



# **The access to antiretroviral therapy for people living with HIV in Romania**

Research Report



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# Content

Summary .....	7
I. Context.....	10
II. Research methods .....	13
III. The results of the research .....	19
Sociodemographic data .....	19
Treatment .....	28
Adherence to treatment.....	42
The access to medical and social services .....	46
IV. Conclusions and recommendations.....	56
V. Bibliographical references .....	65
VI. Appendix.....	68
Appendix 1: Questionnaire applied to beneficiaries ...	68
Appendix 2: The informed consent for participation ..	80

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17. The association "O rază de lumină" [*A ray of light*] Mangalia - Ionică Petriuc
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19. The association "Red Ribbon" Fălticeni - Dorina Vasile
20. The association "Sens Pozitiv" [*Sens Pozitiv*] București - Alina Dumitriu
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## List of abbreviations

<b>ADV/ CTY</b>	Close to You, Foundation
<b>AIDS</b>	Acquired Immunodeficiency Syndrome
<b>ART</b>	Antiretroviral
<b>ARAS</b>	Romanian Association against AIDS
<b>CR/RC</b>	Regional Centre for the monitoring and evaluation of HIV/AIDS Infections
<b>GDASPC</b>	General Directorate of Social Services and Child Protection
<b>HIV</b>	Human Immunodeficiency Virus
<b>IBI/ IDI</b>	Institute of Infectious Diseases “PhD. Matei Balş”
<b>NSC/ WAO</b>	We and the others, Association
<b>WHO/ OMS</b>	World Health Organization
<b>ART</b>	Antiretroviral therapy
<b>RAA</b>	Romanian Angel Appeal
<b>UNAIDS</b>	United Nations Programme on HIV/AIDS
<b>UNGASS</b>	United Nations General Assembly Special Session on HIV/AIDS
<b>UNICEF</b>	United Nations Children’s Fund
<b>UNODC</b>	United Nations Office on Drugs and Crime
<b>UNOPA/ NUOPA –</b>	National Union of Organizations for People living with HIV/AIDS

## Summary

The hereby research, which was carried out by using the social enquiry method, had set as aim the evaluation of the access to treatment and special services and the magnitude of treatment interruptions in the case of people with HIV/AIDS in Romania, with ages of 15 years and above, undergoing antiretroviral therapy at the moment of the research. The research stands as representative at a national level, the number of subjects examined being of 618, with a margin of error of  $\pm 4\%$ . During the year 2009, but especially during the year 2010, several non-governmental organizations have announced interruptions in the antiretroviral therapy in several counties across the country, because of flaws in the systems involved in ensuring the treatment.

The subjects from the group have been undergoing antiretroviral therapy for a long time: 59.2% have been under treatment for more than 10 years and 10% of subjects have been under treatment for more than 15 years. While 17.8% of subjects have been undergoing a single antiretroviral scheme so far, more than half (50.4%) declared to have been under 2 or 3 schemes of treatment so far. The change of the last treatment scheme was linked to the rise of viral resistance in more than half of cases, while 9.8% claimed that the treatment had to be changed because one or several medications became unavailable.

The research recorded worrying answers for the question *“were there any situations in 2010 in which you didn’t receive the antiretroviral medication from your regional*

*centre/hospital?'*. Approximately two thirds (65.2%) of the participants in the research stated that there were such situations while only 34.8% claimed to have received their regular treatment. There are not any significant differences in concern to the access to treatment on demographic criteria (age, sex, ethnicity, education or occupation).

The cessation of the treatment triggered more frequent morbidities, including the relapse of cancer or other severe neurological affections, the hospitalization of the patient and even the dismissal of the patient from his job (in one case). This situation also jeopardized the health of the foetus in the case of the two pregnant women infected with HIV, while, in other cases, the absence of medication led to the change of treatment schemes for 101 seropositive people.

As far as the access to other types of treatment or medical service is concerned, the answers are more than diverse. Thus, over half of the patients claim to have access in great or significant extent to treatment for opportune infections, while more than a third believes that access to treatment is reduced or even scarce. Medical services for which it seems difficult to gain access remain the dental and surgical medical services. Only 44.2% of women investigated believe that the access to medical services of Obstetrics and Gynaecology is satisfactory or very satisfactory while 55.8% state that they had little or almost no access to such medical services.

The most important recommendation refers to the provision of antiretroviral therapy for PLHIV, any interruption of the treatment causing health deterioration. Moreover, the disruptions in the provision of treatment trigger extra financial costs and increase in mortality rate. There is a constant need for fund assignment for ensuring the

monitoring and surveillance in the evolution of HIV/AIDS (virologic and immunologic monitoring) and the treatment of opportune infections, as well as the approval of the National Strategy on HIV/AIDS for the period 2011-2015, which has been in an advanced state of the elaboration process since 2010.

## I. Context

After the HIV/AIDS phenomenon had been, for a very long time, a distinctively negative element in Romania, during the last years it seemed to go unnoticed. Starting with 2001 Romanian authorities (and not only) supported the success of programmes in this field. Still, starting with 2008 Romania doesn't have a national Strategy on HIV/AIDS anymore, even though during both years 2008 and 2010 there were suggestions in this respect which were not finalised.

The antiretroviral therapy (ART) is one of the most important factors which contribute to the maintenance of a good health state of PLHIV. Moreover, the universal access to treatment is one of the objectives considered as reached in Romania, starting from the premises that any person needing treatment will get it. The evaluation realised by the World Health Organization and UNAIDS, which also considers the number of undiagnosed seropositive people, still suggests a coverage ratio of 81% in 2009 (WHO, 2010), which is considered to be a very high level compared to other countries from the same region (Petrescu, 2010). At the end of year 2010 there were 10.405 people diagnosed with HIV/AIDS, out of which 440 newly diagnosed, during last year. The antiretroviral therapy was introduced in Romania between the years 1996 and 1998, and it has significantly reduced the number of fatalities within seropositive people. At a global level it is stated that ART has had as a result the "resurrection" of some individuals who were close to dying,

the syntagm “the Lazarus effect”<sup>1</sup> being used in a metaphorical sense in this case.

During the year 2009, but especially during 2010, many nongovernmental organizations signalled interruptions in the antiretroviral therapy in various counties from the country (Press Releases UNOPA<sup>2</sup> and ADV<sup>3</sup>). The data presented by the Evaluation and Surveillance of HIV/AIDS Department, within the Institute of Infectious Diseases “PhD. Matei Balș”, also include cases of individuals who had interrupted their treatment (PTO Table 1).

**Table 1 Statistical data regarding people with HIV/AIDS – in active inventory**

Patients in active inventory HIV + AIDS	8.916
Adults (> 14 years*)	8.667
Children (0-14 years*)	185
People who received ART prophylaxis	614
Children (0-14 years*)	249
Patients under antiretroviral therapy	7.276
Adults (> 14 years*)	7.091
People having interrupted ART therapy	650

\*Actual age; Source: the Ministry of Health, 2011.

It is well known to specialists in the field that the interruption of the ART therapy leads to the appearance of viral resistance, the deterioration of health and the

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<sup>1</sup> Direct reference to Lazarus’ resurrection by Jesus Christ, mentioned in the Bible. Pto Project “The Lazarus Effect”, an HBO production and the documentary directed by Lance Bangs.

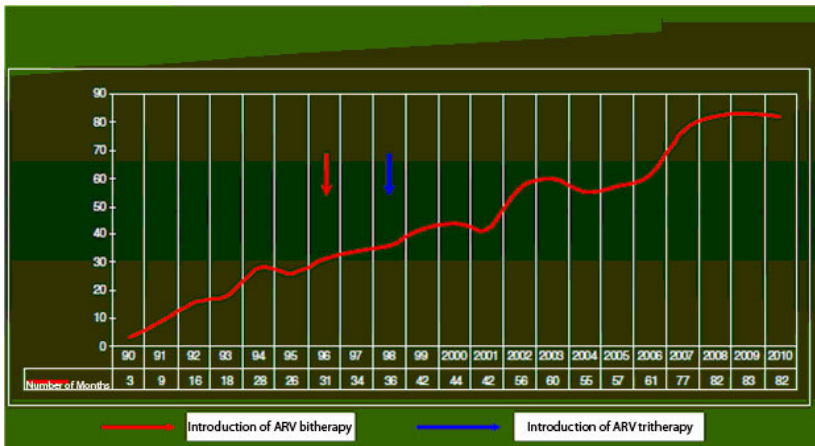
<sup>2</sup> UNOPA/NUOPA, 2010a, b, 2011 – Press releases: Patients with HIV/AIDS from Romania – no treatment, no hope (19.05.2010); Prisoners once more (24.10.2010), Seropositive patients in Romania – victims of an irresponsible sanitary system (26.01.2011). Available online in June 2011 at [http://www.unopa.ro/?page=pagini\\_list&Pageld=Comunicate+de+presa\\_16&m=2](http://www.unopa.ro/?page=pagini_list&Pageld=Comunicate+de+presa_16&m=2)

<sup>3</sup> The Foundation Alături de Voi (Close to you Foundation), the State leave thousands of Romanians to persih. Press release from November 25th and January 26th 2011 ([http://www.alaturidevoi.ro/?webpage=comunicate\\_detalii&id=89](http://www.alaturidevoi.ro/?webpage=comunicate_detalii&id=89)).

reduction of options for treatment, all these contributing to a shorter life span for seropositive people. This situation also applies to Romania, the data regarding life span showing that it increased after the introduction of the ART therapy in years 1996 to 1998.

The data revealed by UNOPA, during 2010, shows that three seropositive people sued the Romanian state for the non-compliance with the rights to medical care, through the interruption of their ART therapy. The factors which contributed to this situation include deficiencies in the medical supply services at county level and the lack of continuous financing for the national HIV/AIDS programme.

**Chart 1 The average survival ratio (no. of months) of people with AIDS, between 1990 and 2010**



Source: The Ministry of Health, 2011

## II. Research methods

The general aim of the research is the evaluation of the access to treatment of people with HIV/AIDS in Romania, focusing on describing the magnitude of treatment interruptions. Thus, the research addresses people undergoing ART therapy according to official data at a national level.

The research was carried out through the opinion enquiry method, using a questionnaire applied to a representative stratified group, at national level, made of people aged 15 years and above, who were undergoing treatment at the moment of the research. The number of subjects was of 618 with a margin of error of  $\pm 4\%$ . The selection of the subjects was made according to the Regional Centre or the county hospital which usually provide the ART medication. For those who obtain their medication from county hospitals, we considered the affiliation of the respective hospital to one of the 9 Regional Centres. Given that some of the seropositive people obtain their medication not only from the hospital in their residential county, but sometimes prefer to go to Bucharest too, to one of the two Regional centres here, in order to avoid being recognised within their community as PLHIV, the inclusion of the initial number of people in the group was not possible, while it was still possible to apply more questionnaires in other locations. For maintaining the initial distribution for each of the Regional Centres, the number of subjects in the group was finally decided to 618, depending on the regional centre to

which the hospital providing the ART therapy was assigned to, thus keeping its representativity.

**Tabel 2 Sampling scheme**

<b>Regional Centre</b>	<b>Population percentage</b>	<b>Sample percentage</b>	<b>Weighting coefficient</b>
Matei Balş	31,6	18,4	1,72
Victor Babeş Bucureşti	17,1	19,7	0,87
Iaşi	15,4	20,0	0,77
Constanţa	10,8	10,7	1,01
Craiova	7,0	7,4	0,94
Timișoara	9,4	11,3	0,84
Braşov	2,4	3,6	0,65
Tg. Mureş	3,7	6,6	0,55
Cluj	2,7	2,3	1,16
<b>Total</b>	<b>100</b>	<b>100</b>	

The collection of the data was possible with the help of non-governmental organisations providing services – associations of people living with HIV/AIDS (members of UNOPA), Sens Pozitiv, ARAS and Alături de Voi, within the period of time March to April 2011. The questionnaires were successfully applied at the central office of the association, in hospital or at the person’s residence (based on the fact that these people were linked to UNOPA member organizations)

**Table 3 The distribution of subject by assignment to Regional Centres and Counties**

<b>Regional Centre</b>	<b>Assigned Counties</b>	<b>Number of patients under ART, aged 20 years and above, registered at the Regional centre</b>	<b>Counties where questionnaires were applied</b>	<b>Applicant Organizations</b>
<b>1. The Institute of Infectious Diseases "PhD. Matei Balș"</b>	BUCHAREST	1282	Bucharest	We and Others (WAO), Sens Pozitiv
	VRANCEA	136		
	VÂLCEA	68		
	PRAHOVA	172	Prahova	WAO
	ILFOV	19		
	IALOMIȚA	31		
	GALAȚI	228	Galați	Life
	DÂMBOVIȚA	134		
	BUZĂU	76		
	ARGEȘ	103		
	<b>TOTAL</b>	<b>2249</b>		
<b>2. Regional Centre Victor Babeș Bucharest</b>	BUCHAREST	933	Bucharest	WAO, Sens Pozitiv
	CĂLĂRAȘI	9		
	BRĂILA	81		
	GIURGIU	155	Giurgiu	Life and Hope Licurici, Firefly
	TELEORMAN	69		
		<b>TOTAL</b>	<b>1247</b>	
<b>3. Regional Centre Brașov</b>	BRAȘOV	125	Brașov	WAO
	COVASNA	15		
	HARGHITA	17		
		<b>TOTAL</b>	<b>157</b>	

<b>4. Regional Centre Cluj</b>	BIHOR	18		
	CLUJ	104	Cluj	ARAS
	MARAMUREȘ	57		
	SATU MARE	11		
	SĂLAJ	13		
	<b>TOTAL</b>	<b>203</b>		
<b>5. Regional Centre Constanța</b>	CONSTANȚA	686	Constanța	WAO, Ray of Light
	TULCEA	21		
	<b>TOTAL</b>	<b>707</b>		
<b>6. Regional Centre Craiova</b>	DOLJ	198	Dolj	ARAS
	GORJ	23		
	MEHEDINȚI	14		
	OLT	222		
	<b>TOTAL</b>	<b>457</b>		
<b>7. Regional Centre Iași</b>	BACĂU	274	Bacău	Lizuca
	BOTOȘANI	156	Botoșani	Tereza
	IAȘI	216	Iași	Close to You
	NEAMȚ	219	Neamț	Alexiana
	SUCEAVA	154	Suceava	Red ribbon
	VASLUI	102	Vaslui	Iris
	<b>TOTAL</b>	<b>1121</b>		
<b>8. Regional Centre TârguMureș</b>	ALBA	20		
	BISTRIȚA NĂSĂUD	7		
	MUREȘ	167	Mureș	Benone, ProKarma
	SIBIU	102	Sibiu	Andreea
	<b>TOTAL</b>	<b>296</b>		

<b>9. Regional Centre Timișoara</b>	ARAD	120	Arad	We and Others AARA
	CARAȘ SEVERIN	165	Caraș Severin	Innocence and Hope
	HUNEDOARA	233	Hunedoara	New Hope
	TIMIȘ	126	Timiș	Hope for the Future
	<b>TOTAL</b>	<b>644</b>		
TOTAL NUMBER OF SUBJECTS UNDER ARTT		7081		
TOTAL NUMBER OF QUESTIONNAIRES APPLIED				

Note: The subjects in the group were chosen according to available data at national level at the Institute of Infectious Diseases "Matei Bals", regarding patients undergoing ART therapy in December 31<sup>st</sup> 2010.

The research focuses on the following topics:

- *Sociodemographic data*: age, gender, ethnicity, residential environment (type of residence), level of education, income, occupation, type of employment contract, history of HIV infection (source of infection, period of time since diagnosis);
- *Treatment*: ART therapy duration, number of schemes used, location for the provision of ART, CD4 value, viremia, last examination/ determinations, the frequency of examinations, actual ART medication, modifications which occurred in the meanwhile, modifications within the last year, reasons for modifications, ART interruptions, the duration of interruptions, attendance to treatment visits – generally and specifically during the last year;

- *Adherence to treatment*: view on the importance of the treatment, number of dosages “skipped” within the last week/ month, the reasons for skipping the medication, methods used for preserving the adherence to treatment;
- *Access to medical services*: the frequency of visits to hospitals - for ART medication / monitoring, the time spent commuting, means of transport used for easy access to hospitals, the cost of commuting. Accessing other medical services, other medical specialties;
- *Access to social services/ social protection programmes*: rights accessed (meal allowance, degree of disability inclusion, disability degree, disability allowance, complementary budget, property and income tax exemption), within the last year.

The research was approved by the Ethics Committee of the Sociology and Social Work Faculty within the University of Bucharest.

### III. The results of the research

#### *Sociodemographic data*

Most of the respondents were interviewed in the South-Eastern Region (Brăila, Constanța, Galați – 21.81%), Bucharest-Ilfov (20.5%) and the Southern Region (Giurgiu, Prahova – 18%), these being the regions where most patients living with HIV infection were recorded.

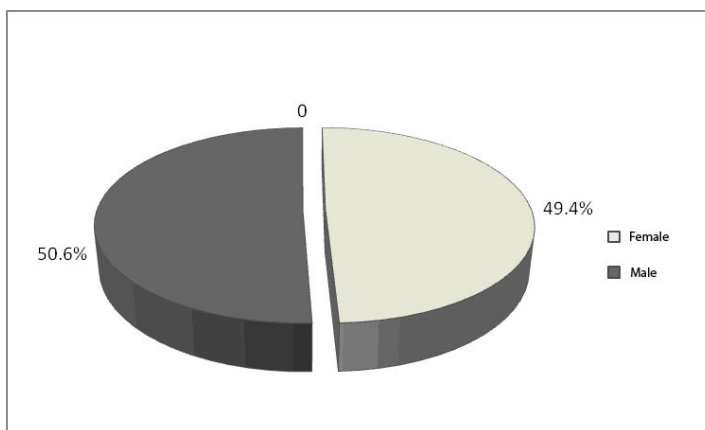


By county of residence, the highest percentage of respondents come from the South-Eastern region (Brăila, Buzău, Constanța, Galați, Tulcea – 23.3%), Southern region (Argeș, Călărași, Dâmbovița, Giurgiu, Prahova, Teleorman – 21.8%) and North-Eastern region (Bacău, Botoșani, Neamț, Iași, Suceava, Vaslui – 15.5%).

**Table 4 The residence of respondents by development regions**

	No.	Percentage
Western region (Arad, Caraș-Severin, Hunedoara, Timiș)	59	9.56
North-Western region (Cluj, Maramureș, Sălaj)	15	2.43
North-Eastern region (Bacău, Botoșani, Neamț, Iași, Suceava, Vaslui)	96	15.55
Central region (Brașov, Mureș, Sibiu)	37	5.99
South-Eastern region (Brăila, Buzău, Constanța, Galași, Tulcea)	144	23.33
Southern region (Argeș, Călărași, Dâmbovița, Giurgiu, Prahova, Teleorman)	135	21.88
South-Western region (Dolj, Gorj, Mehedinți, Olt, Vâlcea)	46	7.45
Bucharest-Ilfov	85	13.77
Total of valid answers	617	100

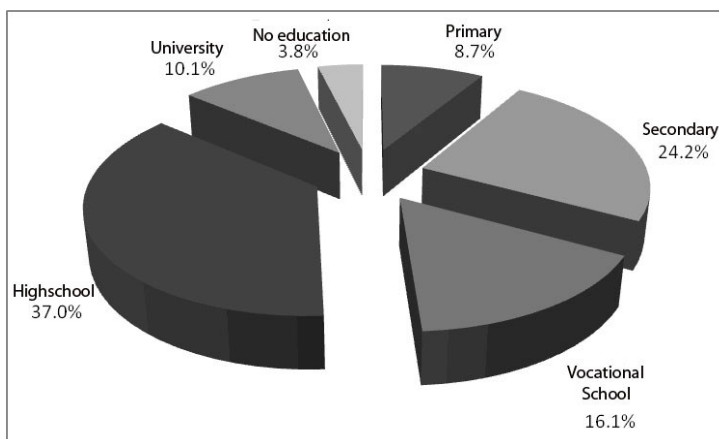
**Chart 2 The distribution of respondents by gender**



The group is balanced in terms of gender, with 49.4% women and 50.6% men, and close as representative population infected with HIV/AIDS, according to data recorded at national level by the National Health Services, where men represent 53% and women 47%.

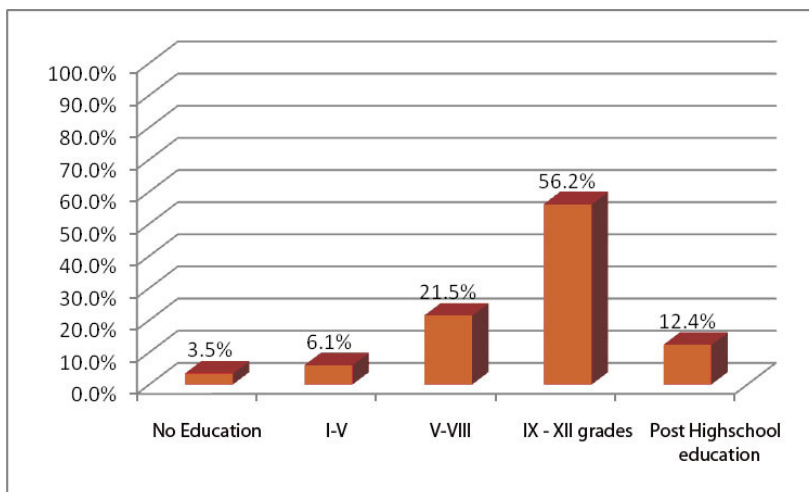
Most of those who answered the questionnaire are averagely educated (53.1%), high school graduates (37%) or vocational school graduates (16.1%), while only 10% of these have a university degree. These data have to be interpreted considering the age of respondents, given that the majority of those who are in the group are around 20 years old (71% of respondents are between 18 and 24 years old) and thus o part of them can be found in the group of those who had declared they had last graduated gymnasium (24.2%). It is to be remarked that a significant percentage from the group is represented by those who graduated primary schools (8.7%), though according to the group structure, a great majority of subjects are above the age when they should have graduated primary schools (0.4% of the group are aged between 15 and 17 years). These data reveal the low level in the education of subjects from the group. Moreover, for the question on current activities, 11.3% stated they were pupils while 14.4% said they were university students.

**Chart 3 The distribution of subjects by last graduated level of education**



By comparing the answers to the questions on the last graduated grade (chart 3) and the last graduated level of education<sup>4</sup> (chart 4), there are small differences to be observed such as a decrease in the percentage of those who are university students or have graduated university and an increase in the percentage of those with average education.

**Chart 4 The level of education of respondents**

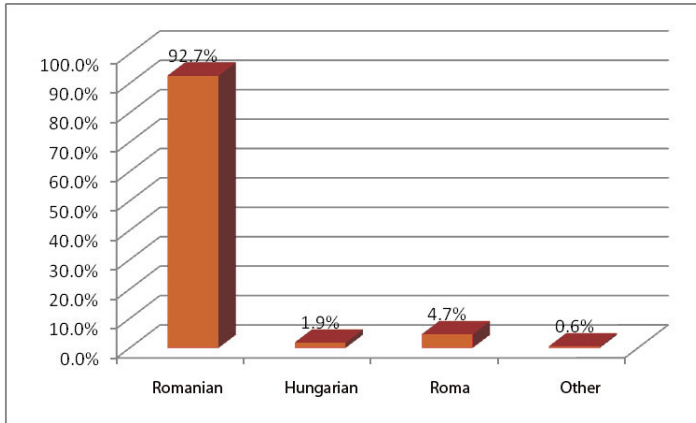


Most of the respondents are of Romanian ethnicity (92.7%), followed by Roma ethnicity (4.7%) and Hungarian ethnicity (1.9%).

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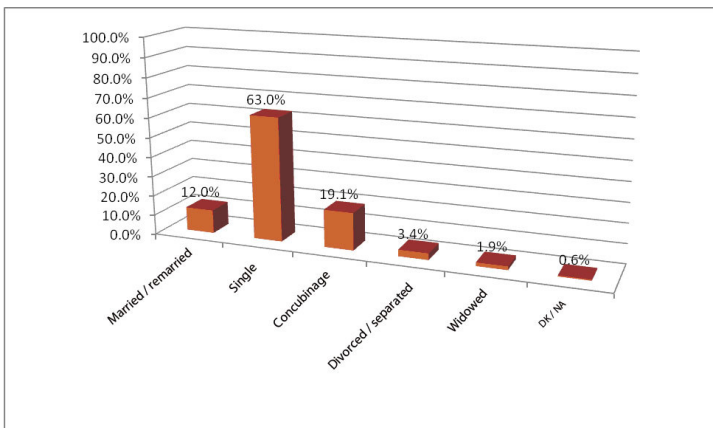
<sup>4</sup> There were two different questions on the topic of education: one which asked students about the last level of education they had graduated and the second asked them about the number of grades/years of school they had attended. This is one reason for such differences.

**Chart 5 The distribution of respondents by declared ethnicity**



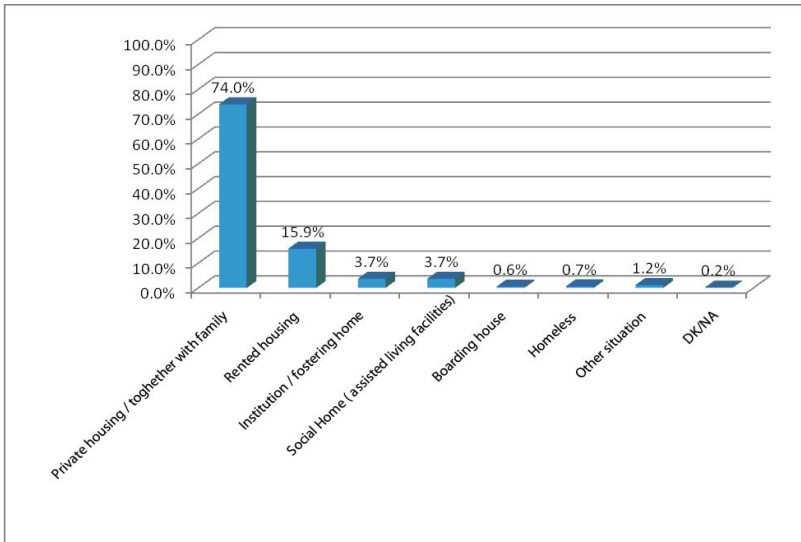
The highest percentage from the analysed group is that of unmarried people, 390 individuals - (63%), followed at great distance by people living in consensual unions and by those who are married (31% per total). A relatively small percentage is that of people who are divorced (3.4%) or widowed.

**Chart 6 Marital status of respondents**



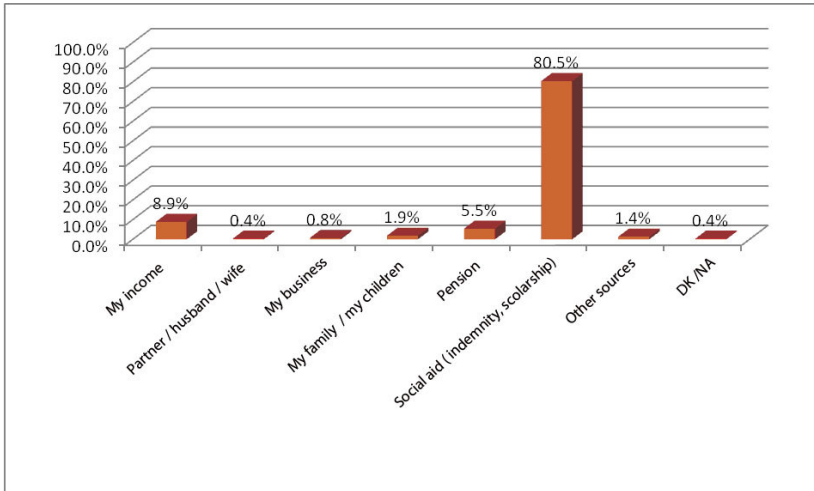
Once more we come across the case where the marital status of respondents has to be analysed in relation to the age categories represented in the group, 71% of the respondents being too young to be married (18-24 years), compared to the average age for marriage in Romania which is of 31 years in men and 27 years in women.

**Chart 7 Type of housing**



When referring to housing, most of the subjects from the research live in their own houses, be it an individual or family private property. A significant percentage is represented by those who pay rent (15.9%) or live in a social housing or benefit from assisted living facilities (3.7%). Those who live in an institution or fostering home or do not have a place where to live are in a far smaller percentage (3.7%). From all subjects from the group, nine have said to be in a different situation from the ones mentioned or did not answer at all.

**Chart 8 Main source of income of respondents**



In regard to income, most subjects (80.5%) have declared as main sources of income the social financial aid or disability allowance, or by case the scholarship. Only 55 subjects, (8.9%) out of the 618 people from the research, have as main income source their monthly salary, the rest being retired (5.5%), and benefiting from the family's or partner's support (2.3%, percentage per total) or owning a business (0.8%).

For out of a total of 9 individuals, who had declared they had a different source of income or even that they didn't have any sources of income whatsoever (1.4% of them are part of the group), the sources of income are jobs on the black market, students' allowance and financial aid from foundations. Still, there are individuals who have declared not to have any source of income, such as one who states not having an income for over 7 months.

**Table 5 The time period since subjects have known their diagnosis**

<b>For how long have you known about the HIV diagnosis?</b>	<b>No.</b>	<b>Percentage</b>
5 years or less	95	15.3
6 to 10 years	229	37
Over 10 years	280	45.1

Almost half of the subjects from the group (45.1%) have known their diagnosis for over 10 years. These are patients who have been under treatment the longest. For a number of 95 individuals from those in the group (15.3%), the diagnosis is known for less than 5 years; out of these ones, 15 know to have been infected for a year or less than a year.

The average time period for diagnosing the infection is of 10 years.

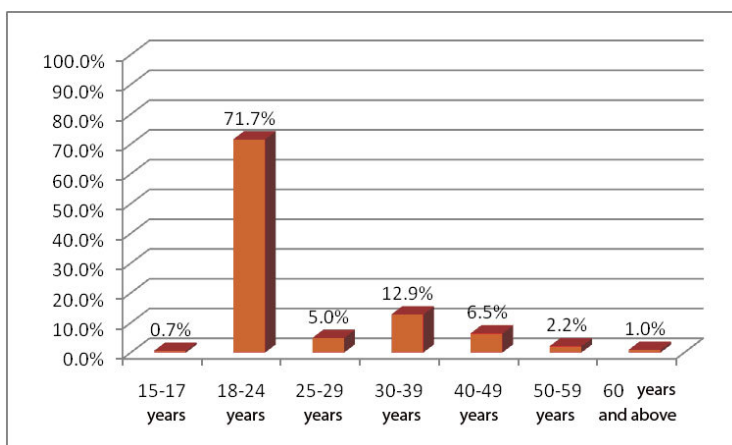
**Table 6 Known sources of infection**

<b>From your recollection, what was the source of your HIV infection?</b>	<b>No.</b>	<b>Percentage</b>
Infected medical equipment/ hospital	397	64.2
Infected blood transfusion	47	7.6
It was transmitted from my mother during pregnancy or child birth	5	0.9
Unprotected sexual intercourse with a person living with HIV	63	10.2
I used medical equipment for the injection of drugs together with other people	7	1.1
Other	19	3
DK/NA	81	13.1
Total	618	100

A great percentage of individuals in the group (397 representing 64.2%) declare to have been infected from infected medical equipment. A number of 47 respondents

(7.6) declare to have been infected through an infected blood transfusion. These two categories gather 71.8% of the total number of individuals from the group. The group seems to be representative from the point of view of the epidemiological pattern recorded in Romania for HIV/AIDS infections, given the number of subjects interviewed, together with the number of years since they have known to have become infected. The results suggest that the subjects were children (under 14) at the time when they were diagnosed. When considering the way in which the infection occurred, a great percentage is that of subjects infected through unprotected sexual intercourse (63 or 10.2%). A much lower percentage is of subjects who were infected by using syringes for injecting drugs together with other individuals (1.1%) and by mother to child transmission (0.9%). A significant percentage of respondents claimed not to know the source of their infection (13%) or that the source of the infection was different from the ones previously mentioned (3%). These last percentages overlap with those mentioned in the epidemiological pattern at national level.

**Chart 9 The distribution of subjects by age segments**



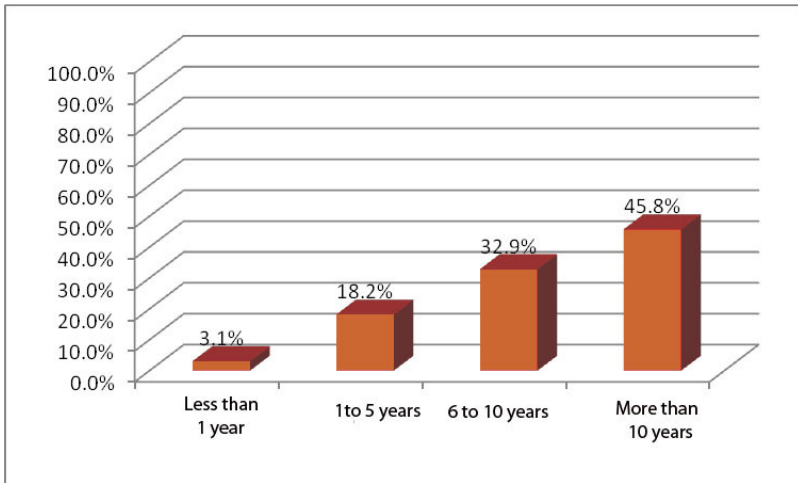
From the point of view of the age segments represented in the group, young adults (18 to 24 years) hold the highest percentage. Thus, 71.7% from the group is formed of 444 young subjects, followed at great distance by the 30 to 39 years age segment (80 subjects, 12.9%). Other representative age segments, in the order of their representativity are 40 to 49 years (6.5%), followed by the segment 25 to 29 years old (5%) and by the segment 50 to 59 years (2.2%).

The least present age segments are formed of subjects over 60 years (1%) and 15 to 17 years (0.7%).

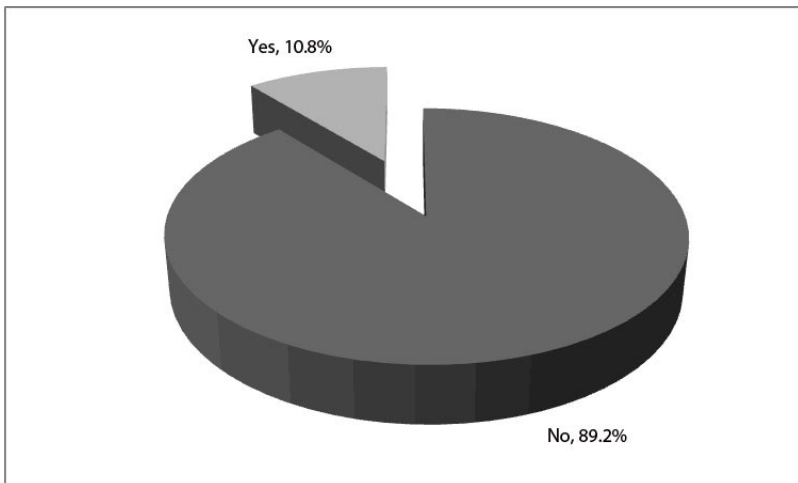
### ***Treatment***

The greatest number of subjects from the group (45.8%) has been under treatment for more than 10 years. Out of these ones, most subjects have been under antiretroviral therapy for 10 to 15 years. Almost 10 % of subjects questioned have been under treatment for more than 15 years. A very significant percentage of subjects from the group (32.9%) have been under treatment for 6 to 10 years, while subjects undergoing treatment for less than 5 years, represent only 21.3% from the group.

**Chart 10 Number of years of ART treatment**



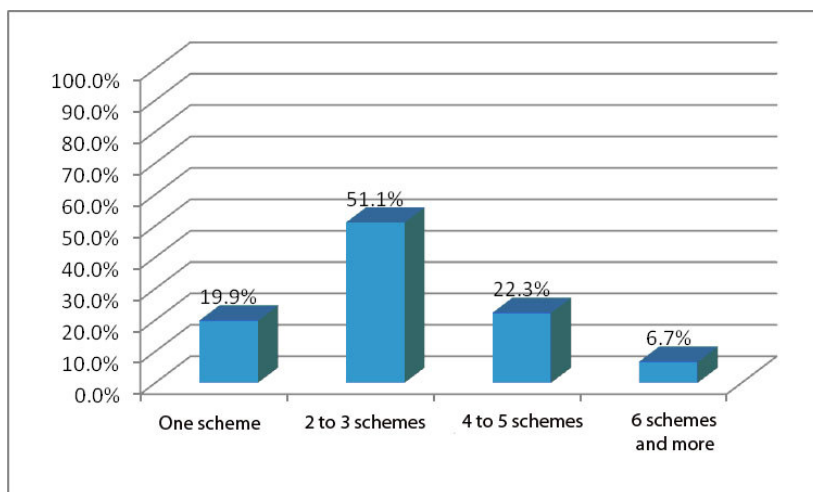
**Chart 11 Using an alternative treatment, except for ART**



A relatively few subjects questioned (66 or 10.7%) use other types of alternative treatment except for the ART. Still, a great majority (89%) avoid using any traditional

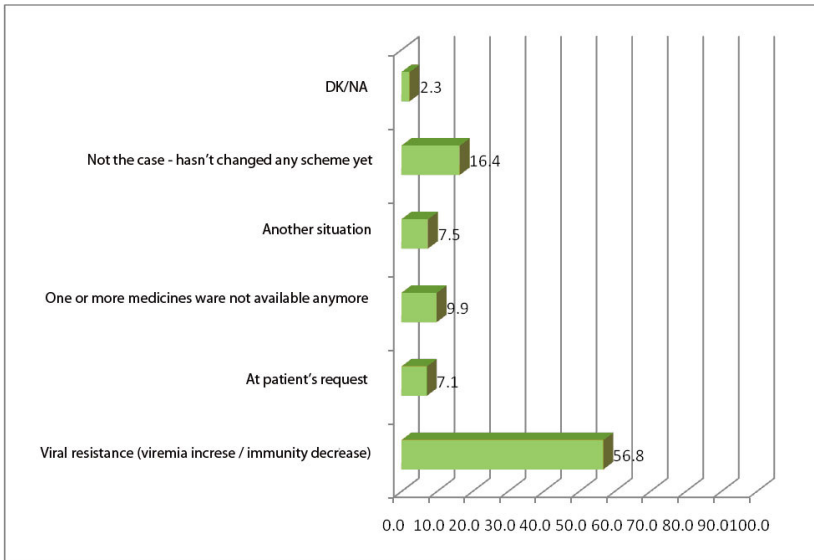
cures. Given the experience of the 90s, when there had been a lot of cases in which the medication was replaced with natural remedies, which eventually led to the worsening of the disease or even to the fatalities among the subjects, it is possible that a great number of subjects, who choose not to use an alternative or natural remedy, to avoid associations between the natural remedies and medication. Whether or not the doctor was informed about any traditional or natural remedies and about how they could affect the subjects, if combined with the ART, has not been investigated.

**Chart 12 Number of administered/changed treatment schemes**



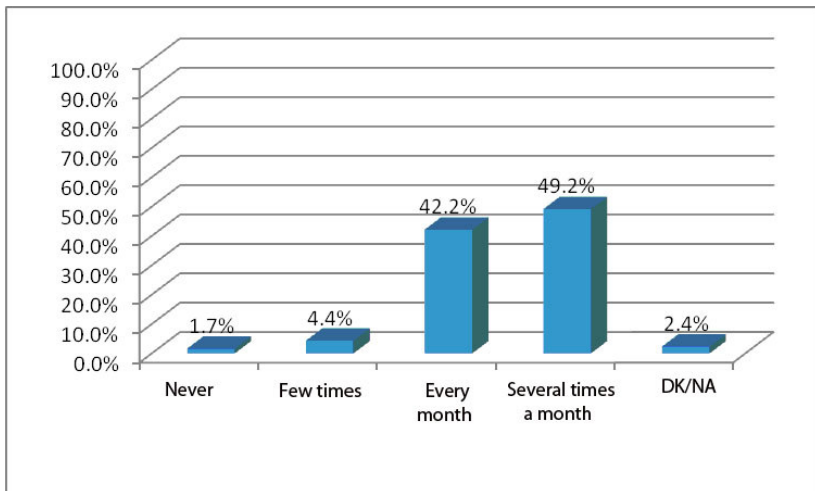
While only 19.9% of subjects examined have been under a single ART scheme so far, more than half of subjects (51.1%) have declared that they used more than 2 or 3 schemes of treatment. In only one case the number of schemes applied reached 15. A significant percentage of subjects (22.3%) have received 4 or 5 different schemes of treatment until the moment of the research.

**Chart 13 The reason for changing the last ART therapy scheme**



In most cases (56.7%) the reason for changing the last treatment scheme was linked to the increased viral resistance, signalled by a decrease in immunity or in the CD4 value (49.8%) or by the increase in the viremia (6.9%). In 61 cases (9.8%) the treatment had to be changed because one or more medicines became unavailable. The change of the therapy scheme was applied at a small scale (7.1% of cases) at patient's request.

**Chart 14 The frequency of hospital visits for obtaining the treatment in 2010**



Most subjects questioned have declared to have been to hospital at least once a month for taking their treatment (91.4%). Out of these, 49.2% (almost half) have claimed to have gone to hospital several times a month. In contrast, 11 patients (1.7%) claim to have never been to hospital during 2010. They are subjects who started their treatment in 2011. A relatively small percentage of subjects (4.4%) claimed to have been to hospital several times during the year.

**Table 7 The access to medical and psycho-social services in 2010**

How often have you been to hospital in 2010?	Never	A few times	Every month	Several times a month	DK/NA
1. To discuss with the psychologist/ social worker	39.7%	38.2%	10.2%	4.1%	7.9%
2. For virologic/immunologic (CD4) monitoring	3.4%	82.4%	2.4%	1.8%	10.1%

3. Because you didn't feel well and you needed to be examined by a doctor.	23.1%	58.6%	3.8%	4.2%	10.2%
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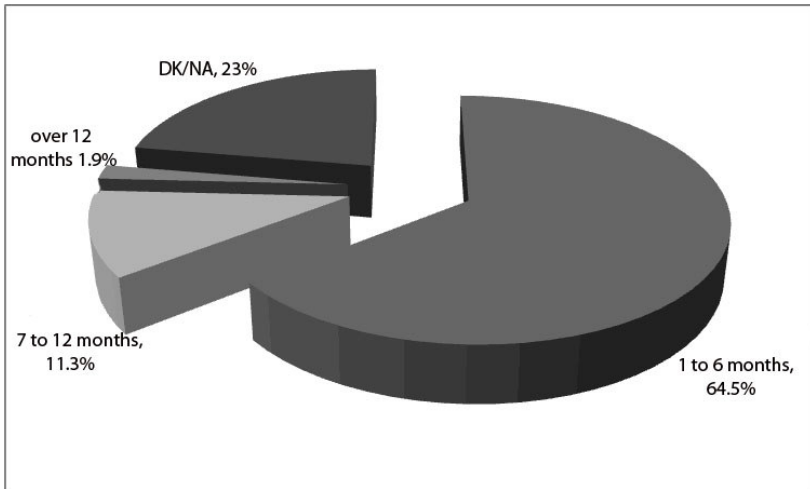
Unlike the previous question, when subjects declared to have been to hospital for obtaining the treatment at least once a month, the attendance to psychological support services was much lower, thus, 245 subjects (39.7%) claim to have never been to hospital during 2010 for discussing with a psychologist or social worker, while 236 subject (38.2%) claim to have been to hospital for such meetings. Only a small percentage of 14.3% of subjects claimed to have been to hospital once or more times a month in order to benefit from the psycho-social support services. The explanation is, on the one hand, the lack of psychological support services in many hospitals from many counties (except for the Regional centres) or, on the other hand, the fact that patients access these services outside the hospital (even though the number of such services has dropped severely during the last two years, due to the lack of funds), or patients are simply not interested or do not understand the purpose of such social services, since Romania seems not to have been educated properly in the sense of social or psychological assistance.

During 2010, most subjects from the group (82.4%) have been examined several times a year for virologic and immunologic (CD4) monitoring. A relatively small number of subjects did not go to hospital for tests, while 26 subjects (4.2%) have been to hospital at least once a month. For this question there was a significant percentage of non-answers (10.1%).

A relatively large number of respondents (362 or 58.6%) claimed to have been to hospital a few times during 2010 because they didn't feel well. Their percentage is even

higher if we add those who have claimed to have been to hospital at least once a month (8%). At the other pole there is an important number of patients who did not need to go to hospital when they didn't feel well (23.1%).

**Chart 15 Time elapsed from the last immunologic determination (CD4)**

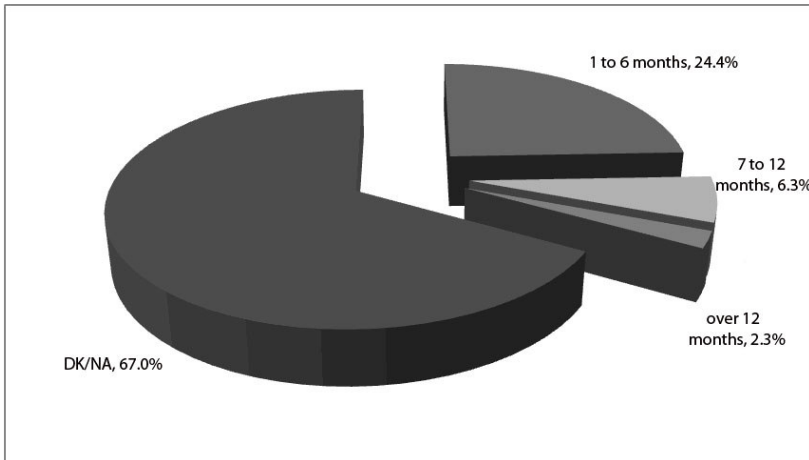


28.8% of the total number of subjects questioned claimed to have had tests for the immunologic determination (CD4) during the last 3 months, 10% of them even during the last month. A percentage of 35.7% have claimed to have had an immunologic determination in the last 6 months, while for another 8.5% an immunological determination was made in the last 9 months. The percentage of subjects who have been tested only once during the last year for CD4 is of 2.7% (10 to 12 months ago). A great percentage of subjects did not answer this question (22.3%).

Most patients (36.7%) were tested for CD4 twice during 2010. A significant percentage of respondents claimed that they were tested only once (14.3%) or 3 times (6.6%) or 4 times (4.9%) during 2010. In a much smaller total

percentage (1%), the subjects questioned claimed to have been tested more than 4 times during 2010. The greatest percentage was recorded for patients who haven't answered this question (35.2%).

**Chart 16 Time elapsed since the last viral load determination**



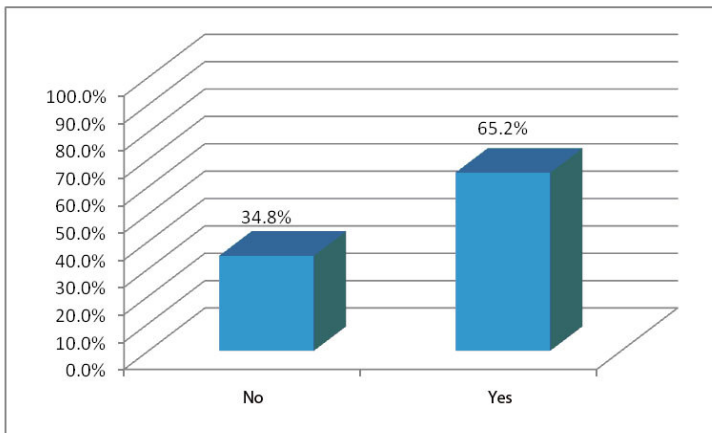
The viral load has been determined in the case of 10.19% of patients within the last 3 months, while the highest percentage (14.4%) is of subjects who claimed to have had this test made in a time period of 4 to 6 months. A total percentage of 6.3% of subjects claimed to have had a viral load determination made 6 to 12 months ago. A significant percentage of subjects did not answer this question (67%).

During 2010, 13.8% of subjects claimed to have been tested for viral load twice, while 11.5% have only had one determination of the viral load made, while a total percentage of 4.4% have been tested 3 or 4 times. As for the previous questions, the number of non-answers is significant (68.6%), suggesting that in these cases there haven't been any determinations of the viral load.

Given that the periodicity recommended for such tests is of 6 months, the fact that two thirds of the subjects questioned could not determine precisely when this test had been last made, reveals a major health risk factor and a risk in monitoring the disease. Without a constant monitoring of the health condition, the effect of the treatment cannot be tracked and the measures for situations in which the health condition deteriorates cannot be properly taken.

It is to be remarked that there were fewer patients who underwent tests for viral load determination in 2010, compared to those who underwent tests for the determination of CD4 (an average of 1.74 compared to 2)

**Chart 17 Interruptions in the ART therapy in 2010**



The answer recorded for the question *“Were there any situations in 2010 which made it impossible for you to obtain the ART medication from the usual Regional centre/hospital?”* was worrying. Almost two thirds (65.2%) of subjects claimed there had been such situations while only

215 subjects (34.8%) claimed to have received their treatment on a regular basis. This situation should raise question marks in concern to the sustainability of the national programme and the risk of health deterioration in the case of a large number of patients who haven't received the medication from the centre they were assigned to.

By analysing the access of patients to the ART therapy, there are some aspects to be remarked:

*1. When discussing the access to treatment, it can't be claimed that there is any discrimination based on demographic criteria.*

Regardless of age, occupation, education, income, gender or ethnicity, a large percentage of subjects claimed to have been in situations in 2010 when they didn't receive any ART therapy from the centres they were assigned to.

If we were to analyse which of the categories above are most prone to have given a positive answer to the question above, in a larger percentage than other categories ("were there any situations in 2010 which made it impossible for you to obtain the ART medication from the usual Regional centre/hospital?"), they include:

- By age – the age segment 40-49 years (72.5%), followed by segments 30-39 years (70.9%); no child from the total of 4 (15 to 17 years) has reported any interruption in the treatment during 2010;
- By gender of respondents – women (64.1%) compared to men (66.5%);
- By ethnicity – other ethnicities (4 individuals, representing 10%) followed by Roma ethnicity (79.3%);
- By last graduated level of education – primary school (75.9%) or without education (73.9%);

- By income – employees (75.9%) and individuals who benefit from allowances/ scholarship (73.9%).

2. *There doesn't seem to be any relation between the regional centres and the fact that the patients claimed there had been disruptions in the administration of the treatment.* Still, there are some extreme cases which have been recorded:

- In regard to hospitals from Hunedoara, Maramureş, Sibiu, Târgu Mureş, Tulcea, which have few patients represented in the group, the subjects have claimed *not to have had any disruptions during the treatment*;
- In the case of other centres such as Constanţa, Dâmboviţa, Galaţi, Iaşi, Piatra Neamţ, Ploieşti, Roman, Sălaj, Suceava, Târgu Neamţ, V. Babeş (Craiova) – 100% of patients declared to have experienced treatment disruptions. Most patients from these centres are from Ploieşti (58 patients) and Piatra Neamţ (14 students), followed by Constanţa (12 patients);
- It is to be remarked that in centres from the same area, with a comparable number of patients represented in the group (Bacău and Botoşani), the situation seems to be very different: for Bacău and its 20 subjects represented in the group, there have been 95% negative answers (there were no disruptions in the treatment), while in Botoşani, from where there are 15 patients in the group, there have been 6.7% negative answers (only one patient benefitted from an uninterrupted treatment in 2010);
- The situation in Bucharest seems aligned to the rest of situations at national level, with 62.2% and 64.2% of the patients in the group claiming to have experienced interruptions of the treatment during 2010.

A number of 31 subjects listed the strategies adopted for replacing the treatment they did not receive. A part of these “strategies” include:

“I called a doctor”; “I had an extra supply of medicines”, “I bought the medicines from another patient who didn’t take it”, “I bought it from another patient who had an extra supply of medicines”, “I got it from the Institute in Bucharest”, “I only took what I had”, “I took other medications for immunity”, **“I reduced the dosage to once a day (I reduced the recommended dosage), “I refused to take it anymore”**, “I asked for it at the pharmaceutical companies”, “Some of the medication has been replaced”, “I got them from the organization”, “Donations from other countries”, **“I’ve been waiting for 16 months to restart treatment”**, **“I took heroin”**, “My scheme was changed”, “My treatment was changed”, “my medication was replaced for 2 days”.

If some of the above mentioned therapies seem to have a relatively small impact or an impact on the short-term only, there can be various situations (emphasized above) which obviously have long term and serious consequences.

**Table 8 Strategies used in the absence of ART therapy in 2010**

What did you do when you didn’t receive the ART therapy in 2010	No.	Valid percentages
I received it from hospital	75	19.90%
I bought it at a pharmacy	12	3.20%
I borrowed from a friend	70	18.70%
I didn’t take any treatment	297	78.90%

297 individuals (78.9%) from those who haven’t answered the question stated they had stopped taking the treatment when the medication became unavailable in 2010. Other

157 patients (21.1%) have looked for alternative solutions for the treatment such as appealing to another hospital (75), borrowing from another patient (70) or buying the medications from the pharmacy (12).

From the 41 subjects whose answers were different from the ones we have earlier mentioned, 10 have reported more frequent morbidities due to immunity decrease. These morbidities have determined the hospitalization of the patient and led to his dismissal (one case), while others led to the relapse of cancer or to neurological complications. Other 11 patients stated that this situation has caused stress, anxiety, a state of agitation and forced them to borrow money in order to be able to buy the necessary medication. The health of the foetus was jeopardized in two extreme cases (pregnant women). When asked about the short periods of interruption in the treatment, 14 respondents claimed not to have been visibly affected by these disruptions while other 6 patients tried to be positive and looked for methods to obtain the medication (from supplies, by buying or borrowing from other patients or by buying directly from the producer).

**Table 9 The replacement of the ART medication due to it becoming unavailable**

<b>How many times was your medication scheme replaced due to the absence of the original medication in 2010?</b>	<b>No.</b>	<b>Percentage</b>
At least once	101	16.3%
DK/NA	517	83.7%

The absence of medication led to the change of the treatment schemes for 101 patients, representing 16.3% of subjects included in the group. Out of these 69 (11.1%) have changed the treatment scheme once, while other 32 (4%) have changed the scheme even twice or more times (1.2%) during 2010.

As a consequence of such disruptions in the ART, most seropositive individuals were forced to stop the treatment and go to the hospital more often for obtaining the medication. Here they got the treatment for periods of time shorter than 1 month, as it usually happens. These more frequent visits to the hospital led to an increase of the travel expenses of seropositive people, as well as to the deterioration of their health.

**Table 10 Consequences of the treatment disruptions**

<b>How was your life influenced by the interruptions?</b>	<b>No.</b>	<b>Percentage</b>
I felt worse	132	36.1%
I went to the hospital more often to take my medication	173	47.0%
I spent more money commuting than I did for the medication	138	37.7%
I was forced to stop the treatment	226	61.5%

From the perspective of seropositive individuals in the research, the most important cause for the absence of the ARV medication (mentioned by 65.5%) is the lack of the necessary budget for the acquisition of medication; the responsible institutions are considered to be another important cause for the absence of medication – the Ministry of Health (58.2%), the National Health Care System (59.7%), the Ministry of Finance (21.7%). The financing delay in the acquisition of the medication is also one of the factors to blame. The producing companies and medical staff are believed to be the least responsible for this situation (2.6% and 5.6%).

**Table 11 The causes for ART medication becoming unavailable in subjects' opinion**

Lack of necessary budget	65.5%
Financing delays	49.3%
Acquisition procedures	32.4%
Doctors	5.6%
Hospital management	18.0%
Distribution companies	16.5%
Pharmaceutical producers	2.6%
Ministry of Health	58.2%
Ministry of Finance	21.7%
National Health Care System	59.7%
Do not know/Cannot tell	10.8%

### ***Adherence to treatment***

The adherence to treatment is disclosed by the majority of positive answers to questions on the self-administration of the treatment schemes. It seems obvious that patients have understood the necessity of not interrupting the treatment, regardless of the temporary modifications in their health condition. Thus, most respondents claim they take their treatment in spite of feeling ill. The cases when the patients didn't take their treatment are incidental (they forgot, they didn't have the medication) and do not reveal any usual habits or lack of interest. Thus, 59.1% of patients claim to have had no interruptions in the treatment prescribed, during the last month, while 36.1% claimed not to have had any interruptions in the treatment prescribed by their doctor.

When asked about the reason for which they hadn't taken their medication according to the doctor's recommendation, most respondents said they forgot (44.6% of those who interrupted the treatment), followed by those who mentioned the fact of not having received the medication in time (34.4% of those who interrupted the treatment, 12.4% of the group). Some referred to the fear of others not finding out about their disease (8%) or to the state of illness that the medication produces (4.9%).

**Table 12 The reasons for which patients do not respect medical recommendations regarding the administration of the ARV treatment.**

<b>What was the reason for not taking your medication?</b>	<b>No.</b>	<b>Percentage of total respondents</b>	<b>Percentage of total group subjects</b>
I got bored of taking it	6	0.9	2.7%
I forgot to take it	100	16.1	44.6%
I feel ill when I take it	11	1.7	4.9%
I don't want people around me to know I have the disease	18	2.9	8.0%
I didn't receive the medication	77	12.4	34.4%
I feel well, the test results are good	3	0.5	1.3%
Another answer	9	1.4	4.0%

Almost two thirds of patients (63.5%) take their medication without anybody reminding them to do so. Even if 41.1% claim to have forgotten to take their medication, more than half (57.3%) claim they had never forgotten to take their medication. The interest shown to keeping the same treatment scheme is high (82%) since only 16% of patients claim it happened that they were forgetful about the treatment. We could analyse these answers in order to conclude what might have generated the lack of interest towards the treatment of these 99 patients examined

(16%) and what was the part played by the lack of medication in centres/hospitals were patients were assigned and in the adherence to treatment. An immediate consequence seems to be the loss of interest towards treatment: 16.2% of patients declare that during the last 4 days they skipped taking their medication at least once (table "Did it happen to forget your ART medication at least once within the last 4 days?")

**Table 13 Adherence to treatment**

AD3. When thinking about your ARV medication prescribed by the doctor	Yes	No	DK/NA
Does anybody remind you to take your medication?	34.8%	63.5%	1.7%
Does it happen for you to forget to take your medication?	41.1%	57.3%	1.6%
Does it happen for you not to care about the medication?	16.0%	82.0%	2.0%
Does it happen to stop taking the medication because you feel better?	6.2%	91.3%	2.3%
Does it happen not to take your medication because you feel worse after it?	7.5%	89.9%	2.6%
Did it happen to forget your ARV medication at least once during the last 4 days?	16.2%	81.6%	2.1%
Did it happen for you to be some hours late from the prescribed time for the ARV medication?	42.2%	56.1%	1.7%
Some people forget to take their medication at the end of the week. Did it happen that you forget one last Saturday or Sunday?	11.7%	85.7%	2.6%

The majority of respondents (91.3%) continue to take the recommended medication even when they feel ill. The percentage drops lightly (to 89.9%) in the situations when patients feel worse after they had taken the medication, but this drop has not influenced the conclusion according to which no matter what the health state is, patients trust

the benefits of the treatment schemes and continue to administer the treatment.

Patients remember to take their treatment and do not generally skip the prescribed medication. For the question “Did you skip any of your medication last weekend?” the majority of subjects (85.7%) answered “No”. From the other answers, we can conclude that the administration of medication became an independent habit, without the need of anybody reminding them about the medication (68.5%), without setting an alarm (76.3%), using a calendar (99.6%) or using special containers for the pills (94.8%). For 70.9% of cases, taking the medication is not linked to daily routines either (meals). Most respondents who use a certain method for remembering to take the treatment (26 out of 32) have claimed that medication became a part of their daily routine (an instinct, reflex, biological clock, “I place them at sight”, before going to bed, “as soon as I wake up”). Others claim there is another person in the family or their close environment (child, parent or physician) who reminds them to take the medication. Some patients use a diary or mark their hand in order not to forget.

**Table 14 Strategies for maintaining the treatment adherence**

I set a clock alarm/phone alarm	23.5%
I use special containers for dosing the number of pills	5.0%
I use a calendar	0.1%
My parents/partner/somebody else reminds me	31.2%
I use other daily routines as reminders (e.g. main meals of the day)	28.9%
Something else	3.2%
I use no special method	34.2%

Parents or other members of the family seem to be partners in maintaining the compliance to treatment. In almost a

third of cases (31.2%) these are the ones to remind the patient about taking the medication.

### ***The access to medical and social services***

- *The necessary amount of time for reaching hospital*

Most subjects from the group (88.9%) reach hospital in an hour (34.8%) or less (54.1%). Still, for 62 of the patients (10.3%), reaching the hospital they are assigned to takes more than 2 hours. Out of the respondents who claim to reach hospital in less than an hour, 132 (21.4) suggest they are hospitalized or institutionalised (average time limit to reach hospital is 0 min). The answers had to be correlated with the fact that the research included 26.9% of subjects who were in hospital. Other 62.6% reach hospital in 30 minutes or less. Only 43.3% of subjects questioned say to have free commutation tickets.

**Table 15 View on the access to medical services**

	<b>Almost unlimited access</b>	<b>Little limited access</b>	<b>Limited access</b>	<b>Almost no access</b>	<b>Not the case/ Can't tell</b>	<b>DK/ NA</b>
ARV therapy	44.6%	42.4%	9.5%	1.3%	1.1%	1.2%
Treatment for opportune infections	21.0%	34.3%	20.2%	14.2%	7.8%	2.4%
Medical exams						
a. Dentistry	10.5%	21.5%	24.7%	13.1%	27.6%	2.5%
b. Maternity	2.0%	5.4%	5.8%	3.5%	73.7%	9.6%
c. Gynaecology	4.3%	12.2%	11.2%	4.7%	59.4%	8.2%
d. Surgery	3.8%	9.0%	10.0%	8.8%	63.1%	5.1%

The percentage of subjects who say they have almost unlimited or little limited access to ARV therapy is significant (87%). Still, a percentage of 10.8% say they

have limited or almost no access to ARV therapy, while 1.1% can't tell. These answers suggest there are discrepancies concerning the equal access to the ART therapy.

- *The access to other specialised medical services*

If we take a close look at the situation of the access to other types of treatments or medical services, the answers become more and more diverse. Consequently, only 55.3% of patients claim to have almost unlimited access or little limited access to treatment for opportune infections, while 34.4% think that access is limited or there is almost no access to treatment. A higher percentage of respondents (37.8%) claim that access to dental treatments is limited, while other 27.6% can't tell (because they didn't try to access these types of services). Only 32% of patients believe that access to dental treatments is almost unlimited or little limited.

Out of a total of 104 women patients who answered the question about the access to maternity medical care (because the other members from the group were not relevant subjects), only 44.2% believed that the access to such services is almost unlimited or little limited, while 55.8% believe that their access to such services was mainly limited or almost not possible. A similar situation is to be observed in the case of women patients who tried to access other gynaecological services, with 51% of the 200 women patients having declared that access was almost unlimited or little limited, while other 98 individuals (49%) believe that access was mainly limited or almost impossible.

The problem regarding the access to other specialised medical care is even more obvious in the case of subjects

speaking about surgical interventions. Thus, out of the 197 subjects who answered questions about this type of services, almost 60% declare that access to such services is mainly limited or almost impossible, while only 40.6% claim that access is almost unlimited or little limited.

A more thorough analysis should offer a fair evaluation of the causes which determine the limited access to specialized medical care for seropositive individuals.

- *The access to social services/ social protection:*

Another element analysed in the research was the access to psychosocial support services. Hence, out of 514 respondents to the question: "Is a psychologist/social worker accessible for you?" 407 (79%) believe to have had an almost unlimited or very little limited access to such services. A relatively great percentage 16.9% of subjects from the research claimed they can't tell or didn't answer the question, which can be interpreted as the fact that these ones did not try to access psychosocial support services. It is to be remarked that a significant percentage of those who wanted to access support services (20.9%) believe their access was limited.

Concerning the access to a support group, out of the 497 respondents who answered this question, 84.7% said that access was almost unlimited or little limited while only 15.3% believed that access was limited. A percentage of 16.9% of all subjects from the research could not tell or did not answer this question.

Another evaluated way for getting psychosocial support was that of discussing with other PLHIV. In this case 82.6% of subjects from the group believed they had the possibility to discuss with other PLHIV.

The freedom of joining social groups, measured by the perception of subjects regarding the opportunity of joining a PLHIV association for defending their rights, was assessed as being largely respected by 85.5% of subjects. Other 14.2% of subjects declared they were not interested in such associations or could not answer, while only 5.1% claimed to have had little or almost no access to such associations.

**Table 16 The perception on the access to psychosocial services**

	<b>Almost unlimited access</b>	<b>Little limited access</b>	<b>Limited access</b>	<b>Almost no access</b>	<b>Not the case/ Can't tell</b>	<b>DK /NA</b>
Psychologist/Social worker	33.5%	32.3%	9.6%	7.8%	14.1%	2.8%
Support group	41.2%	26.8%	7.2%	5.2%	15.5%	4.1%
The possibility to discuss with other PLHIV	53.1%	29.6%	6.8%	4.3%	4.2%	2.0%
Joining a PLHIV association/ defending the rights of PLHIV	56.6%	23.9%	2.7%	2.6%	11.9%	2.3%
Education	34.3%	28.0%	11.3%	7.4%	16.3%	2.7%
Job	9.9%	12.2%	13.1%	17.7%	44.3%	2.7%

Two other elements analysed from the perspective of subjects involved in the research were the access to education or to a better job. Hence, 62.3% of those questioned claimed they had access (28%) or little limited access (34.3%) to education. 18.7% of subjects have experienced limited access to education, while 7.4% suggest that there was almost no access to education.

Most subjects (47%), could not say how limited their access to a job was, mainly because of the age of the respondents. 190 subjects (30.8%) believed that the

access to a job was limited or that there was almost no access, while 22.1% believed they had access to a job.

When taking a closer look at the present situation of respondents, it can be concluded that a great majority of them do not have a job or permanent activity. Thus, 343 of subjects (58.9%) claim they are unemployed/have no occupation, while only 56 (9.3) work with a full time employment contract, or with a part time employment contract (17). Other 146 (25.1%) are now pupils (64) or university students (82). By gathering these results and the answers on the rights of subjects, 18 of those declaring they have an employment contract are employees of protected workshops. The lack of occupation of the respondents is probably influenced by the degree of disability set. Hence, 166 individuals have a personal care attendant, while 210 chose the allowance over the personal care attendant, which means they have an advanced degree of the disability.

Other rights that members from the group could benefit of include: meal allowance (585), disability allowance (497), free travel tickets (474), complementary budget (369), tax exemption for income (16) or housing (56).

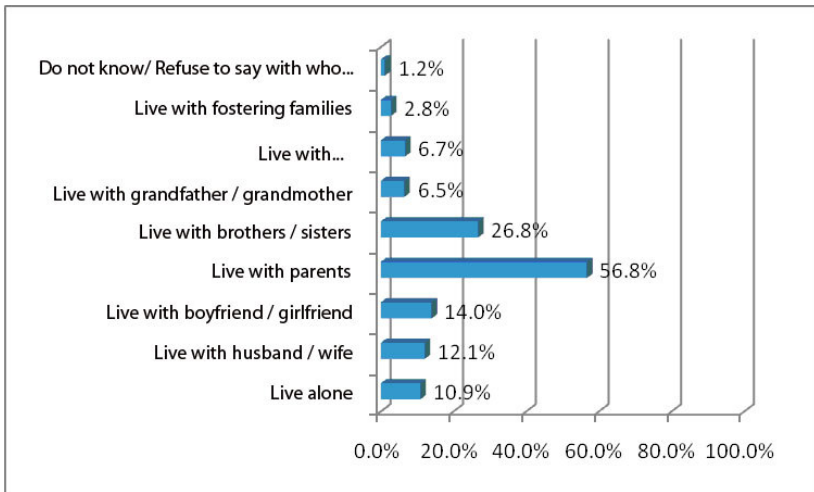
- *The quality of life*

When referring to the quality of life for the subjects in the group, the research analysed some variables: housing, revealing their diagnosis, occupation, rights accessed by subjects.

When speaking about housing, most respondents claim they live with their parents (336) and brothers (159) or with their wife/ husband or girlfriend/ boyfriend (154). A relatively small number of respondents claimed they live alone (64). The sociopsychological factors and family play

an important role in guaranteeing the adherence to treatment. (E.g. Falagas et al, 2008).

**Chart 18 Who does the subject live with**

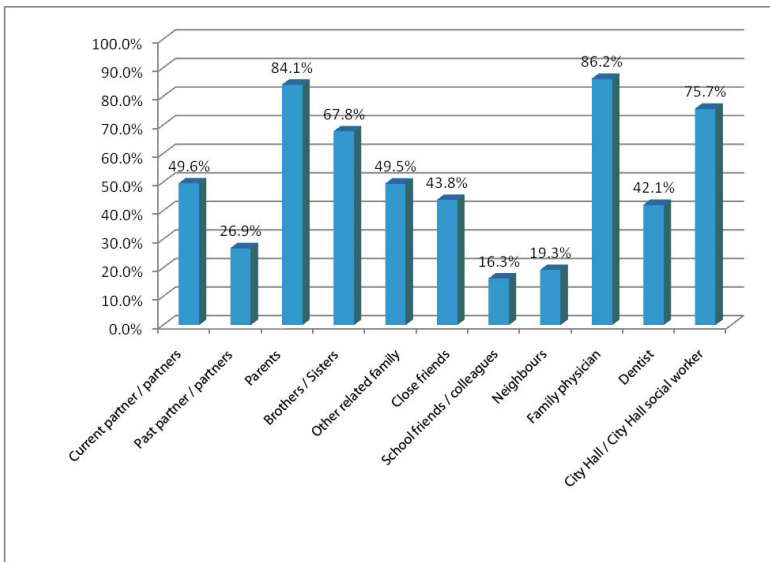


As it was concluded from a series of questions linked to the interest of patients to continuing the treatment, the adherence to treatment is generally good, with constant scores over 80% and up to 98%. Family is a real partner in guaranteeing the compliance - 31.2% of respondents declare that their partner, parents or other people they live with remind them to take their treatment. The involvement of the family is an important indicator for evaluating the life quality of PLHIV. It can also be concluded that the success recorded in Romania concerning the adherence of patients to ARV therapy can be largely explained through the efforts for ensuring a psychosocial support for the family of the infected individual.

Another investigated field is that of revealing the diagnosis. Hence, the results reveal that in most cases, parents (84.1%) and brothers (67.8%) know about the diagnosis. It

was also concluded that the family physician knew as well about the diagnosis of the subject (86.2%) and that many respondents (75.7%) revealed the diagnosis to the social worker from the City Hall (tightly linked to the access to social rights). Lower scores were recorded in regard to the other relatives and close friends knowing about the diagnosis (49.5% and 43.8%). Colleagues/school friends and neighbours held lower scores (16.3% and 19.3%). It is interesting to notice that in 27% of cases, patients have revealed the diagnosis to their past partners, but this fact can be justified by the age of the individuals from the group (it is possible that in many cases there were no past partners) or by the fact that at the time of the relationship, the individual was not yet infected.

**Chart 19 Revealing the diagnosis to people other that the medical staff from the infectious diseases hospital.**



It can be generally estimated that there is a social support network for most respondents, in which the family and

professionals in the field are involved (family physician, social worker from the City Hall). Gathering all these answers with scores recorded for the answers on the access to psychosocial support services, joining an association or the opportunity to create such relationships, we can say that there exists a set of social relationships or opportunities for creating them. These would allow the infected person to openly discuss the problems they are confronted with and receive the necessary emotional support for continuing the treatment.

Another important element in evaluating the quality of life for PLHIV is the social status (Falgas et al, 2008). By analysing the answers to questions on the activities of the subjects in the group, we notice that only 39.45% of these have a constant activity (most of them are pupils or university students), while 58.9% do not have a main activity. It is true that some of these have poor health conditions which do not allow them to go to work on a regular basis, but this is another factor worth being progressively analysed, especially from the perspective of financing opportunities for programmes dedicated to the integration on the existing employment market (POS-DRU Area Operational Programme-Human Resources Development).

**Table 17 Present occupation**

	<b>No.</b>	<b>Percentage*</b>
Present occupation - pupil	64	11.0%
Present occupation – university student	82	14.1%
Full time employee, with employment contract	38	6.4%
Part time employee, with employment contract	17	2.9%
Works on the black market (without an employment contract)	29	5.0%
Unemployed/ no current activity	343	58.9%

Do not know/ Refuse to speak about the current occupation	9	1.6%
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\*Out of 583 valid answers

Finally, the forth analysed factor for the evaluation of the quality of subjects' lives is the access to rights. Based on subjects' answers it can be claimed that rights are accessed in a significant proportion. Thus, 98.4% of subjects benefit from the meal allowance, 83.9% has a disability degree certificate, 83.6% benefit from the disability allowance and 79.8% benefit from free travel tickets. The access to these rights was mainly possible due to nongovernmental organizations and to specialized social services, which have succeeded in achieving both the necessary legal environment and the patients' cognition of the rights they are entitled to access. There is still a need of approximating these percentages since the group was composed of subjects with HIV/ AIDS familiar to organizations and there are no precise data regarding the total percentage of patients with HIV/AIDS who access specialised social services provided by special organizations.

**Table 18 The social rights seropositive individuals benefit from**

	<b>No.</b>	<b>Valid percentages</b>
Which are the rights or facilities you benefit or have benefitted from during the last 12 months – disability degree certificate?	568	95.5%
What is your disability degree?	499	83.9%
Meal allowance	585	98.4%
Allowance instead of personal care attendant	210	35.3%
Disability Allowance	497	83.6%
Free travel tickets	474	79.8%
Personal care attendant	166	27.9%

Complementary budget	369	62.0%
Property tax exemption	56	9.4%
Income tax exemption (for employees)	16	2.6%
Employment in a protected workshop/ protected work unit	18	3.1%

## IV. Conclusions and recommendations

### Conclusions

Romania is considered to be a model country within the region due to the success regarding the universal access to ARV therapy for individuals with HIV/AIDS. Evaluations made by WHO and UNAIDS, which also consider the number of undiagnosed seropositive individuals, still suggests a coverage ratio of 81% in 2009 (WHO, 2010).

Still, nongovernmental organizations noticed several times during 2009, but especially during 2010, that there were many breaches in the system for ensuring the treatment. The hereby research had as aim the evaluation of the access to treatment in the case of people living with HIV/AIDS in Romania, by attempting to describe the consequences of treatment interruptions.

- *Sociodemographic data*

Given that the research is representative for individuals with HIV/AIDS in Romania, the group included representative percentages of subjects from age segments 15 to over 60 years (1%). By source of infection, the group is close to the epidemiological patterns representative for Romania: 71.8% claim to have become infected from infected medical equipment and from infected blood transfusions, other 10.2% became infected through unprotected sexual intercourse, while a far smaller percentage state to have become infected by reusing syringes for injecting drugs

(1.1%). A significant percentage claimed not to know the source of their infection (13%).

Most subjects in the group are averagely educated while only one in 10 has graduated university. At the same time, a quarter of respondents are still pupils or university students.

More than 12% of subjects from the target group have not yet graduated the compulsory education level for their age.

Most of the subjects are unmarried but live, in great proportion, with their families (parents, siblings, grandparents). The main income source is the financial aid, the allowance or the scholarship. Less than one in 10 subjects has monthly salaries as the main income source.

- *ARV therapy*

More than half of subjects in the group (57.4%) have known their diagnosis for over 10 years. We can assume that subjects in the group have been undergoing ARV therapy for a very long time: 59.2% have been under treatment for more than 10 years, while 10% of those questioned have been under treatment for more than 15 years. A relatively small number of them use natural remedies besides the ARV therapy. While 17.8% of those questioned have only had one scheme of ARV therapy so far, more than half of them (50.4%) stated to have had 2 or 3 ART schemes of therapy so far. The replacement of the last treatment scheme was closely linked to the increase of viral resistance in almost half of cases, but still 9.8% claimed their treatment had to be replaced because one or several medications became unavailable. The access to treatment involves frequent commuting to hospital for a majority of patients (91.4% of total number of cases).

- *The access to medical tests and ARV therapy in 2010 and consequences for the patients*

During 2010 most patients in the group (82.4%) were tested several times a year for virologic/immunologic monitoring (CD4): 35.7% claim they have had a CD 4 immunologic determination made within the last 6 months, while 28.8% have had tests within the last 3 months or even within the last month (10%).

The research recorded worrying answers for the question: "How many times, in 2010, was it impossible for you to receive your ART medication from the regional centre/hospital you are assigned to?" Almost two thirds (65.2%) of participants in the research claimed that such situations have existed, while only 34.8% claim to have received their daily treatment on a regular basis.

The access of seropositive patients to ARV therapy was analysed through the access to treatment in each centre from the country. There weren't any significant differences regarding the number of patients in a centre or the region where the centre is located. There were no significant differences concerning the access to treatment on demographic criteria (age, sex, ethnicity, education or occupation).

The most common strategies adopted by the subjects when faced with a disruption in the treatment were:

*"I had an extra supply of medicines", "I took the medication only once a day", "I refused to take it any longer", "I've been waiting for 16 months that treatment restarts" or "I took heroin".* The last quoted strategies certainly have very serious and long-term consequences. Over 65% of subjects claimed to have disrupted the treatment.

The disruption of treatment caused more frequent morbidities, including the relapse of cancer or serious neurological affections, the hospitalization of the patient and in one case the subject was made redundant. This situation jeopardized the health of the foetus in the two cases of infected pregnant women. The absence of medication led to the replacement of the treatment schemes for 101 seropositive individuals.

- *Adherence to treatment*

The adherence to treatment is revealed by the mostly positive answers to questions linked to the self administration of treatment schemes. Almost two thirds of patients (63.5%) take their treatment without anybody reminding them to do so. The interest in maintaining the treatment scheme is large. Only 16% of patients claimed it sometimes happened to them to be careless regarding the treatment. These answers could be analysed in order to conclude what caused the lack of interest towards treatment in the case of these 99 patients (16%) and what was the role that the lack of medication in centres/hospitals, where the patients had been assigned to, played in the diminishing of the treatment adherence. The administration of treatment became an independent habit, ("as a reflex/habit", "the biologic clock", "I place the medication in sight", "before going to bed", "as soon as I wake up"). Parents or members of the family seem to be partners in ensuring the compliance to treatment. In almost a third of cases (31.2%) it is the family who remind patients about the medication.

Most subjects in the group (88.9%) reach hospital in about an hour or less, for more than 1 in 10 patients the trip to the regional centre/ hospital they were assigned to lasts

more than 2 hours, in the situation where 43.3% of those questioned claim to have free travel tickets.

In spite of the treatment disruptions, most subjects in the group believe that access to the ART treatment is almost unlimited or little limited.

- *The access to specialized medical services*

When looking closely at the situation of the access to other types of treatment or medical care services, the answers are more than diverse. Thus, only few over half the patients claim to have unlimited or little limited access to treatment for opportune infections, while more than third of subjects believe that access to such treatment is limited or almost impossible. Medical care services which could face the problem of sinuous access seem to be dental treatments and surgeries. Only 44.2% of women questioned believed that access to medical care in obstetrics and gynaecology is almost unlimited or little limited, while 55.8% think that the access to such treatments is limited or almost impossible.

- *The access to social services/social protection*

Another analysed element was the access to psychosocial support services. Hence, out of the 514 individuals who answered the question "How much access did you have to a psychologist/ social worker?" 407 individuals (79%) believed that their access was almost unlimited or little limited. At the same time, there is a record of positive answers linked to the access to the support group or the chance to discuss with other seropositive individuals (over 80%).

The demand for psychological support is relatively small. Only a little over a third of subjects claimed to have been

to hospital for discussions with the psychologist or the social worker.

The perception of HIV/AIDS infected individuals towards access to education or a job reveals that most subjects (62.3%) have a positive perception regarding the education and employment opportunities. Looking even closer at the present occupation of respondents, it can be concluded that most of them do not have a job or a permanent activity, 58.9% of them being unemployed, while only 9.3% have a job and 25.1% are pupils or university students. Respondents' lack of occupation is probably influenced by the disability degree certificate.

The access to rights is an area which has lately recorded significant progress. Thus, more than half of subjects have a personal care attendant or they have chosen the disability allowance instead of the social worker, which means they have a certificate of advanced degree of disability. Other accessed rights may also include: meal allowance, disability allowance, free travel tickets, complementary budget, housing or income tax exemption.

- *Quality of life*

For evaluating the quality of life, the hereby research analysed some variables: housing, revealing the diagnosis, occupation, rights accessed by the subjects.

Data regarding housing reveal that the majority of respondents live with their parents and siblings, with their wife/husband or with their boyfriend/girlfriend. A relatively small number of respondents claimed to live alone. The psychosocial factors together with the family play an important role in ensuring treatment adherence (Knodel, 2009).

As far as revealing the diagnosis is concerned, another important factor for evaluating the quality of life, the answers showed that in most of cases parents and sibling know about the diagnosis. The diagnosis is also known by the family physician and the City Hall social worker. Colleagues/school friends seem to know the diagnosis in a significantly smaller extent.

It can be generally concluded that there is a social support network for most respondents: family but also involved professionals, specialized organizations or other infected individuals. These allow the infected individual to openly discuss problems they are confronted with and receive the emotional support necessary for the progression of the treatment.

The social status can also represent an important factor in increasing the quality of life in the case of infected individuals (Falgas et al., 2008). By analysing subjects' answers, it can be noticed that only 39.4% of subjects have a constant occupation (most of them are pupils or university students). We believe that this is an element which needs to be continuously investigated, especially from the perspective of opportunities and financing programmes for the integration in an existent employment market. (POS-DRU Area Operational Programme-Human Resources Development).

## **Recommendations**

- *In attention of central public authorities*

The strongest recommendation refers to the **provision of antiretroviral therapy for seropositive individuals**, any interruption of the treatment leading to health deterioration. Moreover, as the research data shows, disruptions in the

provision of treatment trigger financial loss, human fatalities and waste of time.

There is also a need for constant funding for ensuring, first of all, a thorough monitoring and observation of HIV/AIDS evolution (virologic and immunologic monitoring) and, secondly, for ensuring the treatment of opportune infections.

The approval of the National Strategy for the prevention and control of HIV/AIDS is necessary for the time period 2010 to 2015. This Strategy has been in an advanced state of elaboration since 2010.

Given the realities concerning the difficulties encountered when trying to access some of the medical services, the medical staff needs formation through programmes focused on the knowledge and implementation of universal precautions in the medical practice, contributing thus to the a better access of individuals with HIV/AIDS to medical services.

- *In attention of local authorities*

Since the medical units have been transferred into the administration of local authorities, these will play an important part in respecting the terms regarding the acquisition procedures of the ART medication.

It is to be remarked, from the perspective of social assistance services, that the percentage of individuals with HIV/AIDS who access the social security programmes (through their disability degree certificate) is increasing. Still, there are important departments which avoid any contact with the local authorities.

- *In attention of non-governmental organizations*

These organizations need to continue the programmes that address seropositive individuals, by identifying alternative resources of funds to the ones already existing (e.g. other European programmes, funds deduced from the profit sector, from communities, the development of units of the social economy etc).

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## VI. Appendix

### ***Appendix 1: Questionnaire applied to beneficiaries***

Name of operator \_\_\_\_\_ Date (day/month)  
\_\_\_/\_\_\_/2011 County .....

#### **Questionnaire regarding the access to antiretroviral therapy**

<b>I. General Data (GD)</b>
-----------------------------

**GD.1. How old are you (current age)**

**GD.2. Are you currently undergoing antiretroviral therapy?**

- a. Yes
- b. No → *Questionnaire is not applied anymore*

**GD.3. What is your gender? \*Circle the correct option**

- a. Female
- b. Male

**GD.4. What county do you live in?** \_\_\_\_\_

**GD.5. What is your ethnicity? Circle the correct option;**

One answer only

- a. Romanian
- b. Hungarian
- c. Roma
- d. German
- e. other, specifications: \_\_\_\_\_
- f. DK / NA

**GD.6. What is your graduated level of education? One answer only**

- a. primary
- b. gymnasium
- c. vocational school
- d. high school
- e. university
- f. no education

**GD.7. How many years of education have you graduated?**

---

**GD.8. Your present social status is:** One answer only

- a. Married/ Remarried
- b. Single
- c. Concubinage/ consensual union/ couple
- d. Divorced/Separated
- e. Widowed

**GD.9. You presently live in a ...? READ! One possible answer only**

- Private property/ family property ..... 1
- Rented housing ..... 2
- Institution/fostering home ..... 3
- Social home (assisted living facilities, family homes) ..... 4
- Boarding house ..... 5
- I don't have a house ..... 6
- Another situation, **Say which**..... 7
- [DK/ I refuse to say]..... 9

**GD.10. Who do you live with at present? READ! More possible answers**

- I live alone..... 0
- With husband/ wife..... 1
- With boyfriend/ girlfriend ..... 2
- With parents ..... 3
- With brothers/sisters ..... 4
- With grandfather/ grandmother ..... 5
- With friends/ colleagues/ school friends, acquaintances ..... 6
- With the fostering family ..... 7
- Another situation, **Say which**..... 8
- [DK/ I refuse to say]..... 9

**GD.11. What do you do at present?** READ! More possible answers.

- Pupil ..... 1
- University students ..... 2
- Full-time employee, with an employment contract 3
- Part-time employee, with an employment contract 4
- On the black market (no employment contract) ... 5
- Unemployed/ I have no present occupation ..... 6
- Another situation, **Say which?** ..... 7
- [DK/ I refuse to say] ..... 9

**GD.12. Which is your main income source?** One possible answer only.

- a. Monthly salary
- b. My partner/ husband/ wife
- c. My own business
- d. My family / my children
- e. Retirement pension
- f. Social aid (disability allowance/ scholarship)
- g. Another (say which) .....

**GD.13. For how long do you know to have been infected with HIV/AIDS? For \_\_\_\_\_ years**

**GD.14. How did you become infected from your knowledge?** READ! One possible answer only.

- Infected medical equipment/ in hospital..... 1
- I was administered an infected blood transfusion.. 2
- From my mother, during pregnancy or child birth.. 3
- From unprotected sexual intercourse with an infected person ..... 4
- I reused syringes for the injection of drugs together with other people ..... 5
- Another way, How? ..... 6
- Don't know/ NA ..... 9

***II. You and the antiretroviral therapy (T)***

**T1. For how long have you been under ART therapy?**  
 for |\_\_|\_\_| Years (i) or for |\_\_|\_\_| Months

**T2. Do you use any other traditional or alternative methods for the treatment of your HIV/AIDS infection (plants, traditional medicine...)?**

- a. Yes b. No

**T3. What is your antiretroviral medication at present and how do you administer it? You shall fill in each column for each of the medication type.**

Name of anti-HIV medications you are taking	How many times a day do you take the medication?	How many pills of this kind do you need to take each time?	Don't know
1.			
2.			
3.			
4.			
5.			

6. Another situation, say which .....

**T4. How many ART therapy schemes have you undergone so far (the present one included)? \_\_\_\_\_ schemes**

**T5. When was your scheme last changed? (convert years into months) \_\_\_\_\_ months ago**

**T6. What was the reason for the last change? Choose one option only.**

- a. Viral resistance/ they had lost effect  
 a.1. CD4 decrease  
 a.2. Increase of viral load/ Viremia

- b. I brought to the attention of the physician my deteriorating state of health
- c. One or more medications became unavailable
- d. Another situation, give details \_\_\_\_\_

**T7. Where do you get your supply of antiretroviral medication from? One answer only.**

Hospital \_\_\_\_\_ County \_\_\_\_\_

**T8. How often have you been to hospital in 2010 for... ONE ANSWER PER ROW ONLY**

	Never	A few times	Every month	Several times a month	DK/NA
1. For getting your ART supply					
2. For discussing with the psychologist/ social worker					
3. For the virologic/ immunologic (CD4) monitoring					
4. Because you didn't feel well and you wanted to see a doctor.					

**T9. What were the values of the last virologic and immunologic determinations that you have had? Answer for each row and column**

	Value	Months ago	No. in 2010	DK/NA
CD4 Value		..... months	..... times	
Value of viral load		..... months	..... times	

**T10. Where there any situations in 2010 when you didn't receive your ART medication from the Regional Centre/ hospital you generally take them from?**

- a. Yes → Go to T11.1.

b. No → *Go to T15.*

**T.11.1. What did you do when you didn't receive the ART therapy from the hospital anymore?** More possible answers

- a. I received it from another hospital
- b. I bought it from the pharmacy
- c. I borrowed medication from a friend
- d. I ceased the treatment
- e. Another situation, say which.....

**T11.2. Which do you believe to have been the causes for the ART medication becoming unavailable?** More possible answers

- a. The lack of necessary budget
- b. The delay in the administration of the budget
- c. Acquisition procedures
- d. Doctors
- e. Hospital management
- f. Distribution companies
- g. Producing companies
- h. The Ministry of Health
- i. The Ministry of Finance
- j. National Health Services
- k. Don't Know/ I can't tell

**T12. Which was the total duration of these interruptions? (in days) \_\_\_\_\_ days**

**T13. Which was the maximum period of time for a treatment interruption in 2010? \_\_\_\_\_ days**

**T14. How did the lack of the treatment influence your life?**

- a... I felt worse
- b..I went to hospital more often for taking the medication

- c... I spent more money for going to hospital
- d. . I was forced to stop taking the medications
- e... Another way, say how .....

**T15. How many times was your treatment medication changed in 2010, due to some of the medications becoming unavailable? \_\_\_\_\_ (times)**

**III. Adherence to treatment (AD)**

**AD1. It happens for some individuals with HIV/AIDS to skip taking their medications for a day or more. How many times did it happen for you not to take the medications prescribed by your physician during the last 4 weeks?**

...	da ys
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- a. Never → Go to AD3.                      b. DK/NA

ASK QUESTION AD2 IF ANSWER TO AD1 IS DIFFERENT FROM 0. IF NOT GO TO THE NEXT SECTION

**AD2. What was the reason for forgetting to take your medication? READ! ONE ANSWER ONLY**

- I got bored of it ..... 1
- I forgot to take it ..... 2
- I don't feel well when taking it ..... 3
- I don't want people round me to know I am ill..... 4
- I didn't receive the treatment.....5
- I feel well; my test results are good..... 6
- Another answer (which?) ..... 7
- DK/NA ..... 9

**AD3. When thinking about your prescribed ART therapy:**

	Yes	No
1. Does anybody else remind you to take the medication?		
2. Does it ever happen that you forget to take your medication?		
3. Does it happen for you to be careless about your medication?		
4. Does it happen for you not to take your medication if you feel better?		
5. Does it happen for you to stop taking your medication if you feel worse?		
6. Did it happen for you not to take your ART medication at least once within the last 4 days?		
7. Did it happen for you to be more than 2 hours late in the administration of your ART medication?		

8. Some people forget to take their medication at the end of the week. Did you skip any of the medications last Saturday or Sunday?		
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**AD4. What method do you use to remember taking your medications:** More possible answers

- 1. I set a clock alarm/ phone alarm
- 2. I use special containers for dosing my pills
- 3. I use a calendar
- 4. My parents/ partner/ somebody else reminds me
- 5. I use other daily activities as reminders (e.g. main meals)
- 6. Something else \_\_\_\_\_
- 7. I have no special methods

**IV. The access to specialised services (SA)**

**SA1. How long does it take to reach hospital/ counselling centre/ association?** – The approximate number of hours and minutes. For example, when the patient answers “30 minutes”, specify: | \_0\_ | \_0\_ | hour/(s) and | \_3\_ | \_0\_ | minutes

|\_\_|\_\_| hour(s) and |\_\_|\_\_| minutes

**SA2. Which is the average (approximate) cost of transport for reaching hospital?**

- a. \_\_\_\_\_ RON
- b. Not the case, I benefit from free travel tickets/ I don't pay,

**SA3. Given your up to present experiences, how do you evaluate your access to the following? (the option “Not the case” will be chosen if the subject hasn't asked this particular type of service/ was not in the position to do so)**

	Almost unlimited access	Little limited access	Limited access	Almost no access	Not the case/ I can't tell
1. ART therapy					
2. Treatment for opportune infections					
3. Medical examinations					
a. Dentistry					
b. Maternity					
c. Gynaecology					
d. Surgery					
4. Psychologist/ Social worker					
5. Support group					

6. The possibility to discuss with other seropositive individuals					
7. Joining a seropositive individuals' organization for the protection of their rights					
8. Education					
9. Occupation					

**SA4. Who else is aware of your diagnosis except for the medical staff at the infectious diseases hospital? READ! MORE POSSIBLE ANSWERS**

- Partner/ Present partners ..... 1
- Partner/ Past partners ..... 2
- Parents ..... 3
- Brothers/ Sisters ..... 4
- Other relatives..... 5
- Friends ..... 6
- Colleagues/ School friends ..... 7
- Neighbours ..... 8
- Family physician..... 9
- Dentist ..... 10
- City hall/ County social worker ..... 11
- Other people, **WHO?**..... 12
- [DK/ I refuse to say]..... 99

**SA5. Which of the following rights and facilities do you benefit or have benefited from during the last 12 months?**

	Yes	No	I no longer benefit
a. Disability degree certificate			
b. If yes, which is the degree inclusion :			
1. Severe disability			
2. accentuated disability			
3. Moderate disability			

4. Slight disability			
c. Meal allowance for individuals with HIV/AIDS			
d. Allowance instead of social work assistance			
e. Disability allowance			
f. Free travel tickets			
g. Personal Support worker			
h. Complementary budget for individuals with severe disabilities, accentuated or moderate disability degrees			
i. Property tax exemption			
j. Income tax exemption (for employed individuals)			
k. Employment in a workshop/ social work unit			

**Thank you for your time!**

**To be filled in by the interview operator (O)**

O1. Name of the Organization \_\_\_\_\_

O2. Location for the application of the questionnaire

- a. Association headquarters
- b. Hospital
- c. Respondent's residence

O3. Time period for questionnaire application \_\_\_\_\_  
(minutes)

## ***Appendix 2: The informed consent for participation***

- **Which is the purpose of the research?**

We invite you to participate in a research which aims to evaluate the access to treatment for individuals with HIV/AIDS in Romania, by describing the magnitude of treatment disruptions during 2010 and the beginning of the current year.

- **Who will participate in the research?**

Seropositive individuals from all around the country, undergoing ART therapy, aged 15 years or above. The questionnaires are applied with the help of non-governmental organizations, members of UNOPA/ NOUAIP [National Organizations Union for HIV/AIDS Infected People], The Romanian Association Against Aids (RAAA) and the Foundation Close To You (Alături de voi).

- **What am I expected to do?**

Participation in the research involves answering several questions from a questionnaire. Please make sure to answer all questions, answers are not considered correct/incorrect.

- **How much time does it take?**

The completion of these questionnaires takes approximately 30 minutes.

- **What will you do with the accounts I am to provide?**

The aim of this research is of contributing to the general unlimited access to treatment, special care services and support of people with HIV/AIDS from Romania. Your name will not be associated with the answers you are to provide in any document. Your answers are **anonymous**. Moreover, our conversations will be fully **confidential**.

- **What shall happen if I change my mind?**

Participation in this research is voluntary. You are free to change your mind at whatever moment. There will be no penalty or sanction if you wish to leave the research.

- **Can I be informed on the findings of the research?**

If you wish to be informed on the findings of the research or if you have any other questions linked to your participation in the research, do not hesitate to call us at:

Address:

Phone no.:

- **By your signature below you hereby agree to participate to further discussions.**

I have read/ have been read the whole of the hereby document, which includes information on the access to antiretroviral therapy for seropositive people in Romania.

The written consent is provided in two copies, one for the participant and one for the interview operator.

Date,  
location

Participant's  
signature

Operator's  
signature

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