

National



POLICY BRIEF



PROMISE POLICY BRIEF: RUSSIA (1 OF 4)

People living with HIV and HIV activists (St. Petersburg & Kazan)

October 2018

INTRODUCTION

PROMISE explored the ways young people with a history of stigmatisation or conflict participate in society.

In Russia, our research focussed on young people who are engaged in HIV activism. This policy brief is concerned with the difficulties young people living with the HIV virus face in their everyday lives.

The policy recommendations are directed towards changes of the public attitude to young people living with HIV/AIDS and providing them with life chances that are equal to that of others. The aim of the recommendations is to present the problems and variants of their solutions defined by young people with HIV themselves.

KEY FINDINGS AND POLICY RECOMMENDATIONS

1. Provide young people living with HIV with up-to-date antiretroviral therapy.

Participant observation and interview data suggest that children and young people with HIV in Russia experience difficulties because they need to take antiretroviral therapy (ART) in the form of a number of pills (up to 8) every day. Firstly, they experience 'fatigue from therapy', secondly, they are forced to handle possible questions about the nature of the pills from other people during trips, in youth camps etc. and a likelihood of the disclosure of their HIV status. Most young people with HIV keep this fact secret, that is, they do not reveal their HIV status to others, in order to avoid discrimination. Antiretroviral therapy in Russia is provided by public health institutions. The drugs available in Russia require daily intake, in contrast to up-to-date drugs that are taken once a week or once every 1-2 months. Teenagers often stop taking therapy that can lead to the formation of virus resistance to ART.

At first, it all started with syrups, there were syrups, there were huge pills. Now every year and a half, I change my therapy, because, because they get bored, and I want some new drug to get used to it in a different way so that there is at least some, at least some diversity between them. And now I take 8 pills a day one time, in the evening. And it all suits me more or less because when I took them twice a day, in the morning and in the evening, in the morning I could not take them... I can't even drink water properly in the morning, and therefore it was very uncomfortable for me, and every morning I felt sick when I went to study (Rustem).

All over the world, there are already drugs of the fifth generation, there, of the fourth generation. And here we accept, well, most, drugs of the first or second generation are prescribed to primary patients. That is, Efavirenz, from which a strong side effect, and so on, Zidovudine is the same... Patients are in a very difficult situation, they do not understand anything. Drugs are appointed, they get them, feel even worse more often... Most don't know, they get drugs, felt bad, they give up therapy, that is, resistance arises (Arthur).

- **Initiate a discussion of the quality of antiretroviral therapy prescribed to teenagers with HIV in Russia as a problem that limits the life chances of young people.**

2. Initiate a discussion about the lack of sex education in Russian secondary schools.

In Russian secondary schools, the discussion of condom use is excluded due to the Federal Law 'On protecting children from information that is harmful to their health and development'. According to this law, information that is 'represent(ed) as an image or description of sexual relations between a man and a woman' is restricted for children of certain age categories. The permitted information for children who have reached the age of sixteen is defined as 'images or descriptions of sexual relations between a man and woman that do not exploit an interest in sex and are not offensive, except for images or descriptions of sexual acts'. Due to these restrictions, there is no sex education in Russian secondary schools. The HIV activists who recently graduated from school say that topics of sexual relations and condom use are not discussed in lessons, and the theme of HIV is presented only very briefly:

We also didn't talk about this at school. We were briefly told, these ten-minute dudes came and said: 'Here's HIV, blah blah blah, it exists'. But about condoms, no one teacher, no parents, no one spoke openly (Anastasia).

HIV activists try to conduct preventive work in schools, including discussion of the use of condoms, but face school principals' fear.

At schools, it [condoms] is a closed topic and even more than that. I, well, I am also a member of the parents' committee in school, yes, I am also very active there, that's it. I talked with the principal of the school, with whom I had quite a good relationship, and asked: 'Don't you want to, well, people who do know how to do this, come to senior classes and make counseling there, say, some kind of lecture?' She says: 'What are you? If I now do it, parents will then drag me through the trials' (Dina).

In this context, the question of a fifteen year old schoolgirl at the training informing about HIV held by activists is characteristic: 'And if to take birth control pills, but without a condom, can you get [HIV] then?' (field diary, 26/05/2017).

HIV activists include the topic of condoms use in their trainings informing about HIV with schoolchildren, but only if these trainings are conducted outside schools, for example, in a rural cultural house.

- **Initiate a discussion about the lack of sex education in Russian secondary schools as one of the factors contributing to the HIV epidemic.**

3. Provide a support group of teenagers living with the HIV virus with a stable meeting place.

The only support group for teenagers with HIV organised by HIV activists in Russia does not have its own place. The feature of the group is that its participants are not only HIV positive teenagers, but also their friends. During the period of participant observation, from February to May 2017, the teenagers' support group met about once a week, on weekends. The meetings consisted of 'trainings' conducted by students of the Kazan Theater School. Places for the meetings of the support group were provided free of charge by various organisations and communities, each time one has to negotiate the place again.

- **The support group of young people with the HIV virus needs stable premises to meet. These support groups are the only spaces in Russia where people with HIV can openly talk about themselves and their HIV-related difficulties without fears of labelling.**

4. Recommend to refrain from the terms that are morally burden and differentiate people when talking about HIV/AIDS

One of the features of the Russian authorities' rhetoric about HIV/AIDS is an appeal to morality. President Putin in his only speech about HIV/AIDS said: *'Our common task is to promote a healthy way of life and raise awareness of the importance of moral values'* (Putin 2006). The 'State Strategy to Combat the Spread of HIV in Russia through 2020 and beyond' approved by Russian government includes also the traditionalist rhetoric (*'to strengthen traditional family and moral values'*) but doesn't include the provisions on sex education, harm reduction programs and substitution therapy (Government of Russia 2016).

The teenagers living with HIV emphasise that there are no grounds for a special attitude towards them. They are afraid that after learning about their HIV status *'some will not see you as an individual, who you are, but only pay attention to the fact that you are HIV positive'*. *'We are the same as everyone else, we just help our health with pills, but otherwise we are no different from others'* (Pozitivnye deti 2018).

- **Recommend journalists, politicians, bloggers etc. to refrain completely from the terms 'risk groups', 'vulnerable groups', 'marginal groups' and 'moral values' when discussing the topic of HIV/AIDS, as this contributes to the stigmatisation of people living with HIV, including children and teenagers.**

RESEARCH PARAMETERS

This policy brief is based on 29 interviews (10 of them in Kazan and 19 in St. Petersburg) and 28 days of observation (20 in Kazan, 8 in St. Petersburg).

PROJECT IDENTITY

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WEBSITE

<http://www.promise.manchester.ac.uk/en/newsfeed/>

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FURTHER READING

Humiliated and Labelled, part 1: Seven Circles of Hell for People with HIV in Russia (in Russian). 2018. <https://www.idelreal.org/a/29063925.html>

Humiliated and Labelled, part 2: Black Marks for Russians with HIV (in Russian). 2018. URL: <https://www.idelreal.org/a/29095939.html>

Pozitivnye deti [Positive children] (2018). Kazan: Svetlana Izambaeva Foundation (book with life stories of HIV positive teenagers).

HIV and authorities: (de) problematization of the HIV epidemic by Russian authorities (in Russian). 2018. URL: https://events-files-bpm.hse.ru/files/reports/BC3B5C5F-9DEF-4479-AAAA-1A30C9E335F7/Yasaveev_HIV_and_Russian_authorities_2018.pdf