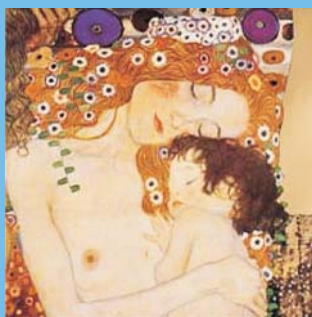


**THE MINISTRY OF HEALTH  
AND SOCIAL DEVELOPMENT  
OF THE RUSSIAN FEDERATION**

**THE PROVISION  
OF MEDICAL AND SOCIAL CARE  
FOR HIV-POSITIVE  
PREGNANT WOMEN  
AND THEIR INFANTS**

**POLICY BRIEFING PAPER**



Moscow  
2007

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# PROVISION OF MEDICAL AND SOCIAL CARE FOR HIV-POSITIVE PREGNANT WOMEN AND THEIR INFANTS

## POLICY BRIEFING PAPER

As stated by the Russian President in his address to the Federal Assembly on 10 May 2005, the government is committed to protecting the welfare of mothers and children and to maintaining and improving health of the population as a whole, as part of the healthcare modernisation agenda, which is aimed at improving the accessibility and the quality of medical and social care.

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### List of Abbreviations

ART	– antiretroviral therapy
MTCT	– mother-to-child transmission of HIV
PMTCT	– prevention of mother-to-child transmission of HIV
ART PMTCT	– antiretroviral therapy for the prevention of mother-to-child transmission of HIV
HAART	– highly active antiretroviral therapy
HIV	– human immunodeficiency virus
AIDS	– acquired immune deficiency syndrome
UNAIDS	– the Joint United Nations Programme on HIV/AIDS

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To: Heads of public health  
authorities of the regions of  
the Russian Federation

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Provision of medical and social care for  
HIV-positive pregnant women and their infants

The Ministry of Health and Social Development of the Russian Federation is distributing this policy briefing paper for the use in medical institutions that provide treatment and prevention services for HIV-positive pregnant women and their infants.

Enclosed: 8 pages, 1 copy of each

Deputy Minister

V. I. Starodubov

## INTRODUCTION

The spread of HIV among the population is one of the most acute problems of the present. HIV is causing an increase in the death rate, a decline in the number of people able to work, their standards of living, a slowdown in economic growth, and, depopulation in a number of countries. As women and children have not escaped the HIV epidemic, there is a pressing need for prevention of mother-to-child transmission of HIV during pregnancy and delivery, and through breastfeeding. There is also a need to provide medical and social care and education for children, abandoned by HIV-positive mothers.

Accordingly, the priorities for public health agencies and providers are as follows: carrying out prevention work aimed at helping HIV-positive women to give birth to HIV-negative children; providing diagnostic, treatment and prevention services for women and children living with HIV; setting up client management services for these groups in outpatient clinics and hospitals; and also providing them with long-term care and support services.

The Federal AIDS Centre reports that between 1987 and the end of 2005 more than 334,000 HIV cases were registered in the Russian Federation, including 17,233 cases among children aged 0–17. However, the real number of people living with HIV/AIDS is higher than official statistics suggest. The Federal AIDS Centre and UNAIDS estimate that in 2005 there were more than 940,000 people living with HIV in Russia. This equates to 1.2% of the population aged 15–49.

In Russia, as in the rest of the world, young people are disproportionately affected by HIV. Indeed, 82% of people living with HIV/AIDS were diagnosed when they were between the ages of 15–30. In 2006, 84% of people living with HIV/AIDS were young people aged 18–35.

The HIV incidence rate is not slowing down in Russia: in 2005 there were 35,526 new HIV cases, which was 1,200 (4%) more than in 2004.

The HIV prevalence rate in Russia is also continuing to rise, reaching 225.6 cases per 100,000 people in 2005 (compared to 200.7 in 2004). By the end of 2005, 0.4% of the population aged 15–49 were officially registered as HIV-positive, and among the 18–24 age group 1% were living with HIV. At the end of 2005, more than 80% of the 100,000 women registered as HIV-positive were of reproductive age. Federal statistics (report № 61, en-

titled “Data on people with HIV”) show that between 1987 and 2006 10,237 HIV-positive Russians died. Moreover, approximately 60% (6,122) of these deaths occurred in 2005. During the same period, 416 HIV-positive children aged 0–17 died, 159 of AIDS.

The HIV epidemic in Russia is now at the concentrated stage (the UNAIDS definition states that this is when the HIV prevalence rate among one or more high-risk populations is higher than 5%, but does not exceed 1% among pregnant women in urban areas). In the years 1987 to 2006 HIV spread extensively among injecting drug users, sex workers and men who have sex with men.

In the last four years Russia has seen an increase in the percentage of HIV cases resulting from sexual contact. Since 2003 the majority of new HIV cases among women of reproductive age have been sexually transmitted. It resulted in the increasing number of HIV-positive pregnant women. In 2005, 12,836 pregnant women out of a total of 2.9 million were registered as HIV-positive (0.44%), and in 2005 more than half of all pregnancies among HIV-positive women resulted in births. Births to HIV-positive women account for an increasing percentage of all births every year, which makes PMTCT ever more important.

HIV cases have been registered in every region of Russia. HIV is spreading fastest in the country’s economically developed regions and it is therefore these areas that will suffer most from the consequences of the epidemic. In 2005 the epidemic became generalised in five Russian regions: St. Petersburg, Samara, Sverdlovsk, Ulyanovsk and Chelyabinsk (the UNAIDS definition states that the generalised stage is reached when the HIV prevalence rate among pregnant women is consistently higher than 1%). Between 1% and 1.8% of all pregnant women in these five regions are HIV-positive. Furthermore, ten Russian regions are on the brink of a generalised epidemic, with HIV prevalence rates among pregnant women reaching 0.7–0.9% in 2005 (Ivanovo, Irkutsk, Kaliningrad, Orenburg, Tver and Tyumen regions, Permskiy Kray, the cities of Moscow and St. Petersburg, and the Khanty-Mansiysk autonomous district). In a number of Russian cities (including Irkutsk, Orehovo-Zuevo, Moscow region, Togliatti, and Samara region) 6–8% of men aged 18–30 are officially registered as HIV-positive. This significantly increases the likelihood that young women will contract HIV through sexual contact.

The number of HIV-positive pregnant women is rising. In recent years there has been an almost 600-fold increase in the rate of new HIV diagnoses among pregnant women

(from 0.2 per 100,000 pregnant women tested for HIV in 1995, to 119.4 in 2002). In 2002 the number of new HIV cases among pregnant women reached a the upper bound of 0.4–0.6% in several areas (St. Petersburg, Moscow, Samara, Sverdlovsk and Ulyanovsk regions and the city of St. Petersburg). In 2003–2004 HIV diagnosis rate among pregnant women remained high (114.2 per 100,000 pregnant women tested for HIV in 2003 and 112.0 per 100,000 in 2004).

In 2005 HIV prevalence rate in Russian regions among pregnant women (per 100,000 pregnant women tested for HIV) was as follows: 504 in Samara region, 408 in Sverdlovsk region, 363 in Irkutsk region, 359 in Ulyanovsk region, 323 in St. Petersburg region, 241 in the city of St. Petersburg, 235 in Chelyabinsk region, 233 in Tyumen region and 232 in Moscow region.

Between 1987 and 2005 there were more than 27,000 births to HIV-positive women in Russia. Moreover, the figure has increased almost ten-fold in the last five years (from 668 births in 2000 to 6,639 in 2005). According to the federal statistics (report № 32 “Data on Antenatal, Labour and Delivery and Postpartum Medical Care”), each year approximately 20% of HIV-positive pregnant women do not register for antenatal care, and by the time they attend a maternity unit they are already in labour.

Between the beginning of the epidemic in 1987 and 2005, there were 27,551 live births to HIV-positive women, 6,699 (24,3%) of which were in 2005 alone. By the end of 2005 almost half the children with perinatal HIV exposure had had their HIV status established and 1,463 children had been diagnosed as HIV-positive (10.8%). A total of 14,031 children born to HIV-positive mothers were still to receive a final diagnosis and were attending outpatient clinics for checkups.

According to federal statistics (report № 61 “Data on People with HIV”), in the Russian Federation prior to 2001 the mother-to-child HIV transmission rate averaged 19.4%. Following the introduction of ART PMTCT the rate dropped to 10.8% in 2002–2003, and by 2004–2005 it was down to 7.5%. Prevention of vertical HIV transmission is hampered by insufficient coverage of ART PMTCT among pregnant women, which is due to the late HIV diagnosis of some of this group (with pregnant women not always registering for antenatal care), and sometimes due to a lack of antiretroviral drugs. In case of universal access to triple HIV therapy and, when necessary, HAART regimens, the risk of perinatal HIV transmission falls to 1–2%.

The Federal AIDS Centre reports that in 2005 4,252 women were diagnosed with HIV only once they were pregnant. This was 33% of the 12,836 pregnant women living with HIV. According to report № 61 «Data on People with HIV», 67% of HIV-positive women who gave birth received ART PMTCT during pregnancy in 2005, and 86% received the therapy during delivery. In 94% of cases their newborns also received ART PMTCT. Caesarean sections were performed on 12.6% of HIV-positive pregnant women.

Monitoring conducted by the Centre for the Prevention and Treatment of HIV among Pregnant Women and Children (the Clinical Infectious Diseases Hospital in Ust-Izhora, St. Petersburg) in accordance with the Russian Health Ministry Directive № 442 “Approval of reports to register children born to HIV-positive mothers” (dated 16 September 2003), shows that as of 12 April 2006 a total of 4,569 reports on children born to HIV-positive mothers in Russia had been submitted in 2005 (this does not include the data for Moscow).

Analysis of the reports reveals that 76.2% of HIV-positive pregnant women did register with an antenatal clinic during pregnancy, while 21.5% did not. Most of the women who did not register were already in labour by the time they attended a maternity unit. Data was not available for 2.3% of the women. Out of those who registered with an antenatal clinic, 29.5% registered before the 12th week of their pregnancy, 30.6% between 12 and 23 weeks, 14.9% between 24 and 35 weeks, and 1.6% after 36 weeks only. In 23.4% of cases this information was not provided. 63% of the HIV-positive women who gave birth had been diagnosed with HIV during their pregnancy, while the remaining 37% had been diagnosed in the preceding two to four years.

84.6% of HIV-positive women who gave birth received ART PMTCT, either during pregnancy and delivery or during delivery only in 2005. In 13.9% of cases ART PMTCT was not given and this was due to the late HIV diagnosis or due to the lack of antiretroviral drugs.

Despite the improvement in figures for the use of ART PMTCT (mothers – 84.6%, newborns – 92.6%), the number receiving triple HIV therapy (mother and infant) remains low at just 56.1%. This lack of treatment is shown by the fact that only 57.6% of women received antiretroviral drugs both during pregnancy and delivery, while 23.4% received antiretroviral treatment during delivery only and 3.6% during pregnancy only.



ART PMTCT was given to 92.6% of newborns, while 6.8% did not receive any antiretroviral medication. This was either due to late HIV diagnosis of the mother or due to medication being unavailable. Data on treatment is not given for the remaining 0.6%.

Caesarean sections, which can potentially reduce the risk of MTCT, were performed on 17.2% of women (primarily for obstetric indications and in accordance with current guidelines) in 2005.

The majority of infants born to HIV-positive women were bottlefed. Just 3.9% of infants were breastfed for a period ranging from a few days to several months.

According to the federal statistics (report № 32 “Data on Antenatal, Labour and Delivery and Postpartum Medical Care”), 5.3% of infants born to HIV-positive women were abandoned in maternity units in 2005. Approximately 2,000 children born to HIV-positive women were abandoned in 1987–2005.

It has been observed that children born to HIV-positive mothers are more susceptible to various serious infections, which often prove fatal. The perinatal death rate of children born to HIV-positive mothers is high in maternity units (two and a half times higher than the rate of the general infant population).

## **MAIN PRINCIPLES FOR PROVIDING MEDICAL AND SOCIAL CARE TO HIV-POSITIVE PREGNANT WOMEN AND THEIR CHILDREN**

Medical and social care for mothers and children is provided in accordance with the Fundamental Legislation of the Russian Federation on Health Protection (as amended by Federal Laws № 30-FZ of 2 March 1998, № 214-FZ of 20 December 1999, № 139-FZ of 2 December 2000, № 15-FZ of 10 January 2003, № 29-FZ of 27 February 2003, № 86-FZ of 30 June 2003, № 58-FZ of 29 June 2004 and № 122-FZ of 22 August 2004 with amendments introduced by the Russian Presidential Order № 2288 of 24 December 1993) and the Federal Law № 38-FZ of 30 March 1995 “On Preventing the Spread of the Disease Caused by the Human Immunodeficiency Virus (HIV) in the Russian Federation” (as amended by Federal Laws № 112-FZ of 2 August 1996, № 8-FZ of 9 January 1997, № 122-FZ of 7 August 2000, № 122-FZ of 22 August 2004), Government Decree № 461 of 28 July 2005 “On the Programme of State Guarantees to Grant Citizens Free Medical Care in 2005”, Go-

vernment Decree № 715 of 1 December 2004 “On Approving the List of Socially Significant Diseases and Diseases that Pose Hazard to other people”, and Government Decree № 856 of 27 December 2004 “On Approving the Rules for Providing Free HIV Medications to Out-patients in Federal Specialised Medical Institutions”, as well as departmental guidelines.

Important aspects of this work include prevention of HIV among teenagers and young people; educating people on methods of contraception; PMTCT; providing women and children with accessible and up-to-date HIV treatment, including HAART; and providing families and children with social welfare and support. Medical and social care for HIV-positive pregnant women, infants with perinatal exposure to HIV and HIV-positive infants is to be based on the provision of comprehensive medical examinations and treatment, including full courses of HAART, as well as the necessary psychological and social support. Monitoring and evaluation of are also essential fore HIV among pregnant women and children (on the regional and federal levels) will also inform service provision.

The relentless rise in the number of HIV-positive women and children born to HIV-positive mothers, involved obstetric and paediatric services into the provision of medical and social services for this group. Addressing the broad range of problems experienced by HIV-positive women and their children requires participation of a large network of specialists from medical, social and other organisations.

Collaboration between healthcare agencies and providers (infectious diseases, maternity and paediatric services) as well as social services, should be aimed at primary prevention, identifying HIV-positive pregnant women and infants, encouraging this group to attend outpatient clinics for checkups and treatment, providing full courses of ART PMTCT with adequate follow-up, and client management.

At present most regions in Russia have just one specialised institution for the prevention of HIV/AIDS and infectious diseases. As it is often impossible for one AIDS centre to address all of the related problems, a need for collaboration between various institutions and organisations that work regularly with HIV-positive women and their children has arisen. It is recommended to create an effective mechanism for the provision of social and medical care for HIV-positive pregnant women and infants that could be used in the different Russian regions. The problems associated with the HIV/AIDS epidemic, in terms of their both qualitative and quantitative nature, can vary from region to region.

A combination of factors determine the specifics of communication between public health providers and social services in a given region, namely the regional HIV prevalence and incidence rates, the appropriateness of the legal and regulatory framework, the resources available to the health and social services, and the financial possibilities of the local authorities.

Interagency cooperation between various public health providers (infectious diseases services, services to protect welfare of mothers and children) and social services that are involved in medical and social care of HIV-positive women and children should be established with the following objectives:

- preventing the spread of HIV;
- providing HIV counselling and timely HIV diagnosis for pregnant women and children;
- delivering antenatal and postpartum care for pregnant women, mothers and children;
- implementing comprehensive PMTCT measures, including wider use of triple HIV therapy;
- providing HAART to those who require it;
- providing infant formula as an alternative to breast milk for children born to HIV-positive mothers;
- operating a client management system for women and children living with HIV;
- evaluating the effectiveness of current prevention work, treatment and client management;
- providing training on HIV-related issues for all medical workers involved in medical and social care of HIV-positive pregnant women and children.

At present, antenatal and postpartum care for HIV-positive pregnant women and their infants, including ART PMTCT, is provided by obstetric and paediatric services. Regional AIDS and infectious diseases centres provide this group with specialised medical care (counselling, diagnostic, treatment and prevention services). However, pregnant mothers and young children are sometimes unable to access these services, either because the AIDS centre is located at a considerable distance from their home or due to other factors, such as the state of health during pregnancy or the health of the child in the first 18 months.

In the last three years, the constant rise in the number of HIV-positive pregnant women, and also children born to HIV-positive mothers, places a considerable burden on obstetricians, gynaecologists and paediatricians working in AIDS centres. They have to provide these women and children with consultations and care, as well as to control the quality of ART PMTCT and HIV treatment received by women and children. Therefore PMTCT should be integrated into the existing healthcare and reproductive health system whenever possible, and this process of integrating PMTCT into obstetric, paediatric and social services is already underway in the regions. However, the functions of medical and social workers in this field need to be more clearly defined.

## **MAIN PRINCIPLES OF PREVENTING MOTHER-TO-CHILD TRANSMISSION OF HIV**

A whole range of measures is required to reduce the level of perinatal HIV transmission. These measures include pre- and post-HIV test counselling for pregnant women; triple combination therapy for PMTCT and, when necessary, HAART; optimum methods of delivery; ensuring that infants receive milk formula; and delivering antenatal and postpartum care for mothers and infants. Timely and proper use of ART PMTCT reduces an infant's risk of infection to 1–2%.

The Coordinating Council of the Russian Ministry for Health and Social Development is responsible for managing and implementing the PMTCT programme at the federal level. Directives, standards and instructions on the prevention of mother-to-child transmission of HIV have been produced and approved.

PMTCT programmes are jointly introduced and managed by mother and child welfare services and regional AIDS centres at the regional level .

In addition, local guidelines that take into account the specific nature of HIV epidemic and the economic and demographic situation in a given region have been issued. Increasing numbers of doctors and social workers, who have some involvement with obstetrics and child health, are participating in PMTCT work, as are nurses, psychologists and paediatricians.

Various non-governmental organisations, both local and international, are working together with state structures on PMTCT.

Despite the current difficulties in providing the PMTCT programme with sufficient resources, priority is given to allocating federal and regional funding to this area. Public health authorities are mobilising material resources at their disposal. They are developing new areas of work that promote service integration as well as introduction of new diagnostic and treatment procedures, and they are monitoring the effectiveness of the current measures. They are also working together with non-governmental organisations.

The multifaceted measures required for programme implementation include all the strategic components of PMTCT being implemented at different levels of medical care provision for pregnant women, young people and women of reproductive age. More than 80% of pregnant women have at least some contact with the PMTCT programme during their pregnancy or during the birth of their child. Work to bring injecting drug users into contact with the programme is underway, and public health education has gained new momentum.

However, there are still many problems to be addressed regarding implementation of the PMTCT programme. These problems require an integrated, intersectoral approach at all levels of medical and social care provision for women and children.

# CONCLUSIONS

## **The key PMTCT measures are:**

### **1. Improving the following guidelines:**

- 1.1. HIV prevention among women;
- 1.2. Provision of medical and social care for HIV-positive pregnant women and their infants (standards and clinical protocols for PMTCT);
- 1.3. Strengthening professional skills of medical workers from the obstetric, paediatric and social services, that provide medical and social care for HIV-positive women and children;
- 1.4. Integrating HIV/AIDS prevention into the work of obstetric, paediatric and social services;
- 1.5. Improving family planning services for people living with HIV;
- 1.6. Placing children with HIV into residential care.

### **2. Improving diagnostic, treatment and prevention measures; enforcing current guidelines and legislation:**

- 2.1. Applying medical care standards (Russian Ministry of Health and Social Development directives № 375 from 30 May 2005 “On Approving the Standard for Prevention of Mother-to-Child Transmission of HIV” and № 374 “On Approving the Standard for Medical Care of Children with HIV”);
- 2.2. Providing counselling to all pregnant women and informed voluntary HIV testing twice during pregnancy – when registering for antenatal care and then at 34–36 weeks. If a test is not conducted at 34–36 weeks, it should be taken when the labour commences (taking into account the “window period”, this allows for HIV to be diagnosed and ART PMTCT to be given);
- 2.3. Increasing triple HIV therapy coverage of HIV-positive pregnant women (during pregnancy and delivery and postpartum treatment of infants);
- 2.4. Using the optimum method of delivery (caesarean section) and ensuring that infants can receive milk formula, which significantly reduces infant’s risk of infection;
- 2.5. Providing HIV-positive mothers with family planning advice in the postpartum period;
- 2.6. Introducing modern approaches to outpatient monitoring of children born to HIV-positive mothers and to early HIV diagnosis of newborns;
- 2.7. Providing comprehensive medical examinations for HIV-positive women and children and providing full courses of treatment, including HAART, to those requiring it;

2.8. Implementing "birth certification" system (as part of the prioritised national project on healthcare) which will encourage timely registration of pregnancies and provision of diagnostic and preventive measures.

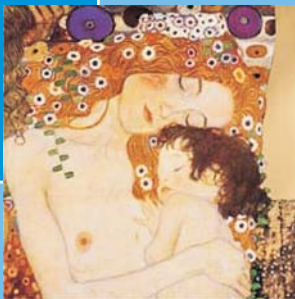
**3. Improving HIV epidemiological surveillance:**

- 3.1. Improving, standardising and unifying reports used by the state statistics services;
- 3.2. Monitoring HIV-positive pregnant women and children;
- 3.3. Evaluating the reach and quality of PMTCT at both regional and national levels;
- 3.4. Improving collaboration between agencies involved in HIV epidemiological surveillance, and also monitoring and evaluating activities conducted to stem HIV epidemic among women and children.

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