



# HIV/AIDS, COMMUNITY BASED, AND CIVIL SOCIETY PERSPECTIVES

## A MISSION REPORT ABOUT BULGARIA



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## Map of Bulgaria



## Glossary

AIDS	Acquired Immunodeficiency Syndrome
ARV	Antiretroviral
CBO	Community-Based Organisation
EU	European Union
GFATM	Global Fund to Fight AIDS TB and Malaria.
HIV	Human Immunodeficiency Virus
IDU	Injecting Drug User
MoH	Ministry of Health
MSM	Men who have Sex with Men
NEP	Needle Exchange Programme
NGO	Non-Governmental Organization
OI	Opportunistic Infection
PLWHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
TB	Tuberculosis
UN	United Nations
UNAIDS	Joint UN Programme on HIV/AIDS
UNDP	United Nations Development Programme
USAID	United States Agency for International Development
VCT	Voluntary Counseling and Testing
WHO	World Health Organization

This country mission and the resultant report are a part of an international project, called Aids Action and Integration. It is coordinated by Aides, France, and is primarily funded by the DG SANCO of the European Commission. The mission of the Aids Action and Integration Project is to support the development of local, community-based HIV/Aids Non-Governmental Organisations (NGOs) in Central and Eastern Europe (CEE), especially in the new and future member states of the European Union .

A team of two consultants, Svilen Konov and Dr Maria Georgescu, and an interpreter, Ioni Gavrizi, carried out the work.

Representatives of 5 community-based organisations (CBOs) and NGOs from Sofia and Varna (see Appendix 1 for map of Bulgaria), as well as an UNAIDS representative were interviewed. None of the interviews followed a structured questionnaire but were in-depth, questions were open, following the lead of the respondents. Duration of interviews varied, depending on when a feeling of 'saturation' in the interviewers was achieved. Consultants were changing roles in interviewing and writing down the responses within each interview. Interviews were not recorded, as there were explicit signals on the side of the respondents that this is perceived as a sensitive subject.

This report is an attempt for presentation of the perception of the situation and the perspective of leading PLWHA organisations and to some extent the perspective of limited number of other NGOs, working in the field of HIV/AIDS. However, as a result of the thus depicted methodological framework limitations, the text and the conclusions may have a subjective character, based on interviewers' discernment and respondents individual perceptions biases.

## Baseline statistics

### *General*

The total population of Bulgaria is about 7.8 million, of whom approximately 68% live in urban areas<sup>1</sup>. Bulgaria is classified by the World Bank as a middle-income country with a gross national income per capita of \$2 740 in 2004<sup>2</sup>. Bulgaria expects to join the EU in the beginning of 2007.

Bulgaria's life expectancy at birth is 69.0 years for men and 76.0 years for women. Infant mortality rate is 12.3 per 1000<sup>3</sup>. In 2002, the per capita total expenditure on health was US\$499<sup>4</sup>. Expenditure on health constituted 7.4% of total government expenditure<sup>5</sup>.

### *Health*

The current health care system in Bulgaria roughly copies the UK system. Namely, the first point of contact for medical treatment and care is the general practitioner, who upon need refers the patient to a specialist. All citizens are taxed on a monthly basis with a compulsory national medical insurance fee that varies according to the income of the individual. Students, pensioners, and specific other sub-groups of the population are covered by the national budget. Private medical schemes are also allowed.

### *HIV/AIDS<sup>6</sup>*

By 10.02.2006 the officially registered HIV-seropositive individuals on a cumulative basis were 605. The analysis of the data shows that about 69% of them are men and 31%-women. About 71% are in the age range of 20-39 years. About 40% of all newly diagnosed are 20-29 years old. Major mode of transmission is the sexual intercourse-in about 90% of the cases, 9%- blood exposure and 1% vertical transmission. Among the sexual intercourse cases, the prevailing mode of infection is heterosexual intercourse-in about 85%. The last cases of infections in haemotransfusions were registered in 1996. The total number of registered IvDUs is 33. Only in 2005, however, 13 new IDUs have tested positive, which on its own represents 41% of the total number of HIV-seropositive IDUs. Almost 61% of all the infected individuals are registered in the capital (Sofia)-an absolute number of 200. In other cities and towns the numbers are: Burgas-77, Varna-48, and Plovdiv-47.

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<sup>1</sup> [http://www.undp.bg/bg/pb\\_population.php](http://www.undp.bg/bg/pb_population.php) Last accessed on 15.03.2006

<sup>2</sup> <http://devdata.worldbank.org/external/CPProfile.asp?SelectedCountry=BGR&CCODE=BGR&CNAME=Bulgaria&PTYPE=CP> Last accessed on 15.03.2006

<sup>3</sup> Ibid.

<sup>4</sup> <http://www.who.int/countries/bgr/en/> Last accessed on 15.03.2006

<sup>5</sup> <http://www3.who.int/whosis/country/indicators.cfm?country=bgr> Last accessed on 15.03.2006

<sup>6</sup> <http://aidsprogram.bg/web/hiv-aids/home.nsf/0/E7803A0333E4175CC2256FAC0048A006?OpenDocument> Last accessed on 15.03.2006

## Overview – exploratory mission in Bulgaria – 10-15 october 2005

Our mission focused on the NGOs involvement in the national HIV/AIDS response, the NGOs capacity for GFATM implementation and to identify their needs.

The mission in Bulgaria was carried out by Svilen Konov - EATG and Maria Georgescu - ARAS. In 5 days 10 NGOs were visited, plus UNAIDS and a hospital.

Bulgaria has 390 HIV/AIDS cases since 1987, with a rapid increase of the new cases from 3-10 in 1988 to 50 in 2004. From the region, Bulgaria has the potential for rapid spread of HIV/AIDS.

The main way of transmission is sexual – 91% of all cases, 88% of which are heterosexual, 4% from injecting drug use and 1% from mother-to-child transmission. The ratio men to women is 1,8:1 and currently half of new HIV positives are below 25 years of age; 7% between 14 - 19 years old. It is alarming that the tendency towards an increase of the number of HIV registered cases is accompanied by a rapid increase of STDs, drug abuse, prostitution, migration and all this happens on the background of the existence of communities with low social and economic status.

Bulgaria experienced its first real epidemic of heroin use in the early 1990s, but given the high rates of hepatitis C (50%) and B (20%) among the IDU population tested, it is clear that a substantial risk for HIV spread through needle sharing exists in Bulgaria. There are an estimated 30 000 heroin users in Bulgaria. Ethnographic studies and surveys confirm high rates of paraphernalia sharing and low knowledge about the risks of injecting and prevention. The 10 cases of HIV among drug users are identified in different districts of the country.

The main determinants of the rapid growth of HIV/AIDS infection in Bulgaria are the following: risky sexual behavior; high prevalence of sexually transmitted infections and risky injecting drug use practices. Some of the indirect factors are: poverty, prostitution, drug and alcohol abuse, high (labor) mobility and geographic position of the country.

The HIV/AIDS Component complements the activities of the Government, MOH and MOE, local governments, AIDS Coalition and different NGOs in the country following the National Program for Prevention and Control of HIV/AIDS and other political documents. A broad range of measures and activities are supported by the national budget, GFATM and different international donors (free of charge ART for PLWHA, free of charge HIV/HBV/HCV/syphilis testing, needle and syringes exchange programs, outreach activities for Roma, CSWs, IDUs, local HIV/AIDS policy development, health education programs and materials development, peer education for Roma, CSWs, IDUs and young people, HIV/AIDS prevention, media campaigns).

Since 1990, there has been a political engagement in the answer to HIV epidemics in Bulgaria. The Council of Ministries adopted at the very beginning of the epidemics a series of political documents:

*National Strategy of Prevention and Control of HIV/AIDS and STIs, 2001 – 2007*

*National Programme of Prevention, Treatment and Rehabilitation of drug addiction 2001 – 2005*

*National Health Strategy and Plan of Action 2001 – 2006*

*National Programme "For Children"*

*Agreement with the GFTAM*

The degree of implementation of all adopted policies vary according to the resources allocated and to the capacity of involvement of other actors besides the state.

An AIDS coalition, founded in 2004, by 44 NGOs, has organised several prevention campaigns and information and education activities.

In 1990 Bulgaria started a mass testing system which stigmatised the vulnerable population. Now the test is confidential and more or less accessible, without pre and post test counselling in all the facilities; IDUs are tested in the National Centre for Addictions, treatment opportunities are limited and there is no improvement in the near future, because of the conditions in the health system.

There are NEPs in Sofia, Varna, Plevna, run by NGOs and financed by international agencies (ex: OSI, as a component of the health program for rroma, NGO Initiative for health, Sofia). The UNDP/UNAIDS report shows a decrease in the behaviour of common use of injecting equipment, an increase in the information about risk behaviours and a decrease in the resistance of public authorities regarding cooperation with civil sector.

The MoH opened a sexual health clinic, in a hospital, which assists persons referred by other NGOs offering services for vulnerable groups. It includes a sexual education centre and a clinical centre for STIs. The tests used there are rapid tests and the result is given at the central laboratory.

The NGO Gemini organizes education activities in bars and discos for MSM and they also have a counseling telephone line.

The Health and Social Development Foundation has a mobile unit that offers outreach activities, needle exchange, education, referrals to testing services and treatment. They work in two Roma communities and in partnership with other service providers, the police, the MoH. They are members of Tampep.

The Initiative for Health Foundation has outreach activities, with a mobile unit for CSW, rroma, IDUs; it has developed exemplary relations with the local police. They have three teams composed of professional staff and volunteers.

There are four organizations of PLWA, among which Kaspar Foundation, Plus Minus Fondation.

GFATM has been implemented since 2003 and it will continue until 2008. The main recipient is the MOH and the coordinator is Mrs Tonka Varleva, a person everybody mentions but who is impossible to be found on the phone, so impossible to meet. From the stories told us by the NGOs we visited we drew the conclusion that there is no transparency in the process of GFATM administration, the contracts with the NGOs are short term ones and at the GFATM discretion, their value is confidential and cannot be made public. The NGOs that complain or express their disagreement are replaced with other NGOs. It seems there are two types of NGOs. The "true" ones, that work and fight for the certification of the services' quality, for adequate funding, for public recognition and, therefore, for a real and dignified partnership with the public institutions, have external funding and less money from the GFATM, because they are not "eligible".

Other NGOs, born from public institutions or still existing inside these institutions, are not very active and representative at the local level, but are well known abroad, as they participate in conferences and networks; they have money only from the MOH, GFATM, do not fight for something in particular and seem somehow satisfied.

UNAIDS is present, but they do not work with NGOs, the only exception are the organizations of PLWA, with whom they are now trying to make a partnership that also includes the EATG.

Even if, in fact, all the NGOs are members of the CCM, they are not informed about how the funds are allocated, they know nothing about the audit that was supposed to take place at the end of phase 1 and they have no idea about how the resources are going to be used in the next years. The only person to know all these is Tonka Varleva!

## Financing

### Treatment and care

The financing of treatment and care, in this respect purchase of antiretrovirals (ARVs), monitoring assays, and supporting the medical infrastructure of the HIV/Aids ward in Sofia, is done by the MoH from the national budget. Certain equipment for the ward and laboratories is purchased with funding, provided by the GF programme. There are no 'out of pocket' patients' expenditures on buying ARVs. However, patients with 'mild to moderate' health complaints that do not need an immediate check-up by a HIV specialist need to contact their GP for advice and care.

At the same time, part of the HIV-seropositive individuals are unemployed and regardless of that, not on social benefits, as they do not qualify. In addition, there are sub-populations of low-educated, marginalized, based on ethnic background, life patterns, sexual behaviour, gender, etc., or PLWHA who choose different life-style. Part of the above-mentioned do not participate in the compulsory health insurance and, therefore, do not have an access to a GP. Paradoxically, they have access to treatment for their HIV-infection, but when it comes to manageable at place of residence opportunistic infections (OIs) or HIV-related symptoms, patients need to travel to the specialized ward in Sofia, as only there they can receive free help.

Apart from that, if the patient participates in the national health insurance scheme, this does not necessarily mean that he/she has disclosed their status to the GP. Consequently, often they do not obtain adequate medical care, and in some cases this situation may jeopardise the health outcomes for them, as certain drug interactions between the prescribed for the OI and ARVs, invasive operations, etc. are not avoided.

The treatment of opportunistic infections is currently covered with resources from the Global Fund project. The programme, supported by the GF, was financed for all its activities with US\$ 6 894 270 for the period of 2003-2005 and US\$ 8.8 million for 2006-2008.

According to interviewed, however, often when the OI is treated locally, they do not have access to the medications bought and kept in the HIV/Aids ward in Sofia, hence they are forced to buy their own.

The travel expenditures that every HIV-seropositive individual incurs as a result of the fact that he/she needs to travel to Sofia (every month if on treatment) or since lately to Plovdiv or Varna, in some cases are covered by the local municipalities. Although, there is no consistent practice or regulation and currently this issue is left to the discretion of the local administration.

## **HIV testing**

Certain amounts of the testing, performed in the country are also financed by the GF programme in 15 offices, especially opened for the purpose. People can have a test on a paid basis also in almost every clinic in the country, as well as in private laboratories. Some NGOs that provide testing service are financed partially or fully by international donors.

## **Prevention**

Major safer sex messages mass campaigns for particular dates (1 December, Valentine's day) tend to attract diverse donors. In this respect: MoH, UNDP, representatives of the public and private commercial sector, media, CBOs, NGOs.

Targeted, daily, throughout the year prevention campaigns, harm reduction via NEP included, are a subject of funding by a limited number of donors-mainly the GF programme and some international NGOs. According to some of the interviewed, even production of leaflet on an independent from the GF basis is deemed difficult to impossible.

## **Services for IDUs**

Medical treatment of dependencies, as well as substitution therapy, is covered by the national budget. International or local independent donors fund the work of several communes or other types of provisional therapy. NEPs, where existent, receive financing from the GF programme and international bodies. Their funding is becoming increasingly difficult as a result of changes in the Bulgarian legislation and the resultant current criminalised drug use.

## **Social care for PLWHA**

Ideally, financed by the National Insurance Institute, but often NGOs and local authorities play a role. Interviewed considered certain donations also a part of the social care, especially for the 'socially-weak' sub-population. Donations, mainly material, are provided inconsistently, and more on an 'one-off' basis by either private donors, or international NGOs.

## **CBOs' activities**

Predominantly funded by the Global Fund programme. Only Plus and Minus Foundation in Varna has a treatment information programme, partially sponsored by international donors.

## Treatment education and capacity building

The education of medical professionals in the field of HIV/AIDS is a task and responsibility of the national institutions and, therefore, is covered by the national budget via the Ministry of Education. At the same time, special educational seminars for GPs are provided via the GF programme. Medical specialists are trained in VCT also via the same programme.

Educational programmes and seminars from for and via the community of PLWHA are organised entirely and only by CBOs using funds obtained from UNDP, international donors and the GF programme.

Generally, the total amount of financial resources spent per year on the above HIV/AIDS activities is difficult to calculate, as the financing is multi-sectorial and for some of the activities obtained on an ad hoc basis. The GF programme, however, is clearly the major donor. All respondents expressed explicit fear about their future and the future of the work in the field of HIV/AIDS after the GF funding finishes. All they were convinced that not enough is being done to ensure the sustainability of the structures and activities by financing it via local donors. In addition, an apparent concern about the power dis-balance that is produced by the fact that the MoH is the main recipient of the financial resource, provided by the GF and the main donor for the CBOs and NGOs of other types at the same time, was expressed. Anxiety about changes in activists' axiology was vocalised within the existing discourse.

## Sites visits

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### The hope against AIDS

President : Bojidar Georgiev – [hopehiv@abv.bg](mailto:hopehiv@abv.bg) tel 359886066148

Objective: advocacy for access to treatment for PLWA in the very centralised Bulgarian medical system. Because the only hospital for HIV is in Sofia, PLWA from Bulgaria need to have at each 2 months a medical check-up and because the transportation is not covered by social insurance this association provides financial support for the trip and help for treatment transportation at home.

80% of the PLWA keep secret the diagnostics from the family doctor, 90% of PLWA are retired.

The association is not happy with the legislation and their effort to advocate for human rights is not well recognised by the national authorities and they are not invited in the public consultation regarding the legislation change.

There are 5 staff members, the funds are now from GFATM and from international cooperation – EATG. Nr. of beneficiaries – 60.

The testing is available but only in the towns where there are centres. They use also rapid tests and the results are given by the hospital. In general, the general practitioners do not recommend the HIV test.

80% of the PLWA are on ARV .

The PMTCT is in place in Sofia.

The relationship with GFATM is not very good, and in the CCM there is only one PLWA. Nobody asks them about their needs and none visited them. They know very little about the second phase of the GFATM, because of the lack of transparency .

They believe there are NGOs preferred by the Government, with preferable access to funding.

Recommendation:

- it is necessary to become member into a network to be powerful
- external pressure is best accepted by the government (UNAIDS has the same attitude as the MOH)

#### **UNAIDS - national representative**

Manoela Grozdanova – UNAIDS Programme Director, [manoela.grozdanova@undp.org](mailto:manoela.grozdanova@undp.org)

She is an observer in the CCM and activates in the first AIDS inter-ministerial commission.

NGOs are involved but not enough, because the selection of their representatives is very difficult. The selection process needs to be developed.

GFATM has no projects for MSM.

UNAIDS is not working with vulnerable population.

The PLWA, municipality and local authority are the priorities. A leaflet for VCTs will be made soon.

For 2006 the key areas are capacity building and advocacy for PLWA in order for them to be more involved in the national AIDS response.

UNAIDS is a mediator between CBOs and media; training for media will be organised .

#### **Association Sante sans Frontieres**

Dr Anna Kostova-Konstantinova, medical coordinator, tel 35929523399

The former Medecins sans frontiers, now Cooperation Suisse, who is the main donor.

The GFATM provide tests but no treatment.

Obj; STIs prevention

Sexual education

VCTs

STIs treatment

STIs and sex education in orphanages

In 6 months 545 tests reported to the central data base.

There are a lot of beneficiaries from CSWs and there are big problems with sustainability.

Recommendations

- to be member in an international network
- to receive from ARAS the manual (English version)

### **Initiative for Health Foundation**

Elena Yankova, executive director, [sofianep@online.bg](mailto:sofianep@online.bg)

Obj. HIV prevention for IDUs, roma population and PLWA

900 beneficiaries, mobile unit and a working car; the HIV, Hep B/C tests – 30 % have back the results

17 staff members: social workers, nurses.

GFATM and PSI in complementarity.

CCM members. They are the best in outreach.

For the IDUs there few alternatives: detoxification hospital, with 14 beds, including methadone.

The substitution public programme: 300 places, with priority for pregnant women and PLWA.

There are 2 private centers – 150 leva /month plus 300 leva for acceptance, 24-30 mg pills (meta-addict) or subutex - 300-400leva/month.

The funds are from more sources, GFTAM is not the main one.

The same project in other 9 cities.

In Sofia the nr of IDUs is 10000, out of which 3600 are beneficiaries of the project.

The heroin is very bad quality and very expensive.

Better and cheaped quality in Plovdiv.

No official info about overdose.

The HR in prison is not implemented in the framework of GFATM , 111 HIV test made and 3 HIV+.

Complaints: the regular donors leave because of the GFATM .

### **Kaspar Hayser Foundation**

Ivailo Kalcev [Kaspar@bgnet.bg](mailto:Kaspar@bgnet.bg)

Objective: social support for PLWA ; legal rights, treatment in the home city.

Staff: psychologists, social workers, nurses

They made partner notification, cover 80% of PLWA

Project with OSI for patient and human rights

Member in GFATM.

An individual treatment history book was translated, with support from EATG

## ANNEX

This table contains the prices of the available drugs in Bulgaria for 2005.

Fuseon available as donations

Drug		Daily dosage	Needed caps/tabl per month	Price per unit in EUR	Cost of a treatment in EUR		
					per month	per year	
1. Ziagen 300mg*60	Tabl	2*1 tabl	60 tabl	3,82	229,20	2750,40	
2. Retrovir 100 mg*100	Caps	2*3 caps	180 caps	1,50	270,00	3240,00	
3. Combivir*60	Tabl	2*1 tabl	60 tabl	4,97	298,20	3578,40	
4. Zerit 30 mg*56	Caps	2*1 caps	60 caps	4,14	248,40	2980,80	
5. Zerit 40 mg*56	Caps	2*1 caps	60 caps	5,52	331,20	3974,40	
6. Stocrin 200 mg*90	Caps	1*3 tabl	90 tabl	1,49	134,10	1609,20	
7. Fortovase 200 mg*180	Caps	3*6 caps	540 caps	0,91	491,40	5896,80	
8. Fortovase 200 mg*180	Caps	2*8 caps	480 caps	0,91	436,80	5241,60	
9. Fortovase 200 mg*180	Caps	2*5 caps	300 caps	0,91	273,00	3276,00	Boosted with Norvir 2*1 caps
10. Fortovase 200 mg*180	Caps	2*2 caps	120 caps	0,91	109,20	1310,40	Boosted with Norvir 2*4 caps
11. Crixivan 400 mg*180	Tabl	3*2 tabl	180 tabl	0,85	153,00	1836,00	
12. Crixivan 400 mg*180	Tabl	2*2 tabl	120 tabl	0,85	102,00	1224,00	Boosted with Norvir 2*1 caps
13. Crixivan 400 mg*180	Tabl	2*1 tabl	60 tabl	0,85	51,00	612,00	Boosted with Norvir 2*4 caps
14. Invirase 200 mg*270	Caps	2*5 caps	300 caps	1,07	321,00	3852,00	Boosted with Norvir 2*1 caps
17. Invirase 200 mg*270	Caps	2*2 caps	120 caps	1,07	128,40	1540,80	Boosted with Norvir 2*4 caps
18. Kaletra *180	Caps	2*3 caps	180 caps	3,04	547,20	6566,40	
19. Viracept 250 mg*270	Tabl	3*3 tabl	270 tabl	1,07	288,90	3466,80	
20. Viracept 250 mg*270	Tabl	2*5 tabl	300 tabl	1,07	321,00	3852,00	
21. Nevirapine 200 mg*60	Tabl	2*1 tabl	60 tabl	3,65	219,00	2628,00	
22. Norvir 100 mg 4*84	Caps	2*1 caps	60 caps	1,38	82,80	993,60	Boosting effect
22. Norvir 100 mg 4*84	Caps	2*4 caps	240 caps	1,38	331,20	3974,40	Boosting effect
23. Norvir 100 mg 4*84	Caps	2*6 caps	360 caps	1,38	493,20	5918,40	

24. Eпивir 150 mg*60	Tabl	2*1 tabl	60 tabl	2,71	162,60	1951,20	
25. Trizivir * 60	Tabl	2*1 tabl	60 tabl	7,41	444,60	5335,20	
26. Videx EC 250 m g*30	Caps	1*1 caps	30 caps	5,93	177,90	2134,80	
27. Videx EC 400 mg*30	Caps	1*1 caps	30 caps	9,48	284,40	3412,80	
28. Fuzeon			60	31,27	1876,20	22514,40	Not available!!!
29. Viracept fl.				38,84			
30. Retrovir fl.				30,02			
31. Eпивir fl.				49,29			

**N.B:**

1. The registered price for Reyataz:

Reyataz 150 mg	528,28 EUR per pack
Reyataz 200 mg	588,16 EUR per pack

2. Stocrin 600 mg:

Information from the local MSD office.

3. Telzir:

4. Kivexa:

Information from the local GSK office.

6. Viread:

7. Emtriva:

8. Truvada:

9. Viracept 625 mg:

Further investigation.

10. Invirase 500 mg: