with the changes in government it is difficult to know how commitments are maintained.300

As of last year, Ukraine provides free ARVs to Ukrainians. IDPs and citizens in the non-government-controlled areas also receive free antiretroviral medication, though the supply is donor-funded. It is also possible to pick up the medication in government-controlled areas, as long as it is possible to cross the contact line. ARVs (e.g. Truvada) for preventive use instead of for treatment are funded by NGOs. Some ARVs are purchased via donor funding for innovation programmes, but the expectation is that the government will pay for this as well, if it is scientifically proven.301

All procured ARVs are on the national essential drug list. The Centre of Public Health makes annual estimates on how many therapies will be needed. 100% Life also procures for the occupied regions in

290 CF Patients of Ukraine and representatives of different patient organisations, interview, Kiev, 10 March 2020.
291 100% Life, interview, Kiev, 10 March 2020.
292 World Health Organization (WHO), interview, Kiev, 10 March 2020.
295 World Health Organization (WHO), interview, Kiev, 10 March 2020.
296 The Global Fund is an international organization that aims to accelerate the end of AIDS, tuberculosis and malaria as epidemics. Source: Global Fund (the), Overview, 14 September 2020, url.
297 World Health Organization (WHO), interview, Kiev, 10 March 2020.
298 100% Life, interview, Kiev, 10 March 2020.
299 100% Life, interview, Kiev, 10 March 2020.
300 UNAIDS and IOM, interview, Kiev, 13 March 2020.
301 UNAIDS and IOM, interview, Kiev, 13 March 2020.
Donbass, as the government cannot provide for people there. The NGO is transferring medication over the contact line.\(^3\)

100% Life, founded in 2001, is the biggest patient-based organisation in Ukraine with 15,000 members. It is financed by Global Fund, the EU, Pepfar\(^3\) and others. It represents HIV positive and other vulnerable groups and advocates for human rights and access to treatment. The mandate has increased over the years. The organisation works in four areas: service provision, advocacy, innovation, and strategic communication with stakeholders.\(^4\)

In terms of service provision, the NGO works with:

- identification/diagnosis of HIV and ART procurement.
- Identification/diagnosis of TB (together with Center of Public Health), social services.
- identification, social services and antiretroviral medicines procurement (ART procurement) and prescription for HIV, TB, Hepatitis C and B patients.
- penitentiary system – testing and social and medical support. Opioid substitution therapy.
- development of a medical information system for HIV patients, which can be installed in all medical facilities.
- registration of HIV cases in the country. All patients are registered to provide epidemiological data and new patients can be added directly through index testing.
- working on systems for labs.
- procurement of ARVs/ART therapy, which is provided by medical centres. The NGO work with MoH and NHSU in this capacity and do not provide medical treatments as a service.\(^5\)

100% Life have also established a non-profit, self-sustained Community Medical Center, which provides only primary health care services for HIV positive patients and for the general population in these areas: gynaecology, paediatrics, narcology (addiction problems), vaccination, family doctor.\(^6\)

In addition, 100% Life has advocated for testing and prescription of ARVs to be handled by family doctors. The legal act is signed but the change is yet to be implemented. The organisation is working on de-stigmatisation and have developed an online, distance learning tool for family doctors on anti-stigma and anti-discrimination. They have also created a map of friendly family doctors, so patients can know e.g. who to sign a declaration with. Other areas of advocacy include decriminalisation of sex work and drug use, and providing legal support for LGBT persons. Human rights in Ukraine for HIV positives, drug users and LGBT is still sensitive, according to the interlocutor.\(^7\)

### 5.4.2. Availability of treatment and medications

There are less than 400 ART sites/HIV centres in 24 regions. Each region has a regional centre which coordinates these services. While there are 50 centres in the Kiev Dnipro region, there is only 1 centre in Chernivtsy, a small region. This means that in rural areas, patients may need to travel a few hours.\(^8\)
ARVs are only available in the AIDS centre pharmacies, not yet in general pharmacies and in community medical centres. This will change soon though.\(^{309}\) The representative from WHO expressed a hope that ARVs would be available in regular pharmacies in the future.\(^{310}\)

According to a WHO representative, the situation for people living with HIV has improved greatly in the last years. Approximately 100 000 people are now on ARV treatment, while in 2007 there were only 4 000. An estimation is that 70% of cases have a diagnosis and 80% of those are treated. The curve of people getting treatment is very good.\(^{311}\) The Public Health Center informed that approximately 113 000 are treated on ARVs. According to the government agency, there are 130 000 HIV cases registered in government-controlled areas, but it is estimated there are 240 000 cases in total (including non-government controlled areas). Mortality has decreased but prevalence (the total number of cases) has increased. 15 000 new cases are found every year; this incidence is stable. It is however difficult to detect cases in rural areas.\(^{312}\)

The electronic medical system centrally monitors patients with HIV, to see how effective the treatment is. Indicators are received on regional levels for TB and HIV and can then be analysed.\(^{313}\)

### 5.4.3. Access to treatment

HIV testing is usually only offered in special clinics (ART sites and HIV centres). According to a WHO representative, 20% of those diagnosed with HIV do not receive treatment. This is mostly because of non-compliant patients, complicated hurdles patients need to pass through, and economic barriers. Among people not receiving treatment for HIV, there is an overrepresentation of the marginalised populations, as services are not always adapted to their needs. It might be a matter of increasing the opening hours at the testing sites and not asking for documentation, for instance. Another obstacle is that people get counselling first and do the test, instead of the other way around. People can be regarded as non-compliant and get kicked out, when e.g. they were not able to make it to the appointment. They may then have to check and pay for a viral load test before getting ARVs. They may also need to get a TB test somewhere else before getting ARVs. WHO has tried to ensure the mindset changes, so patients can get treated.\(^{314}\)

For the marginalised population, especially injecting drug users, there are difficulties accessing treatment. WHO supports opioid substitution therapy, also as a way to retain ARV treatment. Ukraine has the biggest state-financed opioid substitution programme in Eastern Europe, but it would still need to be bigger as it reaches only 7 000 out of over 60 000 who really need it. Dosages are too low, despite being the best in Eastern Europe. In general there is no methadone in Russia, so substitution with methadone stopped in the occupied region Donbass. HIV and TB services ‘were not unduly affected’ by the conflict, but addiction services were affected.\(^{315}\) In a clarification, a representative from the Public Health Center explained that 14 296 patients are included in the programme and the known number of opioid users is 278 318, making the coverage 5.1 %. The dosage is prescribed on an individual basis.\(^{316}\)

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\(^{309}\) 100% Life, interview, Kiev, 10 March 2020.

\(^{310}\) World Health Organization (WHO), interview, Kiev, 10 March 2020.

\(^{311}\) World Health Organization (WHO), interview, Kiev, 10 March 2020.

\(^{312}\) Public Health Centre, interview, Kiev, 10 March 2020.

\(^{313}\) Public Health Centre, interview, Kiev, 10 March 2020.

\(^{314}\) World Health Organization (WHO), interview, Kiev, 10 March 2020.

\(^{315}\) World Health Organization (WHO), interview, Kiev, 10 March 2020.

\(^{316}\) Public Health Center, e-mail, 24 December 2020.
A representative from the Public Health Center pointed out that, historically, marginalised groups with HIV have been the responsibility of NGOs. They become the responsibility of the healthcare system when patients approach it. The NGOs are still important in reaching out to certain key populations.317

The interlocutor for 100% Life stated that the organisation had difficulties in reaching patients outside the traditional groups, but the organisation has a new project on that. The NGO also saw a need to reduce time between diagnosis and prescription of ARVs. The second 90 (in the 90-90-90 UN target318) is a challenge and protocols still need to be adopted. Additionally, there is a need to ensure people are not ‘lost’ after the initial testing. In general though, the NGO have positive results on adherence.319

There is a law which lists which people should be tested for HIV, based on their history, symptoms, behaviour, and so on. Currently, only infectiologists can prescribe ARVs and only at ARV sites, though a draft law is in process which will enable family doctors to prescribe ARVs.320 The intention of the healthcare reform was for family doctors to do HIV tests and prescribe first line medication. The payment to the family doctors includes HIV rapid tests in their cabinets. Complicated cases could be referred to second level/hospitals and a specialist.321 UNHCR ensures asylum seekers get tested and get access to treatment for HIV or get to continue treatment when in Ukraine.322 The HIV centres have infectious disease specialists who can focus on TB (pulmonologist) or HIV.323 For referrals, a family doctor will refer the patient to a regional (raion level) AIDS centre, who can then refer to oblast level AIDS centre, after which the patient if needed can be referred to a specialist hospital.324

The interlocutor from WHO explained that the population at risk of HIV transmission in Eastern Europe are drug injecting people, the incarcerated population, sex workers and LGBT communities, and a second wave of heterosexual transmissions.325

5.4.4. Cost of treatment

Viral load and CD4 tests are available free of charge, and a person with HIV can get free ARV treatment in Ukraine.326 The state also covers treatment for patients with viral hepatitis and TB, as well as OST (Opioid Substitution Therapy).327 Follow-up laboratory tests are not free.328

Incurred costs may involve travel, or if the patients chose to go to private clinics to get faster service.329 There have been no reports of informal payments for ARTs.330

318 By 2020, 90% of all people living with HIV will know their HIV status.
319 100% Life, interview, Kiev, 10 March 2020.
320 Public Health Centre, interview, Kiev, 10 March 2020.
324 Public Health Center, e-mail, 24 December 2020.
325 World Health Organization (WHO), interview, Kiev, 10 March 2020.
In order to get better treatment, people go to the private sector. The WHO representative noted that public sector is lacking compared to the private sector, but it is improving. Incorporating private facilities is in the plan of NHSU. At the last tender for HIV package, there were 500 successful bidders, 100 of which were new on the market. Some facilities are private, and they participate under the same conditions as public ones. The service will be free at the point of delivery in private facilities too, but the facility may offer other services at a cost, e.g. recommend other medications. In general HIV patients have to be tested for hepatitis, but the patients need to pay for the hepatitis test in some health facilities (the interlocutor estimates patients need to pay in about 50% of facilities).

The WHO have encouraged an optimisation of treatment, to increase cost effectiveness and efficiency. By moving to standardized WHO regimen in first line, the cost of medicine was reduced. Before there was too much choice in medication, including combinations that were never used. Now there is a standard first line treatment. There are 36 first line regiments, and ideally the patient is given only one pill a day (containing several ARV’s). They are still reducing the use of some formulations and are moving towards the standardized regimen. The procurement still contains ARVs not recommended by WHO (e.g. lopinavir is 25 times more expensive than the ARV recommended by WHO). WHO wants to reduce the use of overpriced medications and have tried for years to reduce the number of medication.

5.4.5. Consequences of the reform

There are concerns from HIV patients that with the closure of specific AIDS centres and related integration of HIV/AIDS services into regular clinics, the patients may risk encountering more doctors with negative attitudes towards HIV patients. The UNAIDS interlocutor further explained that the at-risk population is discriminated against in general (gay, sex workers, drug users, etc.).

The representative from UNAIDS noted that people with HIV face stigma, but also that it varies over time. Among the patients there is a fear that after step two of the reform has been implemented, the HIV patients must go to general hospitals. There is a history of not respecting the confidentiality of medical diagnosis in the healthcare system, so the patients’ health status may become known to their community. There is also fear that the staff at the general hospital will not be specialised or as qualified as in the current centres.

The interlocutor for 100% Life highlighted a concern related to political insecurity, which is an issue in general for the programmes. Additionally, there is a challenge to identify new HIV positive cases. As demographics are unknown, they do not know their target numbers (see also section 1.3.5. Data collection in healthcare).

5.5. TB patients

TB incidence (number of new cases) is decreasing; in 2019 there was a 3% decrease, and the trend for the past seven years has been a decrease. MDR TB incidence decreased as well in 2020, after some years of stabilisation. However, the UNAIDS representative reported that TB and MDR TB are big problems.
concerns in Ukraine, with TB being the number one cause of death for people living with HIV. All TB patients are tested for HIV, and the yield is quite high. All newly discovered HIV patients get tested for TB.

All TB patients get diagnosis and treatment for free, including the new drugs for MDR and XDR TB.

For complicated MDR TB, the usual DOT (Directly Observed Therapy) strategy is provided by 100% Life. The NGO provides the services which are not provided by the government. A strategy on combating TB was signed last year.

Treatment of TB is changing into a public health approach, like for HIV, with more rapid testing, test & treat (limit the time before treatment starts), standardised regimens, and multi-month prescriptions. All TB programmes and treatment standards are coordinated by the Public Health Center. The new standards of care for TB are similar to EU standards, but adapted to WHO recommendations.

As a result of the reform, TB hospitals will branch out to become something closer to infectious disease hospitals (see section 1.3.4. Changes to HIV and TB services), but there is a lot of resistance to a public health approach for TB treatment. With the ongoing reform, there is a fear among the public of the planned sanatorium closures. The current system keeps patients locked up with their family for nine months in a sanatorium.

There is a reluctance to use short-term medication. For regular TB, the situation is improving and success rates are increasing. For MDR TB, the results are worse due to for example incomplete treatments. There are many reasons why MDR and (extra multi-resistant) XDR TB is prevalent, such as an over-use of certain medications, incomplete treatment schedules and not doing follow-ups. Complicated antibiotics for MDR/XDR TB are available. The WHO promotes a standardised approach, but there is a lot of reliance on the old system.

Regarding co-infection HIV/TB, there is good communication between the two systems in charge, according to the Public Health Center. For TB, there are regional TB dispensaries, and for HIV there are 74 regional medical facilities which coordinate the ART sites. The MoH will be making a new regime/protocol for co-infection, as the old one is no longer valid.

5.6. Oncology patients

The National Cancer institute is a tertiary oncology hospital, accepting referrals from all over Ukraine. On paper this is the leading oncology centre in Ukraine, but the representatives note that each region has one oncology centre and, in reality, the same treatment can be provided in each of the 24 regions. However, the regions tend to send complicated cases to the Institute. One third of patients are sent by regional oncology centres. In theory patients need to be referred from a family doctor, to secondary

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341 100% Life, interview, Kiev, 10 March 2020.
342 World Health Organization (WHO), interview, Kiev, 10 March 2020.
345 World Health Organization (WHO), interview, Kiev, 10 March 2020.
346 World Health Organization (WHO), interview, Kiev, 10 March 2020.
level, and then on to the Institute, but people still come directly to the tertiary level (bypassing the referral system).  

The National Cancer Institute treats all oncologic diseases, except central nervous system tumours that must be sent to a specific centre. There is also a specific oncology centre for children at Okhmadyt Hospital. Leukaemia is treated in a separate centre, and the haematology department at the Institute treats lymphomas only. While the National Cancer Institute has a paediatric ward, solid tumours can also be treated at Okhmadyt for paediatric patients. At Okhmadyt, there are no specialists in onco-haematology, but instead a general paediatrician with additional knowledge treats these patients. The hospital has child haematologists, though. An onco-haematological specialisation is planned, but for now the specialists are either focused on oncology or haematology.

5.6.1. Availability of treatment and medication

The representative of the National Cancer Institute noted that in general the availability and supply of chemotherapeutics (e.g. cytostatics) is fine, but for example the availability of radiation therapy is problematic as there are only a few working machines in the country and the institute has one.

The Institute has one machine for linear radiation therapy (external beam radiation treatments), and there can be two months’ waiting time. There are five linear accelerators in Kiev in total. The machines are expensive, so buying another one would spend most of the budget. For the past five years, the Institute has only bought medicines from their budget.

The Institute has one PET (Positron Emission Tomography) Scan with glucose tracer, used to detect metastasis. There are only three PET-CT scans (two in private, one in public) in Kiev, but more are available in other parts of the country. The Institute does not have radio tracers or do proton therapy. The hospital has two CT machines and one MRI. There is a two-month queue for diagnostics.

At the National Cancer Institute, doctors are stationed in one part, e.g. the inpatient clinic, but they will also assure the follow-up of patients after discharge from the inpatient ward. In the old inpatient wards, there are six beds per room (separate wards for men and women). A new block was opened eight years ago (the construction of the building was delayed due to lack of funds). In the new sections, there are two patients per room. The hospital has about 600 beds in total. All doctor positions are filled, but they lack nurses. The hospital has 17 operating theatres. The interlocutors explained that a lot of the equipment, like beds, is old and donated from other European hospitals. Food for inpatients is cooked centrally in the hospital. The representative explained that not all hospitals have kitchens.

348 National Cancer Institute, interview, Kiev, 13 March 2020.
349 National Cancer Institute, interview, Kiev, 13 March 2020.
351 National Cancer Institute, interview, Kiev, 13 March 2020.
352 National Cancer Institute, interview, Kiev, 13 March 2020.
353 National Cancer Institute, interview, Kiev, 13 March 2020.
in which case inpatients must bring their own food. Department are organised according to the type of cancer and each has its own pharmacy.  

![Picture 3: A room in the inpatient ward in the old part of the National Cancer Institute.](image)

For the supply of chemotherapeutics at the National Cancer Institute, the MoH buys the medication centrally using the ProZorro system. Some drugs are bought by the hospital and some foreign companies purchase medication as well for all oncology departments. At the third phase of the reform, the new procurement department at the MoH will handle it. The interlocutors are not certain this change is good, as it removes control over the medication supply from the hospital. Currently, there is an issue that medication purchased in advance by the MoH has been bought two years ago (see section 4.3. Registration and procurement of medication).

The National Cancer Institute can send patients abroad for treatment, especially for transplantations. Transplantation of bone marrow for adults is only possible through relatives, as there is no donor registry in Ukraine. In fact, all types of transplants are only possible from relative donors. The situation is changing, though. In general, very few patients need to go abroad, usually for liver and heart transplants or haematology cases.

At the private Boris Clinic, the representative noted that while it is rare for patients to go abroad for treatment, the reason is not usually because the treatment cannot be done in Ukraine – it is usually because the services abroad are more qualified or the patients want more qualified care. This usually concerns oncology, e.g. acute leukaemia. In the past children with very specific forms of leukaemia were sent for treatment to Helof Hospital in Tel Aviv, Israel, with which Boris Clinic has an agreement. The government is not involved in sending patients abroad, at least not from the private clinic. The treatment is financed by the patients.

At the National Cancer Institute, while most medications are available, some drugs are not registered due to low demand. The patients should buy the medication abroad in those cases. The institute treats 25 000 patients/year and performed 10 000 surgeries last year.

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354 National Cancer Institute, interview, Kiev, 13 March 2020.
355 National Cancer Institute, interview, Kiev, 13 March 2020.
356 National Cancer Institute, interview, Kiev, 13 March 2020.
357 Raschupkin, Andrey, medical director, Boris Clinic, interview, Kiev, 13 March 2020.
358 National Cancer Institute, interview, Kiev, 13 March 2020.
The Institute does not keep electronic patient files, everything is kept on paper in journals. It is possible to send journals abroad.359

A representative of a patient organisation described the medication list EML as insufficient, and sometimes doctors encourage patients to purchase medications not included in the EML, by stating that the free medication on the EML is ‘not effective.’ The doctor may instead recommend medication sold by a particular provider. The patients do not have access to complaints mechanisms and as there are not enough oncologists, they cannot change doctor.360

5.6.2. Access to treatment

Much oncologic medication, including targeted therapy, is not part of the benefit package but is part of the budget for centrally procured medication. There is insufficient medication for all patients who need it, so once the medication runs out patients need to pay. Doctors decide who receives the free medication, as there is currently no prioritisation on the allocation of centrally procured medicines. The NHSU representative noted that oncologic treatment is ‘highly corrupt,’ so even before the reform doctors would try to sell the medications to patients. This is not a problem for e.g. TB and HIV medication, as the need for treatment is flat per number of patients. For oncology patients, full coverage with targeted therapy or innovation therapies will likely never be economically possible for the Ukrainian state.361

The current system is described by patient representatives as more transparent than in the past, and there are no charges for basic targeted therapy (though more advanced targeted therapy must be paid by the patient) and no shortage. However, doctors still encourage patients to buy medication elsewhere, as they may get a percentage of the sale. The interviewed patient representative told a story about a pharmaceutical company which provided up to 200 free injections worth USD 4 000, but would also ask detailed questions to find out if patients could afford to pay for future treatments. Another example provided by the representative was of a patient who needed surgery which would cost UAH 100 000 (approximately EUR 2 950362) in a public hospital, despite the fact it should be free on paper. The patient was told she would get banned if she went public with the incident. 363

Oleksandra Ustinova noted that there is a high level of oncologic patients in Ukraine; as there are no early diagnostics, people end up in hospital with stage 3 or 4 cancer, which is expensive to care for and hard to cure. 364 Patients need to pay in order to receive a diagnosis, and there is a waiting list. Innovative treatments for melanoma patients in stage 3 or 4 can cost up to USD 4 000, if the patient is part of clinical studies. A patient representative explained that for radiation therapy, there is not enough equipment, and moreover it is old, so there is a waiting list to get treatment. Surgery is paid by the patients, which many cannot afford. There is insufficient staff available for palliative therapy. Lastly, the representative mentioned that there are many cases reported of wrong prescriptions. Locally, the representative stated that at times medical staff lack knowledge, misdiagnose and give the wrong treatment.365

There is an issue that oncology patients get classified as disabled, but when, after targeted therapy, they continue with hormone therapy they lose this qualification and as a consequence are no longer entitled to disability benefits. Breast cancer patients on the other hand can keep their disabled status

359 National Cancer Institute, interview, Kiev, 13 March 2020.
360 CF Patients of Ukraine and representatives of different patient organisations, interview, Kiev, 10 March 2020.
361 National Health Services of Ukraine (NHSU), interview via Webex, 26 January 2021.
362 Xe.com, Xe Currency Converter, 2 February 2021, url
363 CF Patients of Ukraine and representatives of different patient organisations, interview, Kiev, 10 March 2020.
364 Ustinova, Oleksandra, member of parliament, interview via Skype, 26 March 2020.
365 CF Patients of Ukraine and representatives of different patient organisations, interview, Kiev, 10 March 2020.
but need to reapply every 2 years. In case patients are disqualified but still need some treatment, they likely encounter financial problems to continue because they cannot rely on social security anymore. Not being classified as disabled means loss of pension and social security.366

5.6.3. Cost of treatment

80% of treatments are financially covered by the state, and patients pay 20-25%, usually for materials. Emergencies and children are fully covered.367 According to Oleksandra Ustinova, oncologic medication is very expensive and the state covers up to 20% in some cases, and up to 70% for children.368

A representative for a patient oncology organisation noted that, while the situation has improved, it is still not ‘good enough’. While most aspects of the treatment are free, more expensive and efficient medication is not as accessible. Some expensive chemotherapy is not covered and 40% of patients with melanoma do not continue their treatment because they cannot afford it. For this reason, patients sometimes go abroad for treatment. The representative explained of one initiative where patients go to Spain and manage to get free treatment.369

Patients do not pay for treatment at the National Cancer Institute; however, the medical system is underfunded and only 60% of chemotherapy drugs are covered by the state, the patients buy the rest. Patients often have to pay part of the treatment, medication, and/or medical devices themselves. Targeted and immuno-therapy are paid by the patients while chemotherapy is covered up to 60%. Paediatric treatments are covered completely, except for targeted therapy. Targeted therapy is acquired via medical companies, and patients contact the companies directly. As staff costs are low, patients do not need to pay for surgery according to the representatives of the Institute. Patients sometimes need to pay for single-use materials.370

There have been complaints of patients at the National Cancer Institute having to pay for procedures which should be free, and patients who had to pay very high prices for oncological medication. This resulted in the sacking of both previous hospital directors. The Institute has been involved in a trial regarding a tender for maintenance and an anti-corruption body has investigated the Institute. The representative of ANTAC noted however that reports of patients having to pay have reduced greatly.371

5.7. Paediatric patients

The NCSP Okhmatdyt in Kiev is the largest paediatric hospital in Ukraine, annually providing over 20,000 children with inpatient treatment, more than 28,000 with emergency medical care, and more than 70,000 are treated in the consultative-diagnostic centre at the hospital. 2,000 specialists are employed at NCSP Okhmatdyt. The purpose of the hospital is to provide multidisciplinary high-quality medical care to children from all over Ukraine in accordance with international quality standards. The hospital is also a teaching hospital.372

366 CF Patients of Ukraine and representatives of different patient organisations, interview, Kiev, 10 March 2020.
367 National Cancer Institute, interview, Kiev, 13 March 2020.
368 Ustinova, Oleksandra, member of parliament, interview via Skype, 26 March 2020.
369 CF Patients of Ukraine and representatives of different patient organisations, interview, Kiev, 10 March 2020.
370 National Cancer Institute, interview, Kiev, 13 March 2020.
372 NCSP Okhmatdyt, interview, 12 March 2020. See also the hospital website url.
NCSP Okhmardyt is a tertiary paediatric hospital, with a wide range of departments such as orthopaedics (including injuries), orphan diseases department, neonatology, paediatric surgery (for new-borns with weight starting from 600g and higher), neuro-surgery, oncology-haematology, bone marrow transplantations (including non-related bone marrow transplants, but no organ transplants), surgery for genetic diseases, inborn errors of metabolism/congenital diseases, neurology, and paediatric oncology.373

Patients can also be referred abroad, with a Special Committee at the MoH taking the decision to refer the case to another country. The state does not cover all the costs in these cases. Some charity organisations and the government cooperate to cover the expenses, and sometimes parents pay themselves. Charitable organisations contribute a lot to such costs, especially for onco-haematology cases. Usually patients are sent to e.g. Belarus, Italy, Germany, etc. It tends to concern only organ transplants, as everything else can be done at NCSP Okhmardyt.374

Most treatments are free, but spinal reconstruction surgeries, like scoliosis, are not free. There are officially no co-payments at the hospital. The hospital treats patients up to 17 years, and they are completely covered. If patients turn 18 and need ongoing treating, they will continue the treatment at Okhmardyt.375

The state budget finances most medications, and some charity organisations contribute. The interlocutor from Okhmardyt explained that the parents in rare cases buy the medications themselves; sometimes they pay co-payments. Onco-haematology and expensive medications are centrally procured by the MoH. The delivery of the medication is not always well-timed, which causes problems. Other medications are bought from the hospital’s budget. In case the patient or the family pay for medication that should be free, it will not be reimbursed. Some very expensive medication can be obtained as charity donation. The hospital cooperates with charities to obtain medication. Treatments with not registered medication are organised as clinical trials.376

373 NCSP Okhmardyt, interview, 12 March 2020.
374 NCSP Okhmardyt, interview, 12 March 2020.
375 NCSP Okhmardyt, interview, 12 March 2020.
376 NCSP Okhmardyt, interview, 12 March 2020.
The supply for onco-haematology medication is problematic, but for instance the insulin supply is fine. There are problems with supplies of certain reactives, used for testing donors’ blood tests. They have 6,000 blood donors per year which need to be tested. Supplies are usually provided centrally from the MoH. However, the chain is always lagging. Charity organizations cover expenses to avoid delays for surgeries.\textsuperscript{377}

Some patient groups can be classified as disabled and are therefore eligible to free treatment. In reality, the representative for patients with Parkinson noted the classification of disability is delegated to the local authority and there is not enough money. So, there is no automatic access to free treatment for children, most must fight for it according to patient organisations.\textsuperscript{378}

\textsuperscript{377} NCSP Okhmatdyt, interview, 12 March 2020.

\textsuperscript{378} CF Patients of Ukraine and representatives of different patient organisations, interview, Kiev, 10 March 2020.
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Annex 2: Terms of Reference

Objective
The objectives of the mission is twofold. In terms of content, a key goal is to map the changes in the Ukrainian healthcare system over the last few years. Since some years, Ukraine has been in the middle of a healthcare reform, and it should be established how far the initiated reform have come and what changes are yet to be implemented.

The health care reform is focused on five areas:
- Money follows the patient
- Package of guaranteed benefits
- International standards
- Co-payment system
- Family medicine

Additionally, the FFM will collect information in general of the state of the healthcare sector, its limitations and its capacity. The accessibility of the Ukrainian public healthcare system, in terms of economical access (cost to the patient to access treatments and medications) and geographical access (healthcare in rural areas and the referral system) will be studied. To anticipate future user needs, a number of commonly requested treatment areas have been identified, for which treatment options will be investigated more in detail.

A secondary objective is to set a methodology and procedure for conducting fact finding missions (FFMs) for EASO. EASO participated in a FFM led by the Belgian Desk on Accessibility (BDA) in June 2019, and in this mission the intention is to streamline the procedure further to formulate clear internal guidelines for conducting FFMs as EASO representatives.

Mission participants
The mission will be led by Liza Backstrom, EASO information officer in COI. Aurelie Varin, EASO research assistant in MedCOI, co-planned and will participate in the mission. In addition, Albert de Vries, medical advisor at EASO, will join. An invitation to participate was extended to the EU+ countries in September 2019, but no interest was expressed.

Scope
The mission will take place in Kyiv, Ukraine over of five days.

Healthcare system
- Organisation
- Reforms
- Public and private sector (incl. Medical bridge programmes)

Treatment areas
- Paediatrics
- Oncology
- Psychiatry
HIV
Hepatitis

Pharmacological sector

Affordable Medicines National Prescription Drugs Cost Reimbursement Program
Essential Medicines list
Medication prices

Financial issues for patients

Health Insurance
Out of pocket payments, corruption

Intended interlocutors

The intention is to meet with a mixture of interlocutors, from the public sector and the private, in order to get multiple viewpoints on the topics included in the scope:

- Ministries
- NGOs
- Public healthcare facilities
- Private healthcare facilities
- International organisations

Methodology

The EASO FFM methodology will be followed, to ensure a balanced mix of sources and an interviewing and reporting approach that is objective and comprehensive. In order to ensure this, all participants will receive instructions in advance on common conduct during FFM and a clear division of labour between the participants will be established. To the extent possible, first hand visits to facilities will be made and for each topic, different kinds of sources will be consulted.

Reporting

Following the mission, meeting notes from all participants will be collected. This material will then be used as the basis for a number of thematic reports, to be produced in 2020. The reports will be publicly available and be complemented with relevant desk research.