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The Russian HIV/AIDS Case Reporting System

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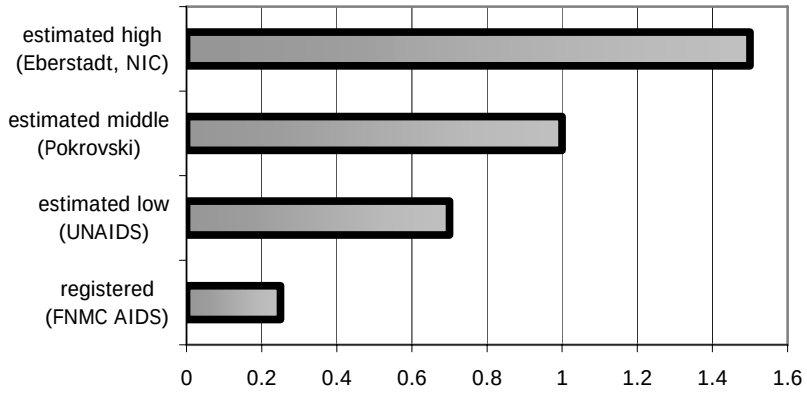
The first AIDS[1] cases were recorded in the early 1980s. The disease was spreading at a fast rate, with its death toll growing, and has developed into a serious challenge to the national healthcare systems and the entire world community. For some time Russia was spared from the epidemic, the first case of HIV infection was registered in 1987. But further developments turned out to be unfavorable for Russia, and some sources describe the national epidemic as the fastest all over the world.

The paper depicts the national HIV/AIDS case reporting system, the tool able to perceive perhaps the fastest HIV expansion, its structure, functions, history (Appendix 1), current situation and probable future development of this system. I wrote it to introduce a European demographer a source of data on commencement and development of one of the merciless modern diseases, which has profound demographic and social impact.

Why?

An effective national response to HIV/AIDS epidemic is a challenge for many countries of the world, and Russia is no exception. It is better to build the HIV/AIDS policy on a solid ground of on an adequate risk assessment. The size of the epidemic is number one priority of this assessment, but the consent on the size of HIV/AIDS epidemic in Russia does not exist. There is an apparent contradiction between the registered and the estimated numbers of HIV+ cases in Russia, see pic. 1. There is some rationale in favor of each approach. While the registration speaks for itself (in this paper), the justification of estimates remains unclear and intuitive in many cases. Risks' understatement as well as their exaggeration could mislead individual, societal, and governmental response to epidemic.

Pic.1 Registration vs. estimates



In 2002[2] different estimates of a number of HIV+ in Russia stretched from 0.7 to 1.5 mln, while the registered number was .25 mln

[1] For abbreviations see Appendex 4

The existing HIV/AIDS surveillance system in Russia had been built basically by the Soviet Union according to the principles prevalent at that time. Transparency was the last one then taken into consideration, this approach remains in tact in current Russia. The adequate appraisal of epidemic presumes the evaluation of the completeness of the existing registration system, and, in case of revealing an undercount, the evaluation of its size. Whatever its possible source(s) and a size of undercount, the counting tool itself must be understood.

No comprehensive overview of the descriptive HIV epidemiology has been done in the Russian Federation since the epidemic became evident. This paper is one of the first steps of the ongoing activities of nonmedical research community aimed on epidemic size appraisal. It mainly formulates questions and problems for the future solutions.

Data

Although the advocacy groups are rather noisy, and an HIV/AIDS issue widely occupies media, the *real politik* usually goes in a shadow well beyond the public lights. This paper is an attempt to distill the evidence from a number of heterogeneous documents, which includes orders of the Ministries of Health, and other government agencies, laws, instructions, etc. The major idea behind this work is: to understand how does the Russian system of HIV/AIDS epidemic surveillance work? The documents for analysis had been selected from *Гарант,* one of the most reliable national data bases on law and legislation. The full text search string was "*СПИД*"[3], which returned more than sixteen hundred various documents. Then the documents which appeared irrelevant had been removed manually to make a short list (Appendix 1 represents this short list chronologically). I am sure the list is not exhaustive, and *Гарант* seems does not contain some earlier documents, concerning the very first steps of newly established system. To reimburse this shortage of information I got in touch with M. I. Narkevich, currently the president of nongovernmental union "MedAntiAIDS", who then was a focal person of erection the system under consideration. In 1985 (the date of the very first document) he was a deputy head of the SU MoH quarantine infections' administration. I am very grateful to Dr Narkevich for his helpful consultations and very interesting narration.

Twenty six issues of Federal Research and Methodological Center on HIV prevention and AIDS control (FRMC AIDS) bulletins constitute an output of the working system, till now they are the only accessible genuine regular quantitative data on epidemic in Russia. Some data come from Russian Agency on Statistics.

The system

The very first document of a new system (1985, June 10) formulated the procedure of *urgent dispatch*[4] about a revealed AIDS (or AIDS suspicion) case:

Revealing the patient, suspicious on AIDS, a doctor of a medical institution[5] is obliged to inform the head doctor of the institution. The head doctor of establishment where the suspicious on AIDS patient is revealed should inform immediately about such a case the

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[2] It is the year of the first research project in HIV/AIDS, which included demographers' participation

[3] СПИД is Russian equivalent for AIDS. The term have apeeared earlier than HIV, and HIV/AIDS which seems like a single word now

[4] I am not sure if *urgent dispatch* adequately translate the style of this term in Russian. In Russian it is very hierarchical in a military sense.

[5] In this case *institution* means any medical establishment

Ministry of Health of a union republic[6] which in turn inform central administratiion of quarantine infections of Ministry of Health of the USSR by phone 221-34-81 or *ВЧ*[7] 58-955 (round the clock), in the order determined for urgent dispatches (the order of Ministry of Health of the USSR #1025 of 4 August 1984) and Institute of immunology of Ministry of Health of the USSR (Moscow, Kashirskoye shosse, 24, building 2, phone #: 111-83-33, 111-83-30, 114-51-35).

Perhaps it is not the very first document devoted to AIDS, and it appeared four years after the very first AIDS publication in *Morbidity and Mortality Weekly Report*. Despite a well known slowness of the Soviet Union, in case of HIV/AIDS its reaction was rather quick. The Soviet health-care system took immediate steps to combat the impending AIDS threat. A well-developed recording system was set up quite rapidly. The collapse of the USSR remained this system unaffected, and now Russia is one of a few countries that have HIV and AIDS data collection based upon *direct observations* of cases of infection and disease. The direct observation is either a positive result of an HIV test, or a case of AIDS diagnosis. A reader may wish to see a respective document, namely the form of this observation, which is placed in Appendix 2. Since till now the HIV+ cases greatly outnumbers the amount of AIDS cases the document by default refers to HIV+ case.

The newly appeared system is sufficiently a joint replica or a blend of the already existed Soviet systems of (1) epidemic and (2) veneral diseases' control, which proved of being effective, despite their inherent violations of human rights. The created system also performs successfully, and seems did the only mistake, which in its turn seems unavoidable.

What was the mistake? The Soviet AIDS control defined the major peril incorrectly. The world available experiences made it expect troubles mostly from unsafe sexual contacts, especially from those persons who arrived from abroad. The danger stemming from drug use had been seriously underestimated. Few individuals in the first half of 1980s had been able to foresee coming soon disintegration of the Soviet Union, even fewer could be able to report such an analysis before Soviet authorities. Those able to do so definitely were not employed by the SU MoH. Anyway now it is hard to imagine an alternative development: the survival of the USSR with its tightly closed borders, no massive penetration of illicit drugs into a population of about 250 mln in size, and thus no epidemic explosion observed at a millenia shift.

There are three basic principles of HIV-infection epidemiological control system created by the Soviets and working in the Russian Federation now:

- Very wide population screening to detect HIV-infected persons, using both obligatory and voluntary testing;
- Unified state registration of all HIV and AIDS cases, changes in the physical condition of HIV-infected people and all tests made for HIV antibodies;
- Obligatory epidemiological investigation of each case of HIV infection;
- The federal law regulates the above activities (this fourth basic principle appeared by the end of the Soviet Union[8]).

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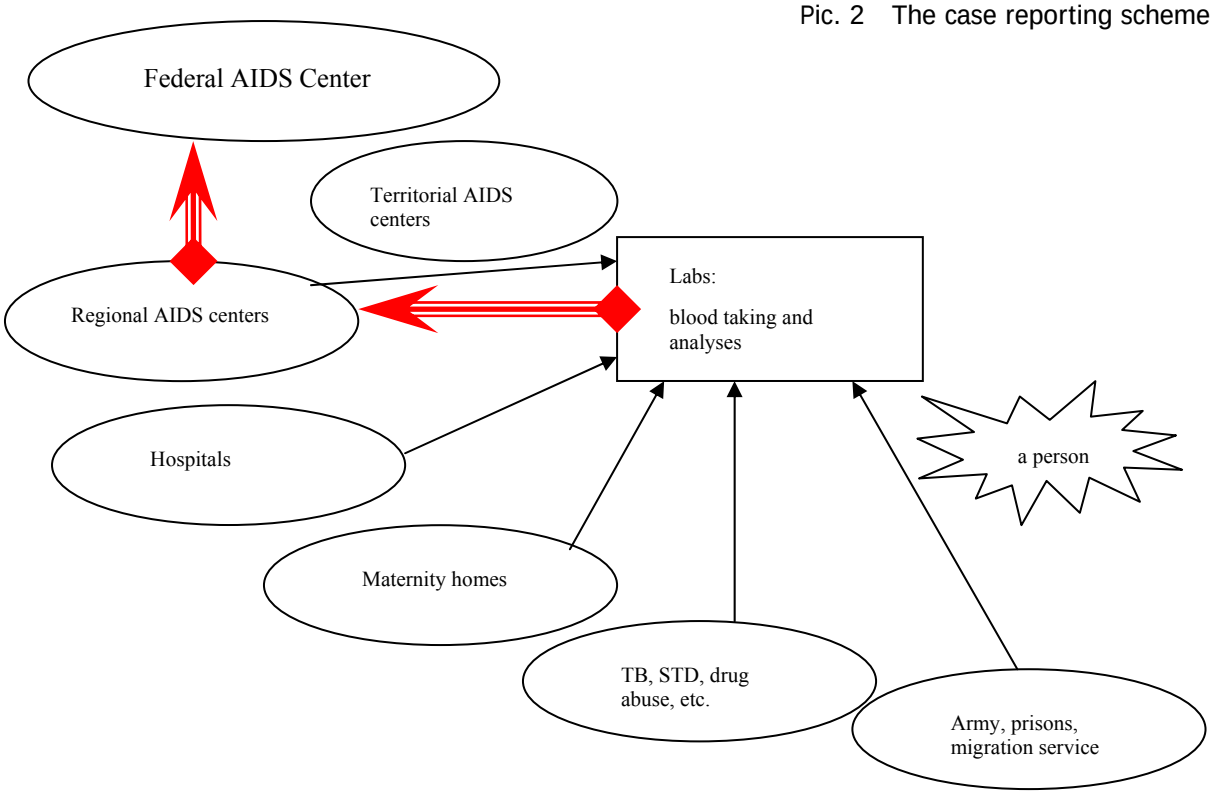
[6] The Soviet Union consisted of fiveteen republics, e.g., Ukrain, Gruzia, Belorussia, etc.

[7] *ВЧ (вертушка, vertushka)* is a special communication network – a secure telephone line with a limited access provided for top Soviet and communist party officials only. The use of this line reflects the priority level assigned to AIDS issues as well as serious worry of them.

[8] The Soviet Union's law on AIDS, consummated on January 1, 1991, had a short life, this same year the USSR was over, and Russian law came in 1995.

The Federal Research and Methodological Center for HIV Prevention and AIDS Control[9], a subsidiary of the Federal service on surveillance in sphere of protection of the rights of consumers and human well-being[10], maintains the data base of all cases of AIDS, HIV infection and tests for HIV. These data come from the territorial and regional centers for AIDS prevention and control which encompass the entire territory of the country. Each year a vast number (more than 20 mln) of HIV tests takes place. Slightly less than twenty per cent of population is tested for HIV. The number of tests for HIV per 1,000 of the population in Russia is greater than in any other European country (Table 2).A blood taking (making of a test) is regulated by Russia's law with specifications in several by-laws.

Pic. 2 The case reporting scheme:



In the scheme above ellipses and rectangular depict major components of institutional part of the system which performs both voluntary and obligatory tests, a splash represents an informal and voluntary part. To perform a test of a person's own free will (s)he usually visits a nearest health care outlet which sends a taken blood sample to a lab to perform the test. In case the test result is positive the dispatch about this event goes to FRMC AIDS, but it is not entered into data base if nothing is known about a carier. A carrier him/her self either remain his/her anonimity, but if s/he expect to obtain a professional help s/he contacts an institutional part of the system making him/her self visible (repeats the test), and thus registered in the data base.

Under *Russian* legislation, there are two categories of persons who are subject to obligatory medical examination to detect whether or not they are HIV-infected:

1. blood, other biological fluid, organ and tissue donors, and

[9] In fact the Federal Research and Methodological Center for HIV Prevention and AIDS Control is a part of the Institute of Epidemiology which belongs to the system of Federal service on surveillance in sphere of protection of the rights of consumers and human well-being, i.e., the intstitute's budget comes from this service.

[10] It is a new name of sanitary part of the former Ministry of Health, the head of this service is Dr Onishchenko whose title is the main sanitary doctor of RF.

2. the personnel in certain occupations and of the businesses, institutions and organizations whose work involves direct handling HIV-infected people (for example, medical examination and treatment) or the materials containing this virus.

Several by-laws *extend* the practices of the law. Perhaps *extend* is a wrong word, actually the role of these by-laws is to justify or legalize the practice which already exists.

The prisons' populations, the personnel of obstetric and gynecologic hospital departments, the military college applicants, the persons intending to serve in the army on a contract basis, those applying for Russian citizenship, and foreign citizens intending to stay in Russia for more than three months are also subject to obligatory medical examination in order to define their HIV status.

In addition to that, the patients who show several clinical symptoms indicating that they may be HIV-infected and the patients suffering (or being suspected ill) from various diseases such as drug abuse, STDs, Kaposi's sarcoma, pulmonary or non-pulmonary TB, hepatitis B and some other illnesses also ought to be tested for HIV.

The pregnant women are tested for HIV, should they perform the abortion and placenta will be gathered to manufacture an immunobiological drug.

Each of the above extensions was introduced by special government decree or order of Ministry of health, but not by law, i.e., their legal status is lower. As a matter of fact, the medical and other services (performing HIV surveillance[11]) frequently violate the legislation towards enlarging the number of those tested. The most common law violation is a widespread practice of HIV test being an obligatory condition for any admission to a hospital. Virtually all pregnant women are tested for HIV, and in some cases such tests are made repeatedly, and these are not the only law violations.

Table 1. Number of tests in specific subpopulations, 1999 and 2003

Subpopulation	1999	2003
Drug abusers	357 950	279 509
Homo and bisexuals	15 895	8 056
Having STD	1 739 964	1 447 066
Having irregular sexual contacts (promiscous)	90 571	-
Being abroad	71 681	-
Donors	3 830 728	3 811 675
Pregnant	2 491 545	3 080 896
Blood products' recipients	2 550	-
Military servicemen	3 792	-
Prisoners	833 071	606 265
Clinically suspicious :		
Adults	5 929 910	4 996 507
Children	59 196	-
Home or medical contacts with PLWHA	160 059	228 291
Other	6 365 419	7 007 888
Anonymously tested	62 134	-
Revealed in course of epidemiological investigation	21 993	75 263
Citizens of Russia	22 036 458	21 541 416
Foreign citizens, arrived for more than three months	69 142	358 884
Total	22 105 600	21 900 300

[11] In addition to routine medical services police (*militsiya*) gives directions to blood taking, particularly for IDU and CSW.

In 1999 the rules of publishing had somewhat changed: five categories had been removed from the set of subpopulations due to very low previous HIV incidence. The respective numbers in italics in the above table are half year figures.

Table 1 is a routinely published table which reflects the origins of the system under study. Tabulation of such a category as *having irregular sexual contacts (promiscous)* reflects the mistrustful paternalist *modus operandi* of the Soviet state, which ideologically enforced the epidemiological mistake (wrong forecast), mentioned above. *Being abroad* mirrors the overall Soviet suspiciousness.

The Russian system of recording and surveillance has its advantages against the respective systems in other countries, where HIV-related statistics give mainly national estimates based on the results of the sentinel epidemiological surveillance conducted, as a rule, by some of the medical institutions. The number of tests for HIV per 1,000 of the population in Russia is generally much greater than in other countries (Table 2).

Table 2. Number of tests for HIV in 2001, selected countries of WHO Europe

No.	Country	Number of tests per 1,000 of the population	No.	Country	Number of tests per 1,000 of the population
1	Russia	135.1	15	Azerbaijan	16.4
2	San Marino	134.8	16	Slovakia	15.4
3	Austria	72.0	17	Moldova	15.1
4	Byelorussia	49.0	18	Malta	13.9
5	Kazakhstan	44.7	19	Uzbekistan	13.7
6	Norway	38.6	20	Turkey	12.5
7	Latvia	38.3	21	Slovenia	9.8
8	Luxemburg	37.6	22	Lithuania	7.6
9	Estonia	35.4	23	Croatia	5.3
10	Israel	31.7	24	Georgia	5.2
11	Czechia	28.3	25	Tadjikistan	2.1
12	Finland	28.0	26	Armenia	1.3
13	Denmark	24.2	27	Macedonia	1.2
14	Ukraine	22.7			

Source: European Centre for the Epidemiological Monitoring of AIDS. HIV/AIDS Surveillance in Europe. End-year report 2001. Saint-Maurice: Institut de Veille Sanitaire, No. 66, Table 21.

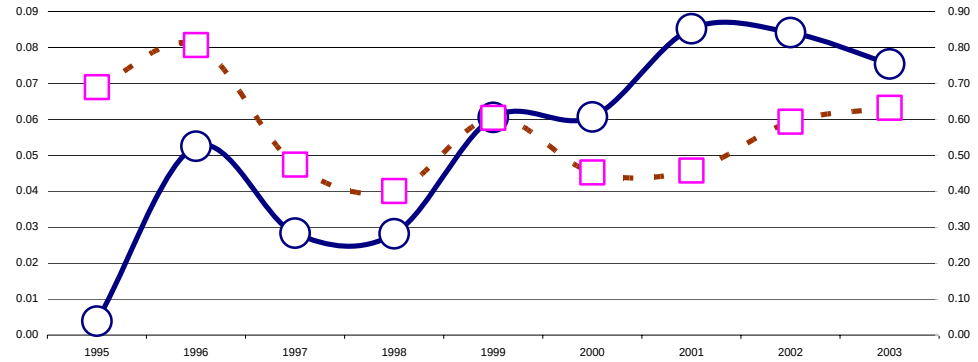
Of the twenty seven countries given in Table 2, thirteen are ex-Soviet republics, another five are the former «socialist countries». Other countries provide EuroHIV no data on tests. One could assume that massive screening reveals socialist approach to health policy in area of HIV/AIDS.

The AIDS control system, established in mid 1980s, followed the structure of sanitaria's section of the Soviet public health system[12], i.e., sanitary epidemic station, a major unit of this system was (and is now) subordinated (reports before, or sends an urgent dispatch) to an upper level unit of this very system, but not to local authorities. Moreover, a local sanitary epidemic station may punish respective local authorities and even must do it in case they do not fulfil station's recommendations or ignore them. From curative medicine, to put it more precisely from the system of dealing with STDs the new system borrowed an idea of epidemiological investiation, and even law enforcement of this investigation.

[12] Unlike sanitaria's section vertical configuration, the curative medicine had been stuctured more horizontally (with few exceptions), and hospitals and policlinics had been subordinated to local/regional authorities.

What does it mean? An STD infected person being under traetment at STD dispensary provides a doctor the information about his/her sexual contacts. Then this doctor claims those persons and examine them, including blood testing. In case a person indicated by the patient avoids to visit the STD dispensary, the doctor report this to a respective police station which provide a support to doctor's claim. There is definite violation of Hippocratic Oath in this situation[13]. Whatever the humanitarian dimension of the issue, the system worked with STDs and it proved to work with AIDS and HIV. The obligatory epidemic investigation is the most effective method of revealing HIV infected. Epidemiological investigations give about a half of HIV+ cases.

Pic. 2 Some indicators of obligatory epidemiological investigations (explanation in text below)



The above picture depicts the probability of success of the obligatory epidemiological investigation (i.e., disclosure of an HIV carrier who was a source of infection), or number of positive tests divided by the total number tested (solid line with circles and left vertical axis), and the proportion of positive tests in course of epidemiological investigations among all positive tests (dotted line with squares and right vertical axis). For the period of available data (1995-2003) these are the greatest values among all subpopulations listed in table 2 for each year except for 1998, when the anonymous testing demonstrated the maximum of 0.0318.

As I have mentioned above, the development of the system in the period of new Russian democracy since 1991 is a series of adjustments of a SU law adopted in 1990 to the reality, which seems remaining stronger than the law. Moreover the Soviet law of 1990 paid more respect to human rights than does the new democratic Russia.

Epidemic Dynamics

The epidemic in Russia has about twenty years' history. By the end of 2005 there are about a third of million HIV-positive people living in Russia. A half of them had been infected in a relatively brief period between 1999 and 2002 (see Table 3 and a picture below). The virus penetration into drug users' community and unsafe practices herein explain the fast growth or genuine exposion of that period. On average 4630 new HIV+ cases were registered monthly in the period of epidemic blast, before 1999 in the period of virus infiltration mean monthly number was about 75 (62 times greater), and it is about 3244 after 2002 (thirty per cent drop) notifying the saturation of epidemic. It seems like HIV epidemic in Russia is repeating the way of other epidemics: slow, warming up start, burning explosion, saturation (currently), and very much expected decay (hopefully in the near future).

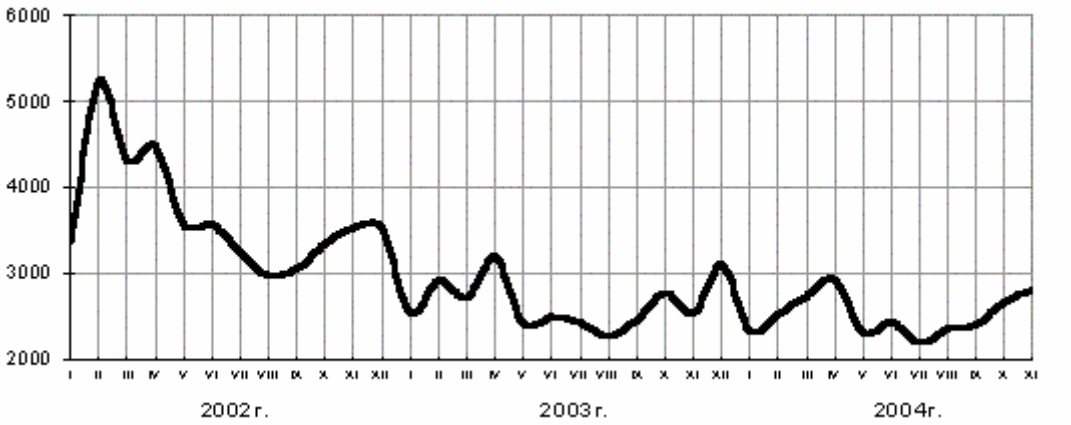
[13] In 1971 the oath of the Soviet doctor took the place of traditional Hippocratic/Asclepiades' Oath (which also did not work before in lots of cases), the main novelty of a new swear was softer relation to keeping patient information confidentially.

Table 3. Stages of epidemic in Russia (registered HIV+ cases)

Cases\Stages	-1998	1999-2001	2002+
New	10 889	166 690	155 753
Cumulative		177 579	333 332

Source: Federal Research and Methodological Center for AIDS Prevention and Control.

Pic. 3 Monthly dynamics of HIV+ cases



Source: www.gsen.ru

Of the total number of those registered by FRMC AIDS, 8 157 HIV-infected persons died. A few of them died of AIDS (about 1/5). Most of the infected people died not of AIDS but of causes not related to HIV infection, such as drug overdose, suicide, accidents, etc. Until now, AIDS deaths are a very small almost invisible portion of the overall mortality.

Table 4. HIV-infected in Russia by main risk factors (MRF), 2004

Main risk factor	Total	Per cent of total	Per cent of known
IDU	10 200	29.7%	68.3%
Homosexual contact	117	0.3%	0.8%
Heterosexual contact	4 472	13.0%	30.0%
Blood transfusion, etc.	4	0.0%	0.0%
Vertical	136	0.4%	0.9%
Known MRF	14 929	43.5%	
Unknown MRF	19 359	56.5%	
Total	34 288	100.0%	100.0%

Source: Federal Research and Methodological Center for AIDS Prevention

Table 5. The shift in MRF structure, 1996 and 2001

Main risk factor	Number of cases		Percent of total		Percent of known	
	1996	2001	1996	2001	1996	2001
Homosexual	95	82	6.3	0.1	7.4	0.2
Heterosexual	121	2807	8.0	3.2	9.4	5.3
Blood transfusion	0	15	0.0	0.0	0.0	0.0
Hospital infection	2	0	0.1	0.0	0.2	0.0
Vertical	1	1076	0.1	1.2	0.1	2.0
IDU	1072	48622	70.8	54.9	83.0	92.4
Unknown	224	35975	14.8	40.6		
Total	1515	88577	100	100	100	100

Source: Federal Research and Methodological Center for AIDS Prevention

Before 1996, the proportions of homo- heterosexual, and hospital infections each comprised a third, with homosexual contact being the main HIV risk factor. At the peak of epidemic unsafe use of drugs embraced more than ninety percent of new cases with known way of transmission.

HIV-Infected by Age and Sex

Table 6. Age-gender composition of HIV+ at the time of testing (1987-2002)

Age groups	Persons		Percentage	
	Male	Female	Male	Female
0-14	3,153	2,750	1.8	4.8
15-19	31,424	14,069	18.3	24.6
20-24	69,909	23,673	40.7	41.3
25-29	38,052	9,448	22.2	16.5
30-35	14,826	3,739	8.6	6.5
35-40	7,172	1,687	4.2	2.9
40+	7,143	1,920	4.2	3.4
Total	171,679	57,286	100.0	100.0

Source: Federal Research and Methodological Center for AIDS Prevention and Control.

Completeness, what for ?

Russian case reporting system has experienced a lot of criticism in many aspects. One of criticism's directions had been wide population screening which revealed HIV positive people that might be stigmatized. Although the aim of the screening definitely was early detection for better and more effective treatment, it was senseless in case of the lack of means of treatment. *Ex post,* an optimism[14], inherent to the Soviet ideology, appears pretty well founded or farsighted and after its death makes tangible returns to modern Russia.

The data already collected encompass the period of epidemic from its very beginning; the continous collection may provide reliable information on disease progression at micro level. This data are particularly useful for forecasting the numbers of HIV+ patients, espected to start the antiretroviral therapy (ART) and thus the amount of ART packages needed. Hence the invention of ART extenuates the seeming absurd previous history of the case reporting systems in Russia and other countries.

FRMS AIDS is very reluctant in providing access to the available data albeit its own analyses are insufficient first of all from the epidemiologic wiewpoint. The data are underused, i.e., do not generate valuable knowledge about epidemic. However, I expect an alternative route to appear soon. Hopefully EuroHIV will finish developing of online access to its data bases at www.eurohiv.org, and at that moment a lucky reader is already prepared to apprehend a Russian portion of EuroHIV data.

Coming future

In the pic. 2 unconnected territorial centers reflect President Putin innovation, a part of so called "administrative reform" in building power vertical. These centers are at a medium level between federal and regional, but as in many other cases the inertia of the system practical work is stronger than administrative novelty – regional centers very unwillingly report before territirial center, and even begin to try to avoid to report to the federal center.

[14] Avoiding unreasonable arrogance, I suppose, that the system had been erected on the default idea of "earlier detect – easier cure", and a belief in an inevitable invention of medicines to cure AIDS and subsequent capabilty of their ample manufacturing certainly is optimism.

Although belonging historically and essentially to the sanitary section of helthcare system, Russian AIDS control is becoming to drift toward curative section with its predominantly horizontal structure. The reason is not only the growth of numbers of AIDS diagnoses and patients on ART which changes the respective volumes of activities, but also the federal government propensity to get rid of expences that might be delegated to a lower administrative levels. If this trend is expanding, Russia will loose the unified national data base of HIV and AIDS cases.

Appendix 1. Time Line

1980, October #1030. The order of the SU MoH #1030 »On forms of primary medical documents in medical establishments» (with lots of ammendments, in 1988, September 5 AIDS forms had been added to this general regulation)

1985, June 10. The order of the SU MoH # 776 “On organization of the search of AIDS diseased persons and monitoring AIDS pathogen in donors” denoted the new disease, with its brief characteristic, the availability of methods to estimate a man immune status which made an AIDS diagnosis possible, defined foreigners and donors as target groups for HIV screening, Moscow and Tashkent were areas of special attention, introduced a vertical procedure of case reporting.

1986, April 18. The order of the SU MoH #539 "Establishments of clinical immunobiology labs" for defining an immune status due to the growth of immine deficiency (twenty labs had been created)

1987, August 25. Presidium of the Supreme Soviet of the UUSR decree # 7612-XI "On measure of AIDS prevention" (ammended 1990, April 24) imposed 5-9 years of imprisonment for transmitting infection to another person.

1987, September 4. The order of the SU MoH # 1002 “On measures of AIDS prevention” introduced the rules of the obligatory HIV testing (Soviet and foreign citizens entering the SU, recipients of blood and its products, homosexuals, drug addicts and prostitutes, those having contacts with HIV+), the punishment for infection of another person (if an infector knew his/her HIV status), provision of the test for those who wish to know their HIV status (voluntary testing). This order had been invoked by the decree of the SU Supreme Soviet.

1988, February 2. The order of the SU MoH and MMBI #65/73 "Improvement in procedures of shipment, purchase, and balance of IFA test systems" required the central budget purchase of test systems

1988, February 10. The order of the SU MoH #91 "On obligatory HIV testing of donated blood" reguired establishment of diagnostic labs on all stations of blood transfusion.

1988, June 1. The order of the SU MoH #444 "On measures to improve the medical certification of persons visiting foreign countries on business and as tourists" requires a result of HIV test of those who was abroad for three months and more.

1988, July 29. MoH Instructon #28-6/26 on the blood collection of donors whose blood contains HBs-antigen (HBsAg), this blood to be used toproduce hepatitis B vaccine, if HIV and siphilis free.

1988, September 5. The order of the SU MoH # 690 “On improvement of account of HIV+ and AIDS cases” defined nine forms of various reports for unified centralized account, including #286/У88.

1988, September 15. The order of the SU MoH # 821 “On measures of enforcement of AIDS control” for the first time introduced world and national data, five AIDS cases, including two citizens of the USSR, 90 HIV cases and 16.5 mln tested (11 mln donors) in 1987-88, both

cases of AIDS had been diagnosed post humously, i.e., HIV/AIDS already had a history in the SU.

1989, March 16. The order of the SU MoH # 173 “On establishment of HIV/AIDS prevention and control centers” obliged each republic of the SU to establish a respective specialized institution; the MoH Institute of epidemiology had been appointed in charge of the centers’ network control.

1989, April 10. The order of the SU MoH # 239 “On organization of HIV/AIDS prevention service” established a special MoH coordinating committee on AIDS prevention, a head/leading center (now federal center), and permitted to established a new HIV/AIDS center in a region if needed.

The order of the SU MoH #438 "On sectoral statistic reports of MoH establishments" confirmed two forms ## 88 and 89 of monthlu reports on the results of IFA tests and availability and use of testing systems.

1989, July 26. The order of the SU MoH #438 appointed the scientific and research institute of epidemiology the head organization on the HIV/AIDS problem, due to establishment of all union center on AIDS prevention and control (now federal center), this order cancelled the previous order of 1984, January 23 (#80), which is yet unaccessible

1989, October 12. The order of the SU MoH # 571 “On changing of HIV/AIDS report provision procedure” in addition to case reporting introduced a monthly summary of IFA tests, and added three new coded items 300 – total persons tested, 400 – total tests, and 500 total of blood takings.

1990, April 23. Supreme Soviet of the USSR decree #1448-I "On the introduction of the USSR law "On AIDS prevention" imposed the responsibility for social security of HIV+ on the government.

1990, November 14. The order of the SU MoH # 442 “On measures of social security provision to PLWHA”, confirmed PLWHA free access to medicines, and a small allowance for families with a child infected.

1991, July 5. The order of the SU MoH # 181 “On obligatory state insurance of the personnel dealing with PLWHA, researchers manufacturers in virology in case of acquiring HIV respective inabilities and death” noting new in terms of epidemic

The USSR collapsed

1994, August 16. The order of the RF MoHMI # 170 “Measures to improve the HIV prevention and treatment in Russia” (amended on 1995, April 18), declared HIV epidemic a national priority, introduced the detailed instruction on HIV/AIDS disease and its treatment

1995, April 18. The order of the RF MoHMI # 100 “On extension of functions of the territorial AIDS centers” (amended on 2000, August 7), added other infections to the subject activities of AIDS centers

1995, March 30. Federal law # 38-ФЗ “On prevention of the disease caused by HIV” (amended on 1996, August 12, 1997 January 9, 2000 August 7, 2004 August 22), adopted by Duma on 1995 February 24, introduced obligatory tests for donors, foreign citizens and some professional groups; established the rights of HIV+ persons, and exclusions: HIV+ may not be a donor, HIV+ foreign citizen must be deported. This law has many additional descriptions and explanations introduced by various types of documents.

1995, September 4. Government decree # 877 “The list of professional groups for obligatory HIV testing at a job beginning and then periodically”.

1995, September 4. Government decree # 877 “The list of professional groups for obligatory HIV testing at a job beginning and then periodically”.

1995, October 13. Government decree # 1017 “The rules of an obligatory HIV test” (amended on 2005, February 1), formalized an already existing practice.

1995, November 25. Government decree # 1158 “On certificate of the lack of HIV for foreign citizens applying for Russian visa” required the ID data on a certificate

1996, July 24. Joint order of MoHMI and SCSEC # 299/220 “On federal program of HIV prevention for 1996-1997 and up to 2000”, served as a model for regional programs (by the way program stated that major transmission is sexual contact, which appeared wrong in the near future)

1997, February 10. The order of the RF MoH # 42 “Comparison of IFA testing systems made in Russia”

1997, August 11. The order of the RF MoH # 238 “The use of IFA tests”, published the results of the above comparison

1998, November 25. Collaborative agreement on solution of HIV-infection problem (signed in Moscow) set up a plan of cooperation in HIV/AIDS prevention and treatment, and declared equal rights for treatment for the citizens of CIS[15], including refusal of HIV- status certificates. Section 6 of the plan promised to develop a computerized epidemiological control package by 2001.

2000, August 7. The order of the RF MoH # 312 “On improving the structure of HIV prevention and AIDS control institutions” according to Putin’s administration reform introduced seven new territorial AIDS centers, their relations with former regional centers (mostly oblast level) remains unclear

2001, July 30. The order of the RF MoH # 292 “The use of IFA tests for revealing HIV in human blood serum”, similar to # 238 (1997)

2002, December 24. Government of Russia decree #923 "The list of foreign and international organizations whose grants are tax free for for Russian organizations, reciepients of these grants" (ammended 2006, January 21), there are 92 items on the list.

2003, January 17. President of RF decree #45 "On the assignment of the status of scientific city to Koltzovo of Novosibirsk region" contains a brief sketch on *Vector,* the major manufacturer of testing systems for HIV and hepatites.

2003, August 4. The indication of the RF MoH # 916-У “Competition of information projects and materials on HIV/AIDS problem”

2003, August 4. The indication of the RF MoH # 1020-У “Seminar on legal issues of standardization molecular biotechnologies in health care”, seminar discussed gene diagnostics of socially important diseases (including HIV/AIDS)

2003, August 15. Government of Russia decree #498 "On the signed agreement between RF and the World Bank on loan for "Prevention, diagnostic, and treatment of TB and AIDS" project

2003, December 19. The order of the RF MoH # 606 “Instruction on prevention of vertical transmission of HIV and a model of a woman informed consent to chemical therapy”

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[15] There are twelve nations in the commonwealth of independent states (CIS) – all former Soviet republics except for Boltic states (Estonia, Latvia, and Lithuania) which are EU members now.

2004, May 13. The indication of the RF MoH # 540-У “International conference on HIV infection and virus hepatitis”, included a section on case reporting system

2004, August 13. The order of the RF MHSD # 292 “Standard of medical care provided to HIV+” extensively describes diagnostic and treatment

2004, August 19. The letter # 2014/04 of FAHCSD confirmed the MoH order # 292 (2001)

2004, October 19. The order of the RF MHSD # 166 “Establishment of the ministry’s coordinating committee on HIV/AIDS problems”, this committee unites the efforts of state and NGO, including PLWHA

2004, November 25. The order of the RF MHSD # 282 “International seminar on interactions of TB and HIV/AIDS services” paid special attention to prisoners and their infections

2005, January 28. The order of the RF MHSD # 99 “Conference on prevention of mother to child HIV transition and problems of HIV+ children in Russia” discussed medical and social prevention of this segment of epidemic

2005, April 1. The order of the RF MHSD # 99 “Establishment of working group for preparation of regulations and recommendations on diagnostic, treatment, epidemiological and behavioral HIV/AIDS and opportunistic infections surveillance” established in the framework of running World bank loan TB and HIV/AIDS diagnostic, treatment and prevention (#4687-RU)

2005, July 16. Government of Russia decision #1020-p made Russian donation to a Global fund greater.

2005, July 29. The order of the RF MHSD # 478 “Establishment of working group for development of education programs aimed on prevention of HIV/AIDS and drug abuse”, from the text of the order it is not clear what is the audience of that program

2005, September 9. The order of the RF Federal administration on control of narcotics’ usage (FACNU) “The instruction on HIV prevention in FACNU”, it is a simple replica of adopted procedures to a newly established government agency

Appendix 2. Basic Document

Basic document

Urgent report on the person whose blood immunoblot reaction revealed HIV antibodies Address (where report goes). _____ Name (in Russian fomat: three entries) _____ Sex_____Date of birth_____ Citizenship_____ Place of residence in the USSR_____ Mail address_____ Address of job or learnng_____ Code of contingent_____ Result of immunoblot reaction : Date_____ Type od a test system_____# of series__ Revealed protein and glicoproteid_____ Institution previously revealed a positive IFA test: Institution_____Address_____ IFA date: _____ Position, name and signature of a reporter _____ Phone number _____ Date "____"_____19__ Note: in Code of contingent indicate all relevant codes	Codes of contingent : 100 – USSR citizen, including 101 – Person having sexual contacts with PLWHA 102 – Drug addict 103 – Homo and bisexual (man) 104 – Person with STD 105 - Promiscuous person 106 – Person being abroad for more than one month 108 - Donor 109 - Pregnant 110 – Recipint of a blood product 111 – Military servant 112 - Prisoner 113 – Tested due to clinical reasons 114 – Tested anonymously 115 – Having contacts with PLWHA 200 – Foreign citizen, including 201 - Person having sexual contacts with PLWHA 202 - Drug addict 203 - Homo and bisexual (man) 204 - Person with STD 205 - Promiscuous person 207 – Entering the USSR for more than three months 209 - Pregnant 210 - Recipient of a blood product 211 - Military servant 212 - Prisoner 213 - Tested due to clinical reasons 214 - Tested anonymously 215 - Having contacts with PLWHA

Appendix 3. Abbreviations

CIS		Commonwealth of independent states
FAHCSD	-	Federal Administration of Health Control and Social Development
FRMC AIDS	-	Federal Research and Methodological Center for AIDS Prevention and Control
HIV+	-	HIV-positive, a person infected with HIV
IFA	-	Immunoferment analysis
MHSD	-	Ministry of Health and Social Development
MMBI		Ministry of medical and biologic industry
MoH	-	Ministry of Health
MoHMI	-	Ministry of Health and Medical Industry
NGO	-	Non Governmental Organization
PLWHA	-	Person living with HIV/AIDS
PLWHA	-	People, living with HIV/AIDS
RF	-	Russian Federation, legal successor to the USSR
SCSEC	-	State Committee on Sanitary and Epidemic Control
STD	-	Sexually transmitted disease
SU	-	Soviet Union
TB	-	tuberculosis
USSR	-	The Union of Soviet Socialist Republics

Appendix 4. Russian original titles of documents mentioned in Appendix 1

Приказ Минздрава СССР от 4 октября 1980 г. N 1030 "Об утверждении форм первичной медицинской документации учреждений здравоохранения" (с изменениями от 5 ноября, 8 декабря 1980 г., 20 января, 16 мая 1983 г., 2 февраля, 19 ноября, 14 декабря 1984 г., 15 марта, 15 апреля, 22, 24 июля, 7 августа, 5 сентября 1985 г., 30 мая, 9 июня, 30 сентября 1986 г., 31 декабря 1987 г., 8 января, 12 мая, 20 июня, 26 июля, 5, 8 сентября 1988 г., 14 декабря 1990 г., 11 февраля 1994 г., 3 февраля, 3 июля 1995 г., 25 февраля, 5, 7 октября 1998 г., 3 июля 2000 г., 20 февраля, 21 мая, 10 июля, 31 декабря 2002 г.)

Приказ Минздрава СССР от 10 июня 1985 г. N 776 "Об организации поиска больных СПИД и контроле доноров на наличие возбудителя СПИД"

Приказ Минздрава СССР от 18 апреля 1986 г. N 539 "Об организации лабораторий клинической иммунологии"

Указ Президиума Верховного Совета СССР от 25 августа 1987 г. "О мерах профилактики заражения вирусом СПИД"

Приказ Минздрава СССР от 4 сентября 1987 г. N 1002 "О мерах профилактики заражения вирусом СПИД"

23-11-1987

Приказ Минмедбиопрома СССР и Минздрава СССР от 2 февраля 1988 г. N 65/73 "Совершенствование порядка поставок, оплаты и учета движения диагностических ИФА тест-систем на СПИД (диагностикум на СПИД)"

Приказ Министерства здравоохранения СССР от 10 февраля 1988 г. N 91 "Об обязательном обследовании донорской крови на ВИЧ"

Приказ Минздрава СССР от 1 июня 1988 г. N 444 "О мерах по дальнейшему улучшению медицинского освидетельствования лиц, выезжающих за рубеж в командировки и туристические поездки"

Инструкция Минздрава СССР от 29 июля 1988 г. N 28-6/26 по сбору крови от доноров-носителей HBs-антигена

Приказ Минздрава СССР от 5 сентября 1988 г. N 690 "О совершенствовании учета лиц, инфицированных ВИЧ и больных СПИД"

Приказ Минздрава СССР от 15 ноября 1988 г. N 821 "О мерах по усилению борьбы с распространением СПИД в СССР"

Приказ Минздрава СССР от 16 марта 1989 г. N 173 "О создании центров по предупреждению и борьбе со СПИД"

Приказ Минздрава СССР от 10 апреля 1989 г. N 239 "Об организации службы профилактики СПИД в СССР"

Приказ Минздрава СССР от 17 апреля 1989 г. N 250

"Об отраслевой статистической отчетности учреждений, предприятий и организаций Минздрава СССР" Приказ Минздрава СССР от 26 июля 1989 г. N 438

Приказ Минздрава СССР от 12 октября 1989 г. N 571 "Об изменении порядка представления отчетности об обследовании населения на СПИД"

Постановление ВС СССР от 23 апреля 1990 г. N 1448-I "О порядке введения в действие Закона СССР "О профилактике заболевания СПИД"

Приказ Минздрава СССР от 14 ноября 1990 г. N 442 "О мерах по обеспечению социальной защищенности лиц, зараженных вирусом иммунодефицита человека или больных СПИДом"

Приказ Минздрава СССР от 5 июля 1991 г. N 181 "О государственном обязательном страховании работников, занятых оказанием медицинской помощи населению, проведением научных исследований по проблемам вирусологии и производством вирусных препаратов, на случай инфицирования вирусом иммунодефицита человека при исполнении ими служебных обязанностей, а также наступления в связи с этим инвалидности или смерти от СПИДа"

Приказ Минздравмедпрома РФ от 16 августа 1994 г. N 170 "О мерах по совершенствованию профилактики и лечения ВИЧ-инфекции в Российской Федерации" (с изменениями от 18 апреля 1995 г.)

Приказ Минздравмедпрома РФ от 18 апреля 1995 г. N 100 "О расширении функций территориальных центров по профилактике и борьбе со СПИД" (с изменениями от 7 августа 2000 г.)

Федеральный закон от 30 марта 1995 г. N 38-ФЗ "О предупреждении распространения в Российской Федерации заболевания, вызываемого вирусом иммунодефицита человека (ВИЧ-инфекции)" (с изменениями от 12 августа 1996 г., 9 января 1997 г., 7 августа 2000 г., 22 августа 2004 г.) Принят Государственной Думой 24 февраля 1995 года

Постановление Правительства РФ от 4 сентября 1995 г. N 877 "Об утверждении перечня работников отдельных профессий, производств, предприятий, учреждений и организаций, которые проходят обязательное медицинское освидетельствование для выявления ВИЧ-инфекции при проведении обязательных предварительных при поступлении на работу и периодических медицинских осмотров"

Постановление Правительства РФ от 13 октября 1995 г. N 1017 "Об утверждении Правил проведения обязательного медицинского освидетельствования на выявление вируса иммунодефицита человека (ВИЧ-инфекции)" (с изменениями от 1 февраля 2005 г.)

Постановление Правительства РФ от 25 ноября 1995 г. N 1158 "Об утверждении требований к сертификату об отсутствии ВИЧ-инфекции, предъявляемому

иностранными гражданами и лицами без гражданства при их обращении за визой на въезд в Российскую Федерацию на срок свыше трех месяцев"

Приказ Минздравмедпрома РФ и Госкомсанэпиднадзора РФ от 24 июля 1996 г. N 299/220 "О Федеральной целевой программе по предупреждению распространения в Российской Федерации заболевания, вызываемого вирусом иммунодефицита человека (ВИЧ-инфекции) на 1996-1997 и на период до 2000 года "Анти-ВИЧ/СПИД"

Приказ Минздрава РФ от 10 февраля 1997 г. N 42 "О проведении сравнительных испытаний диагностических иммуноферментных тест-систем для выявления антител к ВИЧ в сыворотке крови человека, выпускающихся в Российской Федерации"

Приказ Минздрава РФ от 11 августа 1997 г. N 238 "Об использовании иммуноферментных тест-систем для выявления антител к ВИЧ в сыворотке крови человека"

Соглашение о сотрудничестве в решении проблем ВИЧ-инфекции (Москва, 25 ноября 1998 г.)

Приказ Минздрава РФ от 7 августа 2000 г. N 312 "О совершенствовании организационной структуры и деятельности учреждений по профилактике и борьбе со СПИД"

Приказ Минздрава РФ от 30 июля 2001 г. N 292 "Об использовании иммуноферментных тест-систем для выявления антител к ВИЧ в сыворотке крови человека"

Постановление Правительства РФ от 24 декабря 2002 г. N 923 "О перечне иностранных и международных организаций, гранты которых не учитываются в целях налогообложения в доходах российских организаций - получателей грантов" (с изменениями от 21 января 2006 г.)

Указ Президента РФ от 17 января 2003 г. N 45 "О присвоении статуса наукограда Российской Федерации рабочему поселку Кольцово Новосибирской области"

Указание Минздрава РФ от 4 августа 2003 г. N 916-У "О проведении конкурса информационных проектов и материалов по проблеме ВИЧ/СПИД"

Постановление Правительства РФ от 15 августа 2003 г. N 498 "О подписании Соглашения между Российской Федерацией и Международным банком реконструкции и развития о займе для финансирования проекта "Профилактика, диагностика, лечение туберкулеза и СПИДа"

Указание Минздрава РФ от 27 августа 2003 г. N 1020-У"О проведении семинара "Нормативно-правовые аспекты и стандартизация молекулярно-биологических технологий в практическом здравоохранении"

Приказ Минздрава РФ от 19 декабря 2003 г. N 606 "Об утверждении Инструкции по профилактике передачи ВИЧ-инфекции от матери ребенку и образца информированного согласия на проведение химиопрофилактики ВИЧ"

Указание Минздрава РФ от 13 мая 2004 г. N 540-У "О проведении международной конференции по проблемам ВИЧ-инфекции и вирусных гепатитов"

Приказ Министерства здравоохранения и социального развития РФ от 13 августа 2004 г. N 77 "Об утверждении стандарта медицинской помощи больным ВИЧ-инфекцией"

Письмо Федеральной службы по надзору в сфере здравоохранения и социального развития от 19 августа 2004 г. N 2014/04

Приказ Министерства здравоохранения и социального развития РФ от 19 октября 2004 г. N 166 "О создании Координационного совета по проблемам ВИЧ/СПИД Министерства здравоохранения и социального развития Российской Федерации"

Приказ Министерства здравоохранения и социального развития РФ от 25 ноября 2004 г. N 282 "О проведении совещания-семинара с привлечением международных экспертов "Взаимодействие между противотуберкулезной службой и центрами по профилактике и борьбе со СПИДом"

Приказ Министерства здравоохранения и социального развития РФ от 28 января 2005 г. N 99 "О проведении научно-практической конференции "Актуальные вопросы профилактики передачи ВИЧ-инфекции от матери ребенку и проблемы ВИЧ-инфекции у детей в России"

Приказ Министерства здравоохранения и социального развития РФ от 1 апреля 2005 г. N 251 "О создании Рабочей группы по подготовке нормативных правовых актов и методических документов по вопросам диагностики, лечения, эпидемиологического и поведенческого надзора ВИЧ/СПИД и сопутствующих заболеваний"

Распоряжение Правительства РФ от 16 июля 2005 г. N 1020-р

Приказ Министерства здравоохранения и социального развития РФ от 29 июля 2005 г. N 478 "О создании рабочей группы по разработке образовательной программы по профилактике ВИЧ-инфекции и наркомании"

Приказ Федеральной службы РФ по контролю за оборотом наркотиков от 9 сентября 2005 г. N 279 "Об утверждении Инструкции об организации работы по предупреждению распространения в органах наркоконтроля заболевания, вызываемого вирусом иммунодефицита человека (ВИЧ-инфекции)"

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