

Central and
Eastern Europe
and West Asia
Regional Project
of the CML
Advocates Network



1. Introduction

Chronic Myeloid Leukemia (CML) is a type of blood cancer, a chronic disease of the blood and bone marrow that results from a transformation of a stem cell. It is a disease which affects patients throughout the world. There are many organisations across continents working to help patients with CML, their family members and caregivers. Leaders of CML patients groups are united in the CML Advocates Network.

CML Atlas East Europe is the final product of the East Europe and West Asia regional project run by CML Advocates Network.

CML Atlas presents most relevant data on CML which may be useful for local organisations, other regions and global network itself. Moreover, it compresses data from all the countries in the region and therefore organisations can compare data among countries and use that information for advocacy, fundraising and learning. Collected data are following:

- General information about CML (number of CML patients, number of CML organisations, number of hospitals treating CML, number of treating haematologists, hospital registries / national registries)
- Availability of TKIs (percentage of patients having access, prices, ways of drug availability)
- Availability of PCR (percentage of patients having access, prices, frequency of testing)
- Clinical trials (study centers, number of patients)
- Treatment free remission data.

The CML Advocates Network conducted the survey in order to collect the data. The survey started on 1st December 2019 and lasted until 31st March 2020. Respondents come from 19 countries from Central and Eastern EU region. Six of the respondents are CML doctors and 13 are representatives of CML organisations, leading advocates. The web questionnaire was prepared using cloud-based online survey development software SurveyMonkey.

CML Atlas East Europe publishes data using two media: this brochure and on website ceeatlas.cmladvocates.net. Published data are as of July 2020.



Time: 1st December 2019 – 31st March 2020



Respondents: 19 country representatives (CML doctors & CML advocates)



Questionnaire: online survey



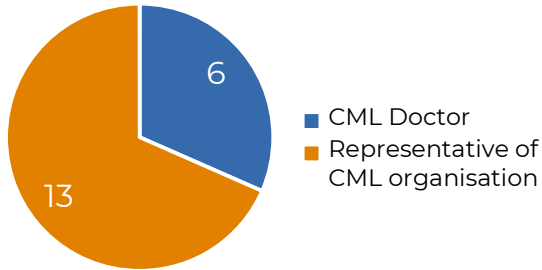
Data as of July 2020

2. The Characteristics of Respondents

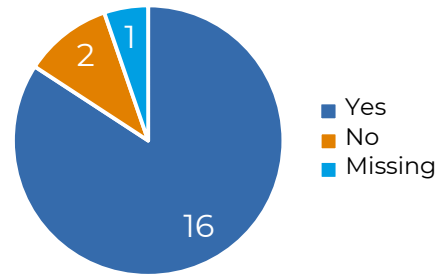
Out of 26 countries that were invited to participate the survey 19 completed the whole questionnaire.



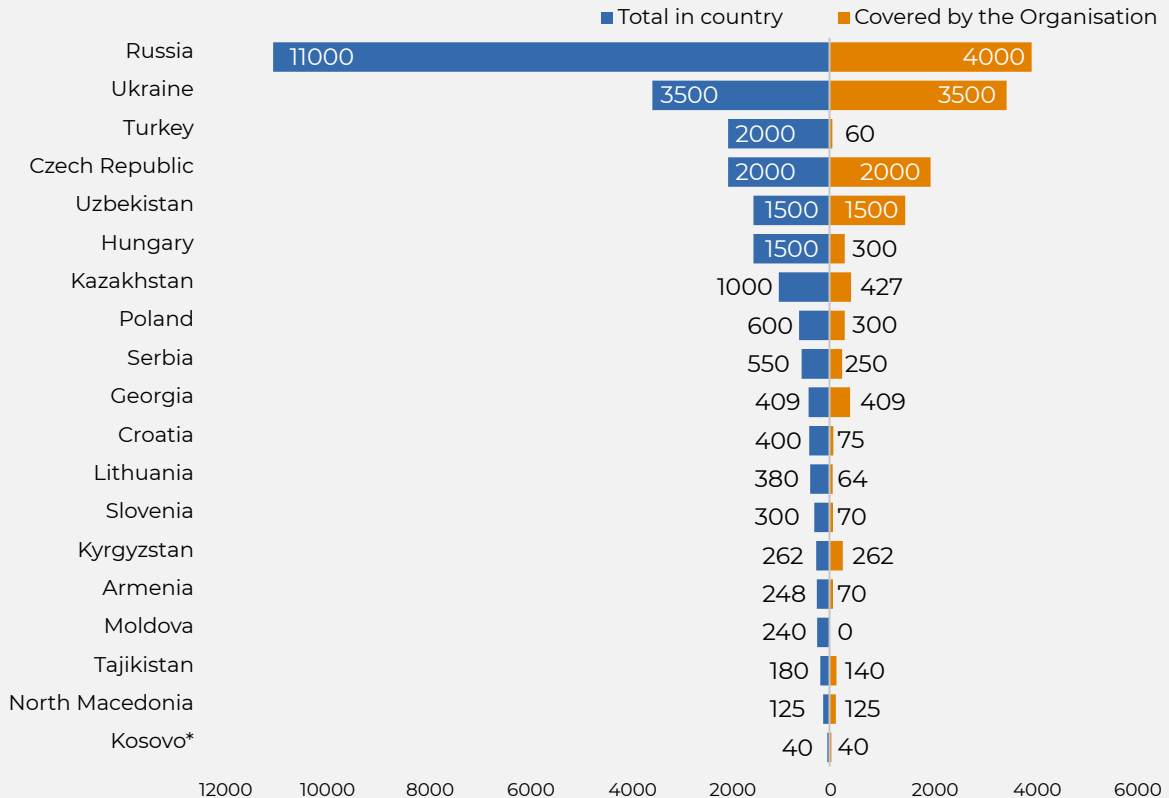
Respodents



Member of the CML Advocates



Number of CML patients



Is there another organisation for CML patients in your country?		Are there cancer / CML patients registries in your country?		
Yes	No		Hospital registry	National registry
Hungary	Armenia	Armenia	✓	✗
Lithuania	Croatia	Croatia	✓	✗
Poland	Czech Republic	Czech Republic	?	✓
Slovenia	Georgia	Georgia	✓	✓
Ukraine	Kazakhstan	Hungary	✓	?
	Kosovo*	Kazakhstan	?	?
	Kyrgyzstan	Kosovo*	✗	?
	Moldova	Kyrgyzstan	✓	✓
	North Macedonia	Lithuania	✓	✗
	Russia	Moldova	✓	✓
	Serbia	North Macedonia	✓	?
	Tajikistan	Poland	?	✓
		Russia	✓	✓
		Serbia	✓	✓
		Slovenia	?	✓
		Tajikistan	✓	?
		Turkey	✗	?
		Ukraine	✓	✗
		Uzbekistan	✓	✗

Number of			
	Hospitals treating CML	University and Research hospitals for CML	CML doctors
Armenia	1	1	10
Croatia	25	3	10
Czech Republic	8	7	10
Georgia	2	0	5
Hungary	20	5	-
Kazakhstan	2	5	82
Kosovo*	1	0	4
Kyrgyzstan	1	1	14
Lithuania	3	2	10
Moldova	1	1	3
North Macedonia	1	1	22
Poland	24	24	700
Russia	112	42	790
Serbia	5	3	10
Slovenia	8	2	23
Tajikistan	2	1	15
Turkey	-	-	400
Ukraine	30	3	30
Uzbekistan	14	1	31

"-" denotes No information

3. Access to medicines

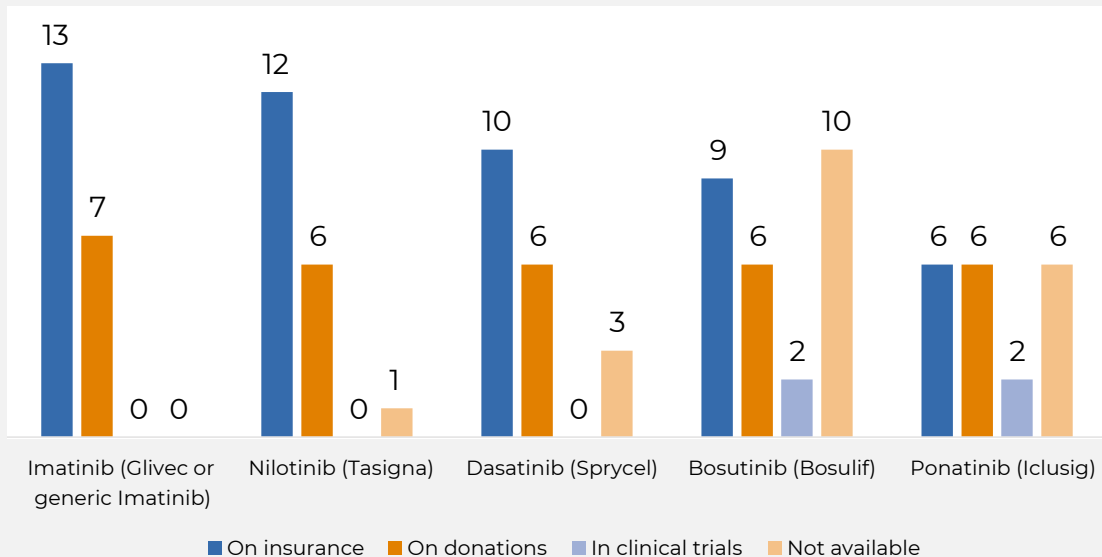
Access and availability of all drugs used for treating CML nowadays were part of the CML Atlas survey. Analysed drugs are:

- Imatinib (Glivec or generic Imatinib)
- Nilotinib (Tasigna)
- Dasatinib (Sprycel)
- Bosutinib (Bosulif)
- Ponatinib (Iclusig)

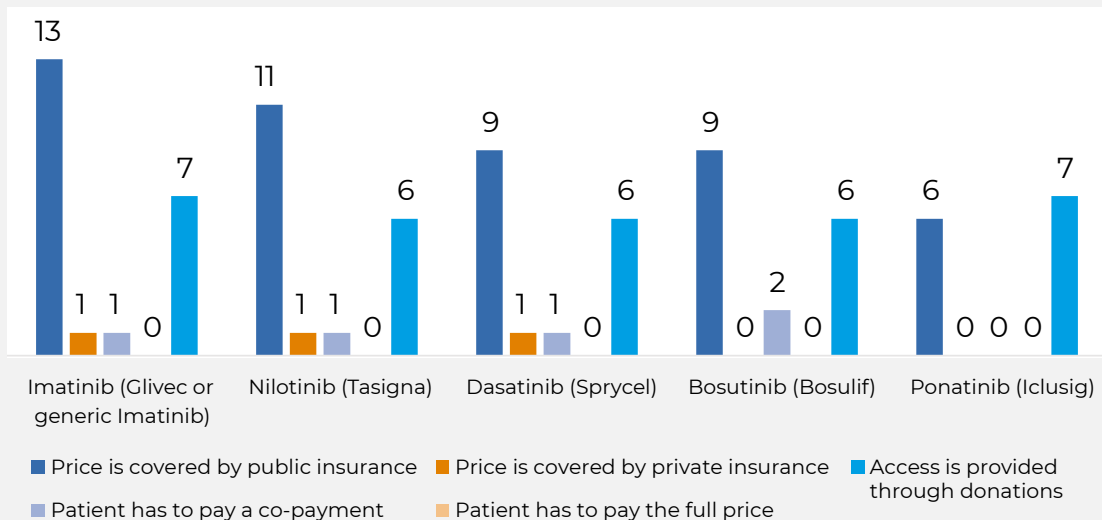
The survey covered several topics regarding the drug:

- Is the drug available to the patients in the country and if yes how the drug is available: on insurance, on donation and/or in clinical trials
- What percent of patients is receiving specific drug in the moment of the survey
- How the costs of the therapy are being covered and
- What is the price for monthly therapy (28 days).

Number of countries where medicine is available, by type of availability



Number of countries where medicine is available, by cost coverage



Availability of Imatinib (Glivec or generic Imatinib)					
	On insurance	On donations	In clinical trials	Not available	% of patients with Access
Armenia	✗	✓	✗	✗	88.0
Croatia	✓	✗	✗	✗	55.0
Czech Republic	✓	✗	✗	✗	64.25
Georgia	✗	✓	✗	✗	96.7
Hungary	✓	✗	✗	✗	40.0
Kazakhstan	✓	✓	✗	✗	73.0
Kosovo*	✓	✗	✗	✗	100.0
Kyrgyzstan	✗	✓	✗	✗	81.0
Lithuania	✓	✗	✗	✗	70.0
Moldova	✗	✓	✗	✗	79.0
North Macedonia	✓	✗	✗	✗	80.0
Poland	✓	✗	✗	✗	88.4
Russia	✓	✗	✗	✗	75.0
Serbia	✓	✗	✗	✗	78.2
Slovenia	✓	✗	✗	✗	80.0
Tajikistan	✗	✓	✗	✗	82.0
Turkey	✓	✗	✗	✗	?
Ukraine	✓	✗	✗	✗	70.0
Uzbekistan	✗	✓	✗	✗	88.0
Region total	13	7	0	0	

“?” denotes lack of information

Costs for Imatinib (Glivec or generic Imatinib)						
	Price is covered by public insurance	Price is covered by private insurance	Patient has to pay a co-payment	Patient has to pay the full price	Access is provided through donations	Price per monthly therapy in €
Armenia	✗	✗	✗	✗	✓	467.04
Croatia	✓	✗	✗	✗	✗	636.16
Czech Republic	✓	✗	✗	✗	✗	1171.24
Georgia	✗	✗	✗	✗	✓	DK
Hungary	✓	✗	✗	✗	✗	690.67
Kazakhstan	✓	✓	✗	✗	✓	2479.68
Kosovo*	✓	✗	✗	✗	✗	280.00
Kyrgyzstan	✗	✗	✗	✗	✓	532.00
Lithuania	✓	✗	✓	✗	✗	125.44
Moldova	✗	✗	✗	✗	✓	DK
North Macedonia	✓	✗	✗	✗	✗	37.33
Poland	✓	✗	✗	✗	✗	1985.00
Russia	✓	✗	✗	✗	✗	146.72
Serbia	✓	✗	✗	✗	✗	420.00
Slovenia	✓	✗	✗	✗	✗	467.00
Tajikistan	✗	✗	✗	✗	✓	504.00
Turkey	✓	✗	✗	✗	✗	?
Ukraine	✓	✗	✗	✗	✗	28.00
Uzbekistan	✗	✗	✗	✗	✓	DK
Region total	13	1	1	0	7	

*Monthly therapy is 400mg per day, 28 days

"DK" denotes medicines that are available on donations and therefore, the price is unknown

"?" denotes lack of information

Availability of Nilotinib (Tasigna)					
	On insurance	On donations	In clinical trials	Not available	% of patients with Access
Armenia	✗	✓	✗	✗	8.0
Croatia	✓	✗	✗	✗	36.0
Czech Republic	✓	✗	✗	✗	18.4
Georgia	✗	✓	✗	✗	3.3
Hungary	✓	✗	✗	✗	40.0
Kazakhstan	✓	✗	✗	✗	14.0
Kosovo*	✗	✗	✗	✓	-
Kyrgyzstan	✗	✓	✗	✗	8.4
Lithuania	✓	✗	✗	✗	15.0
Moldova	✗	✓	✗	✗	12.5
North Macedonia	✓	✗	✗	✗	16.0
Poland	✓	✗	✗	✗	7.0
Russia	✓	✗	✗	✗	10.0
Serbia	✓	✗	✗	✗	21.8
Slovenia	✓	✗	✗	✗	15.0
Tajikistan	✗	✓	✗	✗	5.8
Turkey	✓	✗	✗	✗	?
Ukraine	✓	✗	✗	✗	25.0
Uzbekistan	✗	✓	✗	✗	10.0
Region total	12	6	0	1	

"?" denotes lack of information

"-" denotes medicines that are not available in specific country

Costs for Nilotinib (Tasigna)							
	Price is covered by public insurance	Price is covered by private insurance	Patient has to pay a co-payment	Patient has to pay the full price	Access is provided through donations	Price per monthly therapy in €*	
						600mg pd	800mg pd
Armenia	✗	✗	✗	✗	✓	1125.6	1500.8
Croatia	✓	✗	✗	✗	✗	2592.24	3456.32
Czech Republic	✓	✗	✗	✗	✗	2371.27	2913.72
Georgia	✗	✗	✗	✗	✓	DK	DK
Hungary	✓	✗	✗	✗	✗	1086.21	1448.28
Kazakhstan	✓	✓	✗	✗	✗	3009.00	4012.00
Kosovo*	-	-	-	-	-	-	-
Kyrgyzstan	✗	✗	✗	✗	✓	1239.84	1653.00
Lithuania	✓	✗	✓	✗	✗	2766.96	3688.53
Moldova	✗	✗	✗	✗	✓	1761.74	2348.98
North Macedonia	✓	✗	✗	✗	✗	2682.00	3575.00
Poland	✓	✗	✗	✗	✗	1956.00	2608.00
Russia	✓	✗	✗	✗	✗	1137.00	1516.00
Serbia	✓	✗	✗	✗	✗	2415.00	3222.00
Slovenia	✓	✗	✗	✗	✗	2264.20	3018.93
Tajikistan	✗	✗	✗	✗	✓	1181.25	1595.00
Turkey	?	?	?	?	?	?	?
Ukraine	✓	✗	✗	✗	✗	828.24	1104.32
Uzbekistan	✗	✗	✗	✗	✓	DK	DK
Region total	11	1	1	0	6		

*Monthly therapy is 600mg or 800mg per day, 28 days

"DK" denotes medicines that are available on donations and therefore, the price is unknown

"?" denotes lack of information

"-" denotes medicines that are not available in specific country

Availability of Dasatinib (Sprycel)					
	On insurance	On donations	In clinical trials	Not available	% of patients with Access
Armenia	✗	✓	✗	✗	0.4
Croatia	✓	✗	✗	✗	8.0
Czech Republic	✓	✗	✗	✗	15.2
Georgia	✗	✗	✗	✓	-
Hungary	✓	✗	✗	✗	18.0
Kazakhstan	✓	✗	✗	✗	6.0
Kosovo*	✗	✗	✗	✓	-
Kyrgyzstan	✗	✓	✗	✗	2.8
Lithuania	✓	✗	✗	✗	5.0
Moldova	✗	✓	✗	✗	0.0
North Macedonia	✗	✓	✗	✗	0.8
Poland	✓	✗	✗	✗	4.0
Russia	✓	✗	✗	✗	10.0
Serbia	✗	✓	✗	✗	0.4
Slovenia	✓	✗	✗	✗	3.0
Tajikistan	✗	✓	✗	✗	10.2
Turkey	✓	✗	✗	✗	?
Ukraine	✓	✗	✗	✗	3.0
Uzbekistan	✗	✗	✗	✓	-
Region total	10	6	0	3	

"?" denotes lack of information

"-" denotes medicines that are not available in specific country

Costs for Dasatinib (Sprycel)						
	Price is covered by public insurance	Price is covered by private insurance	Patient has to pay a co-payment	Patient has to pay the full price	Access is provided through donations	Price per monthly therapy in €*
Armenia	✗	✗	✗	✗	✓	DK
Croatia	✓	✗	✗	✗	✗	3482.36
Czech Republic	✓	✗	✗	✗	✗	3146.64
Georgia	-	-	-	-	-	-
Hungary	✓	✗	✗	✗	✗	2100.00
Kazakhstan	✓	✓	✗	✗	✗	3910.67
Kosovo*	-	-	-	-	-	-
Kyrgyzstan	✗	✗	✗	✗	✓	DK
Lithuania	✓	✗	✓	✗	✗	2695.67
Moldova	✗	✗	✗	✗	✓	DK
North Macedonia	✗	✗	✗	✗	✓	3971.19
Poland	✓	✗	✗	✗	✗	3408.00
Russia	✓	✗	✗	✗	✗	1107.87
Serbia	✗	✗	✗	✗	✓	DK
Slovenia	✓	✗	✗	✗	✗	2815.76
Tajikistan	✗	✗	✗	✗	✓	DK
Turkey	✓	✗	✗	✗	✗	?
Ukraine	✓	✗	✗	✗	✗	936.31
Uzbekistan	-	-	-	-	-	-
Region total	10	1	1	0	6	

*Monthly therapy is 100mg per day, 28 days

"DK" denotes medicines that are available on donations and therefore, the price is unknown

"?" denotes lack of information

"-" denotes medicines that are not available in specific country

Availability of Bosutinib (Bosulif)					
	On insurance	On donations	In clinical trials	Not available	% of patients with Access
Armenia	✗	✗	✗	✓	-
Croatia	✓	✗	✗	✗	2.0
Czech Republic	✓	✗	✗	✗	0.6
Georgia	✗	✗	✗	✓	-
Hungary	✓	✗	✗	✗	1.0
Kazakhstan	✗	✗	✗	✓	-
Kosovo*	✗	✗	✗	✓	-
Kyrgyzstan	✗	✗	✗	✓	-
Lithuania	✓	✗	✗	✗	10.0
Moldova	✗	✗	✗	✓	-
North Macedonia	✗	✗	✗	✓	-
Poland	✓	✗	✗	✗	0.5
Russia	✓	✗	✗	✗	4.0
Serbia	✗	✗	✗	✓	-
Slovenia	✓	✗	✗	✗	2.0
Tajikistan	✗	✗	✗	✓	-
Turkey	✓	✗	✗	✗	?
Ukraine	✓	✗	✗	✗	2.0
Uzbekistan	✗	✗	✗	✓	-
Region total	9	6	2	10	

"?" denotes lack of information

"-" denotes medicines that are not available in specific country

Costs for Bosutinib (Bosulif)						
	Price is covered by public insurance	Price is covered by private insurance	Patient has to pay a co-payment	Patient has to pay the full price	Access is provided through donations	Price per monthly therapy in €*
Armenia	-	-	-	-	-	-
Croatia	✓	✗	✗	✗	✗	3421.60
Czech Republic	✓	✗	✗	✗	✗	?
Georgia	-	-	-	-	-	-
Hungary	✓	✗	✗	✗	✗	3304.00
Kazakhstan	-	-	-	-	-	-
Kosovo*	-	-	-	-	-	-
Kyrgyzstan	-	-	-	-	-	-
Lithuania	✓	✗	✓	✗	✗	842.80
Moldova	-	-	-	-	-	-
North Macedonia	-	-	-	-	-	-
Poland	✓	✗	✗	✗	✗	3165.00
Russia	✓	✗	✗	✗	✗	1344.00
Serbia	-	-	-	-	-	-
Slovenia	✓	✗	✓	✗	✗	3071.47
Tajikistan	-	-	-	-	-	-
Turkey	✓	✗	✗	✗	✗	?
Ukraine	✓	✗	✗	✗	✗	1120.00
Uzbekistan	-	-	-	-	-	-
Region total	9	0	2	0	0	

*Monthly therapy is 500mg per day, 28 days

"?" denotes lack of information

"-" denotes medicines that are not available in specific country

Availability of Ponatinib (Iclusig)					
	On insurance	On donations	In clinical trials	Not available	% of patients with Access
Armenia	✗	✓	✗	✗	3.0
Croatia	✓	✗	✗	✗	0.0
Czech Republic	✓	✗	✗	✗	1.5
Georgia	✗	✗	✗	✓	-
Hungary	✓	✗	✗	✗	1.0
Kazakhstan	✗	✗	✗	✓	-
Kosovo*	✗	✗	✗	✓	-
Kyrgyzstan	✗	✓	✗	✗	8.0
Lithuania	✗	✗	✗	✓	-
Moldova	✗	✓	✗	✗	8.5
North Macedonia	✗	✓	✗	✗	0.8
Poland	✓	✗	✓	✗	0.1
Russia	✗	✗	✓	✗	?
Serbia	✗	✗	✗	✓	-
Slovenia	✓	✗	✗	✗	0.0
Tajikistan	✗	✓	✗	✗	2.0
Turkey	✓	✗	✗	✗	?
Ukraine	✗	✗	✗	✓	-
Uzbekistan	✗	✓	✗	✗	1.0
Region total	6	6	2	6	

"?" denotes lack of information

"-" denotes medicines that are not available in specific country

Costs for Ponatinib (Iclusig)						
	Price is covered by public insurance	Price is covered by private insurance	Patient has to pay a co-payment	Patient has to pay the full price	Access is provided through donations	Price per monthly therapy in €*
Armenia	✗	✗	✗	✗	✓	DK
Croatia	✓	✗	✗	✗	✗	8263.92
Czech Republic	✓	✗	✗	✗	✗	?
Georgia	-	-	-	-	-	-
Hungary	✓	✗	✗	✗	✗	?
Kazakhstan	-	-	-	-	-	-
Kosovo*	-	-	-	-	-	-
Kyrgyzstan	✗	✗	✗	✗	✓	DK
Lithuania	-	-	-	-	-	-
Moldova	✗	✗	✗	✗	✓	5039.16
North Macedonia	✗	✗	✗	✗	✓	DK
Poland	✓	✗	✗	✗	✗	10052.00
Russia	✗	✗	✗	✗	✓	DK
Serbia	-	-	-	-	-	-
Slovenia	✓	✗	✗	✗	✗	8215.90
Tajikistan	✗	✗	✗	✗	✓	DK
Turkey	✓	✗	✗	✗	✗	?
Ukraine	-	-	-	-	-	-
Uzbekistan	✗	✗	✗	✗	✓	DK
Region total	6	0	0	0	7	

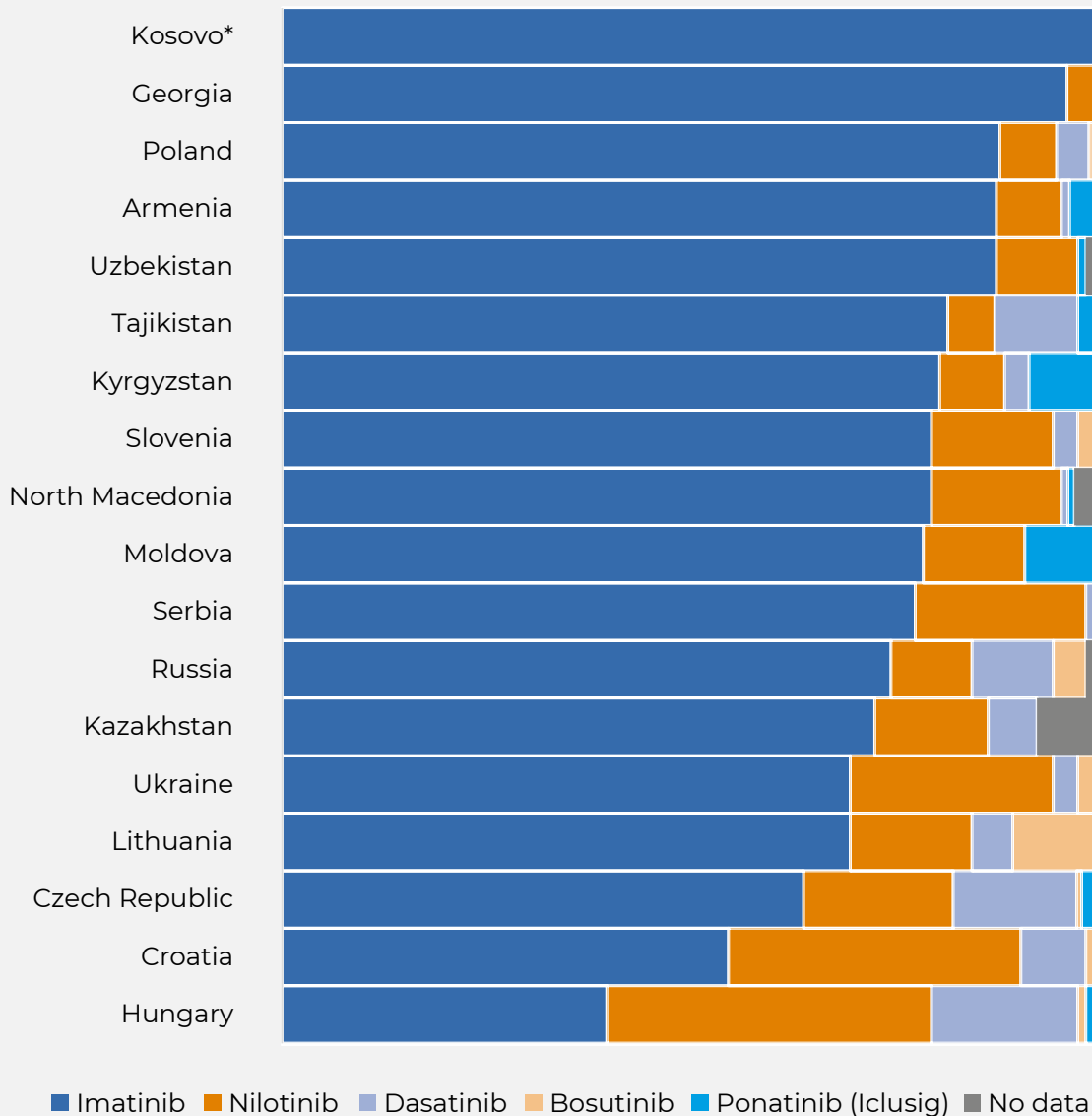
*Monthly therapy is 45mg per day, 28 days

"DK" denotes medicines that are available on donations and therefore, the price is unknown

"?" denotes lack of information

"-" denotes medicines that are not available in specific country

Patients covered with specific medicine in %



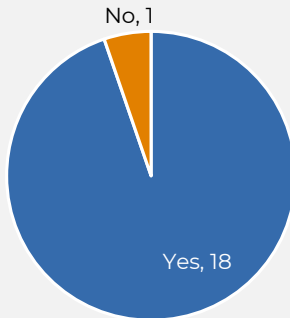
4. Tests availability

There are a few tests used for diagnosing and monitoring CML patients, such as PCR test, cytogenetic, FISH and Gene Xpert. Polymerase chain reaction (PCR) is a test which can detect the presence of BCR-ABL. It can be performed on the blood or bone marrow and it is most important test in monitoring CML patients. PCR is available in all countries responded to the survey, except Kosovo.

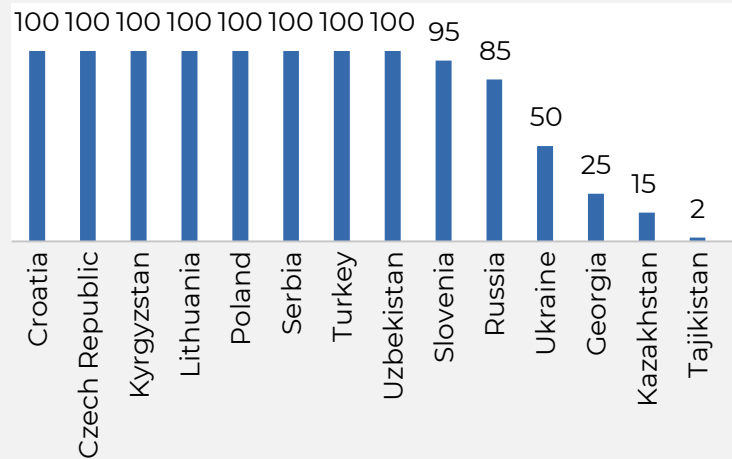
Availability of tests				
	PCR	Cytogenetic	FISH	Gene Xpert
Armenia	✓	✓	✓	✓
Croatia	✓	✓	?	?
Czech Republic	✓	?	?	?
Georgia	✓	✓	?	✓
Hungary	✓	✓	✓	?
Kazakhstan	✓	✓	✓	✗
Kosovo*	✗	✗	✗	✗
Kyrgyzstan	✓	✓	?	✓
Lithuania	✓	✓	✓	✗
Moldova	✓	✓	?	?
North Macedonia	✓	✗	✗	✓
Poland	✓	✓	✓	?
Russia	✓	✓	✓	✓
Serbia	✓	✓	✓	✓
Slovenia	✓	✓	✓	✓
Tajikistan	✓	?	?	✓
Turkey	✓	✓	✓	✓
Ukraine	✓	✓	✗	✗
Uzbekistan	✓	✓	✗	✗

Availability of PCR

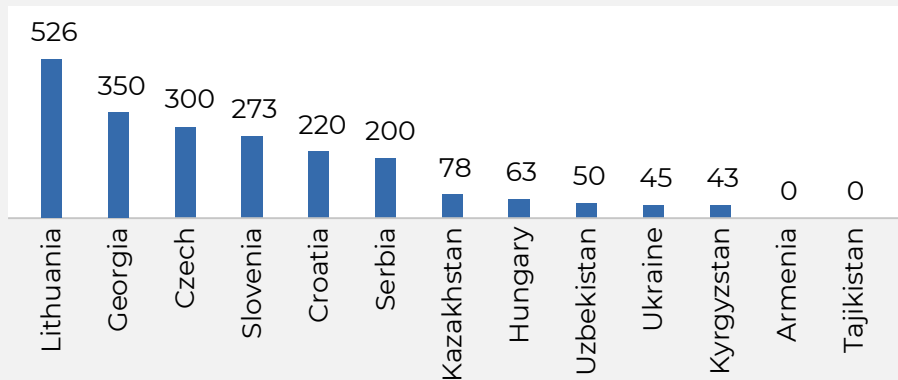
PCR is available in all countries that responded to the survey, except Kosovo*



What percent of patients in your country is PCR tested at least once per year?



What is the price of one PCR test (in EUR)



Price of PCR						
	Price is covered by public insurance	Price is covered by private insurance	Patient has to pay a co-payment	Patients have to pay full price	Access is provided through donations	Price of one PCR test in EUR
Armenia	✗	✗	✗	✗	✓	DK
Croatia	✓	✗	✗	✗	✗	220.00
Czech Republic	✓	✗	✗	✗	✗	300.00
Georgia	✗	✗	✗	✓	✓	350.00
Hungary	✓	✗	✗	✗	✗	63.00
Kazakhstan	✓	✓	✗	✓	✗	78.00
Kosovo*	-	-	-	-	-	-
Kyrgyzstan	✗	✗	✗	✗	✓	43.00
Lithuania	✓	✗	✗	✗	✗	526.00
Moldova	✓	✗	✓	✗	✗	?
North Macedonia	✓	✗	✗	✗	✗	?
Poland	✓	✗	✗	✗	✗	?
Russia	✓	✗	✗	✗	✗	45.00
Serbia	✓	✗	✗	✗	✗	200.00
Slovenia	✓	✗	✗	✗	✗	273.00
Tajikistan	✗	✗	✗	✗	✓	DK
Turkey	✓	✗	✗	✗	✗	?
Ukraine	✗	✗	✗	✓	✗	45.00
Uzbekistan	✓	✗	✗	✗	✗	50.00

"DK" denotes PCR available on donation and therefore, the price is unknown

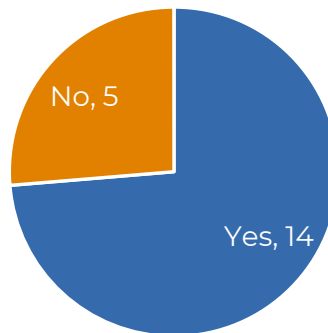
"?" denotes lack of information

"-" denotes countries with no PCR available

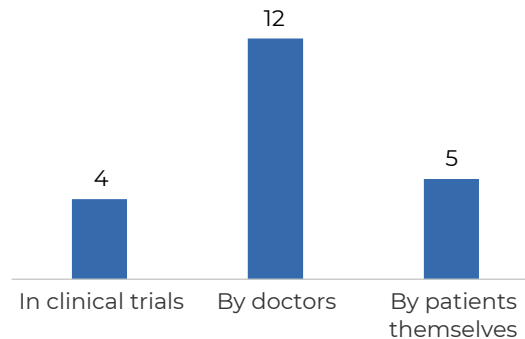
5. Treatment Free Remission

In CML, treatment-free remission (TFR) refers to having a stable deep molecular response without the need for ongoing tyrosine kinase inhibitor treatment.

Availability of TFR



How is TFR is attempted in clinical practice



Treatment Free Remission				
	Available	How is TFR is attempted in clinical practice		
		In clinical trials	By doctors	By patients themselves
Armenia	✓	✗	✓	✓
Croatia	✓	✗	✓	✗
Czech Republic	✓	✓	✗	✗
Georgia	✓	✗	✗	✓
Hungary	✓	✗	✗	✗
Kazakhstan	✓	✗	✓	✓
Kosovo*	✗	✗	✗	✗
Kyrgyzstan	✓	✗	✓	✗
Lithuania	✓	✗	✓	✗
Moldova	✗	✗	✗	✗
North Macedonia	✓	✗	✓	✓
Poland	✓	✓	✓	✗
Russia	✓	✓	✓	✗
Serbia	✓	✓	✗	✗
Slovenia	✓	✗	✓	✗
Tajikistan	✓	✗	✓	✗
Turkey	✓	✗	✓	✓
Ukraine	✗	✗	✗	✗
Uzbekistan	✓	✗	✓	✗

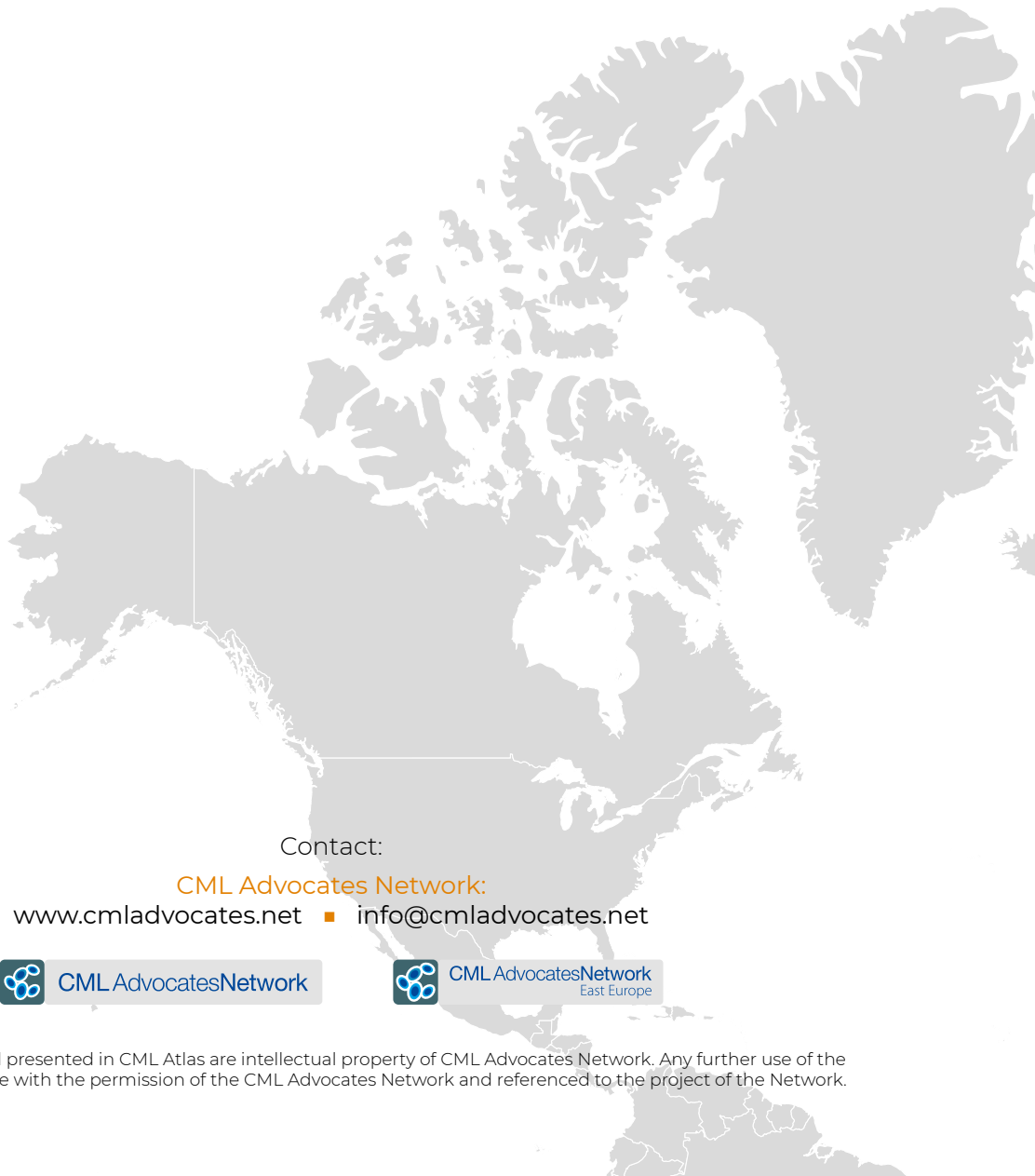
6. Clinical trials

Clinical trials are not common in interviewed countries.

Clinical trials			
Number of recruiting clinical trials in the country at the moment			
0	1	2	DK
Armenia Georgia Kazakhstan Kosovo* Kyrgyzstan Lithuania Moldova North Macedonia Serbia Slovenia Tajikistan Uzbekistan	Ukraine (20)	Russia	Croatia Czech Republic Hungary Poland Turkey
Number of ongoing, but not recruiting, clinical trials at the moment			
0	1	2	DK
Armenia Georgia Kazakhstan Kosovo* Kyrgyzstan Lithuania Moldova North Macedonia Tajikistan Uzbekistan	Russia Serbia (3) Slovenia (2) Ukraine	-	Croatia Czech Republic Hungary Poland Turkey

Number in () denotes the number patients in a country that is involved in the clinical trial

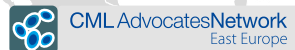
Country	City	Name of the CT	Name of the hospital
Ukraine	Kiev	Radotinib	State institution "National scientific center of radiation medicine of the National Academy of medical Sciences of Ukraine"
Russia	Moscow /Petersburg	ASCEMBI (CABL001A2301)	
	Moscow, Petersburg, Chelyabinsk, Kemerovo, Rostov - na- Don, Samara, Saratov	OPTIC	
Serbia	Belgrade and Novi Sad	ABL001	Clinical Center Belgrade and Novi SAD



Contact:

CML Advocates Network:

www.cmladvocates.net ■ info@cmladvocates.net



All data collected and presented in CML Atlas are intellectual property of CML Advocates Network. Any further use of the data needs to be done with the permission of the CML Advocates Network and referenced to the project of the Network.