



# HIV treatment access, delivery and uncertainty

A qualitative study in Serbia and in Montenegro

Sarah Bernays Tim Rhodes Ana Prodanović

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Person sitting in cube. Mark Weber/ Getty images.

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# Glossary

## CD4 Cell

Also known as helper T cell or CD4 lymphocyte. A type of infection-fighting white blood cell that carries the CD4 receptor on its surface. CD4 cells coordinate the immune response, signalling other cells in the immune system to perform their special functions. The number of CD4 cells in a sample of blood is an indicator of the health of the immune system. HIV infects and kills CD4 cells, leading to a weakened immune system.

## CD4 Cell Count

A measurement of the number of CD4 cells in a sample of blood. The CD4 count is one of the most useful indicators of the health of the immune system and the progression of HIV/AIDS. A CD4 cell count is used by health care providers to determine when to begin, interrupt, or halt anti-HIV therapy; when to give preventive treatment for opportunistic infections; and to measure response to treatment. A normal CD4 cell count is between 500 and 1,400 cells/mm<sup>3</sup> of blood, but an individual's CD4 count can vary. In HIV-infected individuals, a CD4 count at or below 200 cells/mm<sup>3</sup> is considered an AIDS-defining condition.

## Global Fund to Fight AIDS, Tuberculosis and Malaria

The Global Fund to Fight AIDS, Tuberculosis and Malaria, established in 2001, is an independent public-private partnership. It is the largest global fund in the health domain, to date (January 2007) it has committed over US\$7 billion in 136 countries. The purpose of the Global Fund is to attract, manage and disburse additional resources to make a sustainable and significant contribution to mitigate the impact caused by HIV, tuberculosis and malaria in countries in need, while contributing to poverty reduction as part of the Millennium Development Goals.

## HIV therapy/ HAART (Highly Active Antiretroviral Therapy)

The name given to treatment regimens recommended by leading HIV experts to aggressively suppress viral replication and slow the progress of HIV disease. The usual HAART regimen combines three or more different drugs such as two nucleoside reverse transcriptase inhibitors and a protease inhibitor, two NRTIs and a non-nucleoside reverse transcriptase inhibitor or other combinations. More recently, a new drug has been developed to prevent the virus from entering the cell. These treatment regimens have been shown to reduce the amount of virus so that it becomes undetectable in a patient's blood. The term ART (antiretroviral treatment or therapy) can be used if it clearly refers to a triple antiretroviral drug combination. In this report HAART will be referred to as HIV therapy.

## HIV

Human Immunodeficiency Virus is the virus that weakens the immune system, ultimately leading to AIDS.



## Opportunistic infections

Illnesses caused by various organisms, some of which usually do not cause disease in persons with healthy immune systems. Persons living with advanced HIV infection may suffer opportunistic infections of the lungs, brain, eyes and other organs. Opportunistic illnesses common in persons diagnosed with AIDS include *Pneumocystis carinii* pneumonia, cryptosporidiosis, histoplasmosis, other parasitic, viral and fungal infections; and some types of cancers.

## PCR (Polymerase chain reaction) test

A sensitive lab test to determine a patient's viral load. It works by repeatedly copying genetic material using heat cycling and enzymes. A viral load test is used to see how well a drug regimen is working. The lower the viral load the better.

## Viral load (viral burden)

Amount of viral genetic material (RNA or DNA) in the blood or other tissues, often expressed as number of copies per millilitre (mL). The presence of HIV RNA indicates that the virus is actively replicating; changes in HIV RNA level may be used to gauge disease progression and whether a treatment is working. Standard HIV viral load tests are the polymerase chain reaction (PCR) assay and the branched-chain DNA (bDNA) test.

\*Glossary compiled from UNAIDS, AIDSMAP, SFAIDS and AEGIS

# Summary of Key Findings

## Background

There is unprecedented global commitment to ‘scaling-up’ HAART (referred to in this report as HIV therapy), with a goal of near universal access in transitional and developing countries by 2010. While there is research investigating the extent of HIV treatment scale-up as well as the factors influencing HIV treatment outcome, there is an absence of qualitative research investigating HIV treatment access and delivery from the perspectives of people living with HIV (PLHIV).

During 2005-2006 the London School of Hygiene and Tropical Medicine (LSHTM) at the University of London and the HIV Prevention for Vulnerable Populations Initiative (HPVPI) at the United Nations Development Program (UNDP) undertook the first qualitative study to describe the ‘lived experience’ of being HIV positive in Serbia and in Montenegro.

The study set out to describe, from the perspectives of PLHIV, how they manage their HIV/AIDS on a daily basis and the issues they face. Informed by our initial findings, the research focused on the realities of delivering HIV treatment (HIV therapy and monitoring tests) in a resource stretched healthcare setting, and the impact that this has on HIV positive individuals. The study also examined the HIV treatment system from the perspectives of key service providers. In addition the study focused on other aspects identified by PLHIV as important, including: non-HIV related health care; stigma and discrimination; and community participation.

## Methodology

To best capture the detailed accounts of people living with HIV in Serbia and in Montenegro, the study adopted a qualitative methodology, using in-depth interviews. The study interviewed 42 people living with HIV/AIDS during 2005-2006 (number of PLHIV in Serbia, 1118 [2]; number of PLHIV in Montenegro, 43 [1]). Gender, age, place of residence, time since diagnosis, treatment history, contact with non-government organisations (NGOs) and association with vulnerable behavioural groups were all key sampling characteristics. Service providers (n=18) representing key links within the treatment system were also invited to participate in the study.

With informed consent, the interviews were tape recorded, and later transcribed and translated. All data are presented anonymously. The data were analyzed thematically using a grounded theory approach and the key findings are presented in this report. This is a qualitative study so the emphasis is on representing the key themes emerging in participant accounts. The study makes no claims to the wider generalisability of the findings to PLHIV or HIV treatment service providers in Serbia and in Montenegro as a whole. Since the study was undertaken, the situation of HIV treatment access and delivery may have changed.

## HIV treatment supply

The key finding of the study was that anxiety about the continuity of supplies of HIV therapy and monitoring tests (tests to monitor CD4 count and PCR) was the over riding concern of PLHIV in Serbia and in Montenegro. Despite improvements over the course of the study for those able to access treatment in Belgrade, the fragility of access and delivery remains an ongoing concern. Amongst some service providers’ accounts there was disagreement about the extent and gravity of the treatment supply problems. Whilst some felt that the situation was unacceptable and alarming, others felt that it was an inevitable result of managing HIV in a resource-stretched health service and that the consequences were minor and manageable.

In the event of a shortage in therapy supplies there are two strategies employed: altering the prescribed treatment combination to what is available or, less commonly, interrupting treatment until the appropriate therapy became available again. These decisions are made more difficult, and more precarious, by intermittent shortages of monitoring tests. PLHIV are very concerned about the effect these treatment shortages are having upon their development of drug resistance and long term health.

PLHIV's anxiety about the treatment situation was exacerbated by a lack of available information. In the absence of trusted information from those within the treatment system, rumour is rife, further fuelling anxieties and feelings of insecurity. This has affected PLHIV's perception of HIV being a manageable chronic illness, their treatment literacy, trust in the healthcare system, as well as perceptions of their social positioning.

- The findings of the study demonstrate the need for a thorough review of the treatment procurement and delivery system to identify bottlenecks and areas of leakages within the system. Some of the areas that need attention are:
  - analysis of the cost-effectiveness of the delivery system;
  - defining responsibilities in the treatment supply system (to include accuracy of projections, timeliness of delivery, and solving day to day issues);
  - accountability of each stakeholder in the treatment supply system and their mutual communication;
  - setting up systematic collection of accurate information, required to order supplies and for monitoring current stock.
- There is a need for information dissemination systems for patients on treatment and testing availability to be put in place, as well as further information about managing HIV treatment and maintaining health to be made available.
- There is a need for more psychosocial support for those dealing with intensely difficult situations, often alone.

### Relations with HIV Clinics

Despite reported treatment problems, PLHIV were keen to differentiate between their anxiety surrounding HIV treatment and the medical care they received at the HIV clinic in Belgrade. Participants frequently commented on the commitment, competence and expertise of the three clinic doctors who they felt did their best with the resources available, and they spoke of the doctors' frustration when they were not able to provide more for the patients.

The decentralisation of HIV care to other clinics in Serbia and in Montenegro, although broadly welcomed, is also a source of concern for a number of PLHIV who fear that the doctors in the new clinics do not have the sufficient level of knowledge to treat them as well as those in Belgrade.

- There is a need to create well coordinated working relationships between the newer clinics in Serbia and in Montenegro and the established clinic in Belgrade. As much as possible, it is important to create confidence among PLHIV in the treatment, care and services that they will receive in the newer clinics.

## Non-HIV related medical care

Whilst a few PLHIV participants had positive experiences of accessing generic medical treatment, many PLHIV reported that they had been refused medical treatment, directly or indirectly, on account of their HIV status. The fragility of access to general medical care was described as humiliating, exhausting and intensely stressful. This seems to be particularly acute in the specialist areas of dentistry, gynaecology and surgery, although a number of participants reported that they had also encountered problems at their primary health centres.

Weak adherence to the codes of medical confidentiality by healthcare personnel is also perceived to be an issue for PLHIV. Incidences and the consequences of porous medical confidentiality appear to be particularly severe for those outside of Belgrade and in Montenegro.

- There is a demonstrable need for the HIV education workshops with medical staff to continue and for further educational and advocacy work to be done with medical professionals. Addressing the knowledge gaps and prejudices of medical personnel is a key initiative not only because it will improve the medical care that PLHIV are likely to receive, but also because they occupy a leading role in influencing the attitudes of the general population towards PLHIV.
- More information and support need to be made available to PLHIV in accessing non-HIV related medical care. This is necessary to address both improved access to medical care and alleviate the burden on the clinic.

## Social impact of HIV

The study found that a key factor constraining access to health care among PLHIV was a fear of discrimination. For many PLHIV, the perceived reactions and attitudes of others towards them were as significant, if not more so, than the uncertain medical prognosis of HIV/AIDS. Many people's lives were shattered by the social implications of being HIV positive, even if for some their fears of mistreatment were not fully realised.

The social consequences of being HIV positive within this social environment are numerous and complex. This report focuses specifically on the impact that discrimination within the family and within the employment market have upon the capacity of PLHIV to manage their HIV treatment access in a context of uncertainty. The support offered by families is often restrained by fear and misinformation about the risks of transmission. This reinforces societal constructions of HIV. For PLHIV the existing fragile employment market is significantly worsened by the disclosure of their HIV status. The study found that the loss of earning opportunities as a result of being HIV, directly weakens financial independence and this also undermines capacity to manage other HIV related problems, in particular uncertain HIV treatment access.

- There needs to be accessible information available about the rights of PLHIV to work, as well as clear advice and information about pension options for PLHIV. The necessary support needs to be given so that PLHIV can use these opportunities to alleviate the financial problems they face as a result of their illness.

## Community participation in NGOs and self support

The dominant factor undermining the participation of PLHIV in self-help and community action is the stress of chasing therapy, monitoring tests, referrals and healthcare. This was said to drain their energy as well as undermine self-confidence and independence to the extent that many do not feel they are in a position to participate in HIV advocacy efforts and community activities. This is reinforced by the perceived risks of antibody status disclosure.

This cycle reduces the visibility of the problems PLHIV are facing and weakens the chances of them being resolved.

The study found that some PLHIV were disillusioned with NGOs, as through experience or hearsay they had become sceptical about their sustainability. They were therefore reluctant to invest in becoming involved. The accounts of a few PLHIV also emphasised that PLHIV were not adequately respected within NGOs and government commissions and that they were unable to make a significant contribution. However, there were many who spoke with praise about the crucial role certain NGOs play in the provision of key support services for PLHIV and that being involved in NGO was an extremely important and positive influence in their lives.

- Service providers, in particular NGOs need to enter in to a more meaningful communication with PLHIV on this issue so that there can be an improved cooperation. For example, one way to move forward on this could be to jointly address the treatment issues through advocacy and to implement the findings from a review of the HIV treatment system, which would both demonstrate that the views of PLHIV are being listened to and respected, and that positive change is achievable.

## Montenegro

In Montenegro the situation faced by PLHIV is changing due to the independence of Montenegro in May 2006. The numbers of PLHIV resident in Montenegro are low (n=43), with 22 currently receiving HIV therapy care [1]. Through extensive recruitment efforts five PLHIV living in Montenegro participated in the study. Four service provider interviews were also conducted. The accounts of PLHIV characterised their access to consistent HIV treatment and related help as precarious. Participants reported experiencing frequent shortages of therapy. Some participants unable to afford the initial purchase of therapy in Belgrade (which would subsequently be reimbursed), felt they had no choice but to stop HIV therapy until their drugs became available in Montenegro again. Amongst the service providers, there was divergence in perspectives with clinicians describing the fragility of the HIV treatment situation as less alarming than that portrayed by PLHIV.

Despite efforts to improve access to health care services and reduce stigma, with a few exceptions, high levels of fear surrounding the risk of disclosure persisted. This prevented many PLHIV from participating in HIV community activities such as support networks or advocacy efforts. Other than the support given by the NGO 'CAZAS' and by the recently established Voluntary Counselling and Testing Centre PLHIV reported feeling isolated and unsupported, in particular about the treatment situation which they felt was a neglected issue.

- There is a need for a treatment system review to be conducted in Montenegro. This may be timely to inform decisions about the changes in the health insurance and healthcare system likely to be implemented over the next few years.
- Meanwhile, immediate efforts need to be taken to address the significant concerns of PLHIV who feel that they are unable to obtain continuous access to HIV treatment in Montenegro. It is important that measures are put in place to support PLHIV when their treatment is not delivered to Montenegro and instead need to travel to Belgrade.
- The highly stigmatised social environment makes community participation extremely difficult for PLHIV. Addressing the treatment problems will encourage an environment in which PLHIV are more able to participate and address issues of stigma which currently seriously curtail efforts to support PLHIV and HIV prevention.

# Introduction

During 2005- 2006, the London School of Hygiene and Tropical Medicine, University of London and the HPVPI project at the United Nations Development Program (Belgrade) undertook research which aimed to contribute to HIV prevention among vulnerable populations and service provision for PLHIV in Serbia and Montenegro. This research aim was in keeping with and sought to support the efforts of the Ministries of Health and Republican AIDS Commissions of both Republics. One branch of the research was to undertake qualitative research to describe the experience of people living with HIV/AIDS (PLHIV) in Serbia and Montenegro.

Serbia and Montenegro have a low level of epidemic (Serbia: 1,118 PLHIV in December 2005 [2]; Montenegro: 43 PLHIV in 2006), though situational and structural factors coincide to create an HIV risk environment [3]. Political, social and economic transition, exacerbated by major conflict, has resulted in widespread poverty and a weakened public health infrastructure. Latest data suggests that there are currently 570 people receiving HIV treatment in Serbia [2] and 22 in Montenegro [1]. Since 2003 there has been 100% access for HIV positive citizens to HIV treatment covered by the Health Insurance Fund. Within a burgeoning market of HIV drugs not all are funded by the Health Insurance Fund in Serbia and in Montenegro. Those that are fully funded are on the positive list, which is compiled and revised by the Ministry of Health. Some other drugs, not on the positive list, are available with 'participation' in which additional funds must be found to contribute a specified amount towards the cost.

Little has been documented about the experiences of PLHIV in Serbia and in Montenegro. Previous research is limited to a survey conducted in 2005 by the Institute of Social Medicine which was commissioned by the Centre for Sustainable Development and Project Hope. The findings of this report have not been published.

This is the first qualitative study amongst PLHIV to be conducted in Serbia and in Montenegro. The study aimed to capture the experience of HIV treatment in a resource stretched setting where the national healthcare and health insurance systems are already overstretched and to describe the impact that these experiences have on PLHIV's lives and their management of HIV as a chronic illness. The study also aimed to identify challenges to delivering sustainable treatment to PLHIV in Serbia and in Montenegro, and contribute to its improvement.

Within this highly stigmatised environment PLHIV are a hidden and marginalised population, whose voices are ironically silent within the epidemic. This qualitative research therefore provides a key contribution in efforts to facilitate a better understanding of the reality that PLHIV face in Serbia and in Montenegro amongst policy makers, service providers and the general population. In addition the study hopes to contribute to informing national health policy reform in HIV/AIDS and treatment advocacy efforts in Serbia and in Montenegro.

This research into the HIV treatment experience in a transitional setting is relevant both locally and within the broader global context. The high profile commitments to ensuring increased access to HIV treatment globally has meant that HIV increasingly should become a manageable chronic illness across the world and not just the privilege of resource rich Western countries. However evidence suggests that serious structural constraints present problems in ensuring stable and sustainable treatment in some countries [4]. Whilst both Serbia and Montenegro offer 100% access to HIV treatment, an impressive level of coverage

particularly within the region, 100% delivery of HIV treatment is crucial if HIV is to be effectively treated as a manageable chronic illness. The treatment situation found in Serbia and in Montenegro – characterised by a fear of interruption and uncertainty – is becoming increasingly common. Treating HIV effectively is a long term commitment and it is essential that the lived experiences of inconsistent HIV treatment are systematically documented to inform policy on treatment systems and delivery, treatment advocacy and the development of appropriate psychosocial interventions for PLHIV. This study is one of very few to address the marked absence of research on the impact of fragile HIV treatment delivery in resource stretched and transitional settings.

Whilst the principal focus of the study was HIV treatment experience, as a highly stigmatised group little has been documented about the problems that PLHIV experience more generally. The study therefore aimed to describe these experiences, with a particular focus on: non-HIV related medical care; the management of stigma and discrimination; and participation in HIV community support and advocacy.

The findings of the study can be used to: inform the design and implementation of PLHIV support services; to foster greater understanding and more effective dialogue between service providers and PLHIV in strengthening HIV community participation; and to address, through advocacy efforts, the demonisation of PLHIV in the public' consciousness, through the personal accounts within this report.

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The study was undertaken by the Centre for Research on Drugs and Health Behaviour in conjunction with HPVPI and was funded by DfID.

The Centre for Research and Health Behaviour was formerly at Imperial College (London) and is now at the London School for Hygiene and Tropical Medicine: <http://www.lshtm.ac.uk/crdhb>. CRDHB is an international leader in multi-disciplinary and intervention-based research on the social, behavioural and epidemiological aspects of drug use and health behaviour.

HIV Prevention Among Vulnerable Populations Initiative (HPVPI) Project, at United Nations Development Program, Belgrade office: [www.undp.org.yu](http://www.undp.org.yu). HPVPI supported the development of a cohesive programme of evidence-based HIV prevention interventions and policies targeting vulnerable populations in Serbia and Montenegro (2004-2006)

Department for International Development (UK), Belgrade: [www.dfid.gov.uk](http://www.dfid.gov.uk) DfID is part of the UK Government that manages Britain's aid to poor countries and works to eliminate extreme poverty. DfID funded the HPVPI project in Serbia and Montenegro.

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# Methods

This qualitative study was conducted during 2005-2006 using in-depth interviews to capture the lived experience of HIV treatment in Serbia and in Montenegro. The study interviewed 42 PLHIV and 18 service providers.

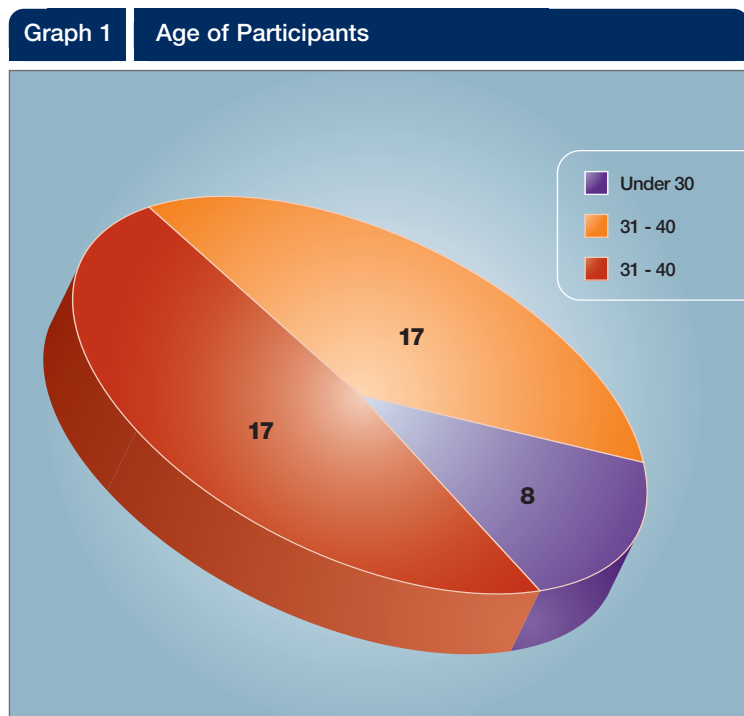
## Sample

The study adopted purposive sampling that reflected an appropriate distribution of age, gender, place of residence and vulnerable group for the PLHIV population in Serbia and in Montenegro. Of the 42 PLHIV interviewed during the course of the study, the majority were recruited through NGOs (20) and snowballing<sup>1</sup> (15). In addition participants also became involved in the study through responding to adverts displayed in the HIV Clinic (4), requesting to be interviewed (2) and the penitentiary hospital (1). Of these 18 were women and 24 were men.

The breakdown of ages is displayed in Graph 1. The age of participants varied from 22-80 years old. However it is worth noting that the study encountered difficulty in recruiting younger PLHIV. It appears that this is in part a consequence of younger individuals' recent diagnosis and turbulent feelings around diagnosis, heightened concern about the risk of disclosure, and weak involvement with NGOs and PLHIV community. Recruitment was also hindered by the reticence of some service providers to actively approach younger individuals to be involved. Therefore, the findings may reflect the experiences of those 'more experienced' in dealing with their HIV/AIDS. One may reasonably assume that the experiences amongst the younger PLHIV may be more severe than those which are reflected in this report.

Whilst the sample is heavily on Belgrade (25) because that is where 80% of PLHIV live [5], the study was also able to access 8 PLHIV resident in Vojvodina, 4 in the area around Niš and 5 in Montenegro. As displayed in Map 1.

Recruiting participants in Montenegro was particularly difficult despite concerted efforts by the research team and trusted members of the HIV community. In conjunction with the study findings, this arguably reflects how hidden HIV/AIDS is in Montenegro and how the fear of



<sup>1</sup> Starting with an initial contact, the researcher asks for referrals to others. The study asked a number of initial informants, unconnected to each other, to ask other PLHIV that they know to be involved.



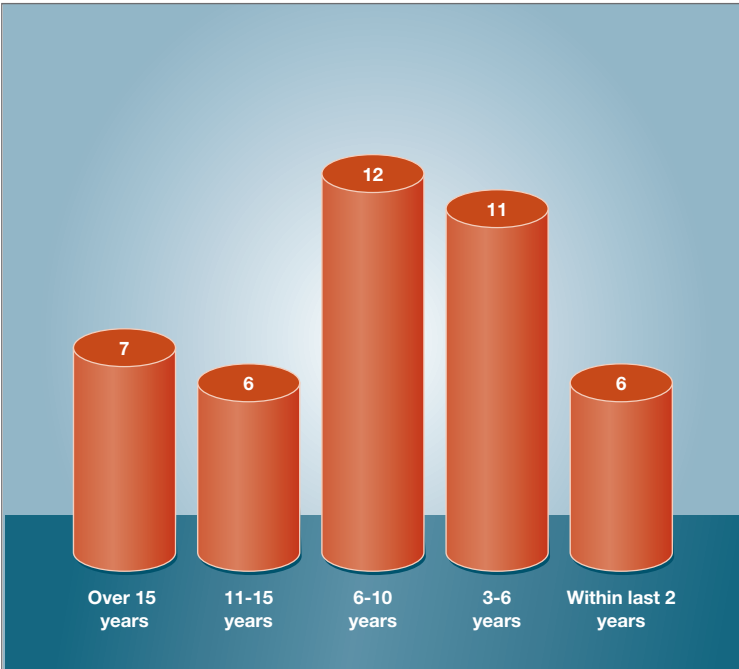
**Map 1** | Geographic Spread of Study Participants



discrimination resulting from accidental disclosure hinders PLHIV's participation not only in this study, but also in accessing support services and even HIV treatment.

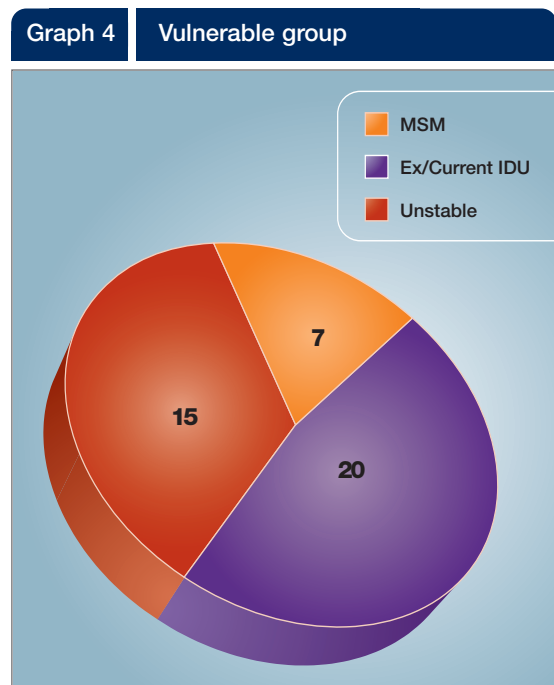
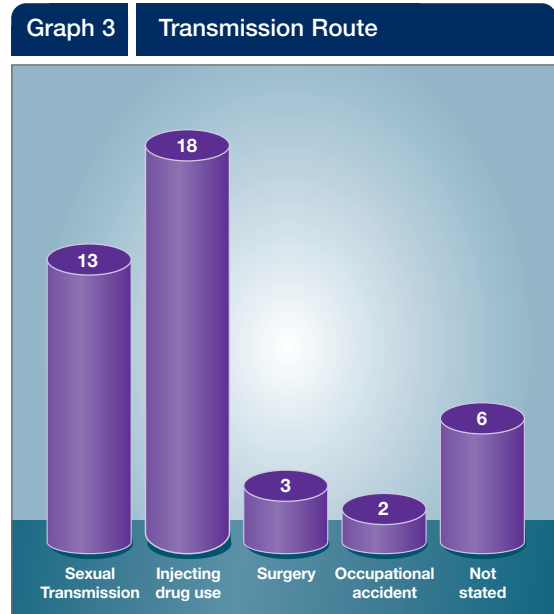
The study included those who are at different stages of the illness trajectory and treatment. The study also included seven participants who are not on treatment, either because their condition meant they had not yet started or they had chosen not to begin. The time since diagnosis of participants is displayed in Graph 2.

**Graph 2** | Time Since Diagnosis



The transmission routes (Graph 3) and vulnerable group characteristics (Graph 4) in our sample profile have been comprised from the information that participants offered in the interviews. It became clear from participants' accounts that PLHIV frequently feel an unnecessary emphasis is placed by others on ascertaining information about their transmission route. Many PLHIV saw this as indicative of the morally judgmental and negative approach that is often taken towards those who have HIV/AIDS. Therefore as the information was not necessary to the study, the researchers deliberately did not directly ask for this information. The information contained in Graph 3 and Graph 4 is compiled from the unprompted information offered by participants.

The study interviewed 18 service providers from Serbia and in Montenegro. The sample was designed to include representation from all the key institutions involved in the provision of treatment, care and support to PLHIV in Serbia and in Montenegro. All key links in the treatment prescription and supply chain were invited to participate. Each link was represented in the study except for the central pharmacy where PLHIV obtain their medication. The sample included representation from: Ministry of Health; Health Insurance Fund; Pharmaceutical Companies; Pharmacists; HIV clinicians; Doctors dealing with PLHIV, but not specialising in HIV; and NGOs. The remit of the study was to capture the perspectives of service providers on the treatment system and the experiences faced by PLHIV, not to provide a comprehensive system study.



### Methods of data collection and analysis

The aim of this study was to produce a detailed description of the lived experience of HIV/AIDS and the treatment system from the perspective of both PLHIV and service providers. The data was collected through in-depth interviews. These were conducted in Serbian or via translation. The researchers followed a semi-structured topic guide and were able to explore pertinent issues as they arose. These interviews lasted between one and two hours and were tape recorded with consent. Interviews took place wherever was convenient for the interviewee and private enough for the material to remain in confidence. In addition to the tape-recorded interviews, the study also drew on informal conversations and field observations. The recorded interviews were transcribed and the Serbian transcriptions were translated into English. This was undertaken by the two study translators.

### **Key areas of discussion in interviews**

- HIV history: time since diagnosis; treatment history.
- Diagnosis: when and how found out about status.
- Immediate aftermath of diagnosis (first two months): experience; knowledge of HIV at time.
- Disclosing status: decision whether to disclose status and to whom; experiences of disclosure and after effect.
- Experience of accessing and receiving health care.
- Experience of treatment and care at the HIV clinic.
- Experience of HIV treatment: whether receiving treatment; current combination; number of combinations been on; reasons for changes; impact of treatment on everyday life.
- Information about HIV: access to information.
- HIV community: extent of contact with other PLHIV; attitudes towards PLHIV; contact with NGOs and services- experiences and impressions.
- Daily life: how time is spent

Qualitative studies aim to understand the experiences and attitudes of participants, in this case PLHIV and service providers. Qualitative research produces non-numerical data. The study used thematic analysis as it is the most appropriate analytical method for analyzing the data (transcripts of interviews) for such health services research. The aim of this analytical method is to identify key themes or recurrent issues in the data. Data collection and analysis adopted an 'inductive' approach where the emergence of key categories and findings throughout the data collection period informed the focus of further investigation and analysis. Such an approach ensures that the hypotheses generated throughout the qualitative study, and during ongoing coding and analysis, are 'grounded' in the data gathered.

This is a qualitative study so the emphasis is on representing the key themes emerging in participant accounts. The study makes no claims to the wider generalisability of the findings to PLHIV or HIV treatment service providers in Serbia and in Montenegro as a whole. It is also important to recognise that since the study was undertaken, the situation of HIV treatment access and delivery may have changed.

Ethical approval was received to conduct the study from Charring Cross Research Ethics Committee in London and was conducted with the support of the Republican AIDS Commission in Serbia and Montenegro. All study participants were required to give their consent to participate in the study, and to the interviews being recorded, and were able to refuse to participate or withdraw from participation at any point should they have chosen to. The research team were conscious of the sensitivity of the issues discussed for PLHIV and worked with NGOs to ensure that support would be available if required. The study was also a leading partner in the development of a counselling service for PLHIV, funded by Catholic Agency For Overseas Development (CAFOD) and HPVPI, and implemented by International Aid Network, Belgrade (IAN).

### **Research team and partners**

The research was conducted by Tim Rhodes and Sarah Bernays from the London School of Hygiene and Tropical Medicine and Ana Prodanović from the HPVPI Secretariat, Belgrade. The translation was conducted by Ljubica Gavanski and Zoran Lojanica. The study was funded by DfID and administered by UNDP.

The study has been guided and supported by an Advisory Group. This Advisory Group is comprised of key figures within the HIV setting in Serbia and in Montenegro, including HIV policy makers, healthcare professionals treating PLHIV, NGOs supporting PLHIV, and PLHIV representatives from both Serbia and in Montenegro.

# HIV treatment supply

A key finding of the study was that problems with continuous supplies of HIV therapy and monitoring tests (PCR tests and CD4 cell counts) were the overriding concern of PLHIV in Serbia and in Montenegro. These fears around the ongoing availability of free HIV therapy and monitoring test supplies (referred to as HIV treatment) arose from either direct experience of treatment supply problems or from what they had heard from other PLHIV. Despite improvements over the course of the study for those able to access treatment in Belgrade, the fragility of access and delivery remains a serious ongoing concern.

## The pervasive impact of fragile HIV treatment:

'If this wasn't like this maybe I could feel better and maybe try to form my life a bit, to start with my adaptation. I don't know maybe I will start to think about how to make a bridge between me like I was before and me which I'm now. But now I cannot do that. You have to imagine these five months, my birthday, new year and I could only think - my God, this constant uncertainty, this fear, maybe I will be dead about three or four months later. You cannot rationally take these thoughts out of you. They are inside of you, this fear, fear yes. So this fear is always here.'# 21.

## Description of the HIV treatment supply

For patients in Serbia and in Montenegro, HIV therapy (Highly Active Antiretroviral Therapy) is prescribed by doctors at the HIV Clinic of the Institute for Infectious and Tropical Diseases in Belgrade. The medications are usually prescribed for the following month, and patients obtain the medication at the pharmacy "Clinical Centre of Serbia" which is part of the network of Belgrade pharmacies (this differs from the internal network of pharmacies which supply medications to the Clinical Centre of Serbia). Patients take the medications daily, sometimes several times a day, and often under strict timelines and dietary specifications.

HIV therapy and monitoring tests are available to patients in Serbia and in Montenegro and are financed by funds from the respective Republican Institutes for Health Insurance. This has been the situation since 2003, when Serbia placed these medications on the positive list of medications approved by the Serbian Government. All medications on the positive list are funded by the Republican Institute for Health Insurance in full or with minimal participatory payment. Before 2003 patients were refunded for medications they bought on their own, following the doctors' prescription. There is now 100% access to HIV therapy in Serbia and in Montenegro in that all citizens are able to access the HIV medications on the positive list. In Montenegro patients still get reimbursed for therapy they buy, usually in Belgrade. 'Despite there being 100% access the study found that because of problems within the treatment supply system there is not always 100% delivery of HIV therapies.

Almost without exception PLHIV and service providers reported problems in the supply of HIV therapy and monitoring tests:

'So the doctors, as our beneficiaries tell us, were actually prescribing the medicines on the basis of what was available, so they were not monitoring the state of the patient and

### Extract codes

extracts labelled # are quoted from interviews with PLHIV and extracts labelled SP are from interviews with service providers.

what would be the best medication for that person but what is there. I would say that in the last six months they are very, very concerned about this main HIV problem'. 3 SP

'The treatments are just each month what they have in the pharmacy, now you are taking that or now you are...without any medical check you know, without any check of blood or some support so that you can see those tests says that, OK you can take that. It is a very big problem for now, now my treatment is available at the pharmacy but I don't know for how long. Now in the meantime, I have to find some connection to go somewhere, outside of the country to see what other possibilities for treatments so that I can plan my life. Everything is so expensive and so uncertain'. # 16.

However the study found that there was great variety in the experience of the treatment system both amongst PLHIV and service providers. Amongst service providers there were differences in how seriously the treatment supply difficulties were perceived and the impact this had on patients. Those within the treatment system articulated the implications and extent of treatment supply problems differently than those outside of the treatment system and PLHIV. In general the service providers who described the situation as serious did not work directly within the treatment system. It is worth noting that it may have been difficult for those who share some responsibility for the effective functioning of the system to admit the gravity of the problems.

Some reported that whilst treatment shortages occurred they fortunately had no major consequences:

'What we experience here from time to time is, we lack some necessities like... laboratory tests, sometimes some drugs, so it's not very smooth.... Since we introduced HAART in our drugs, we always have had these shortages and without major effects by means of shortage.' 1 SP

Others, whilst acknowledging the gravity of the problem, had a pragmatic attitude to the impact and consequences of the supply problems within the context of the overstretched health system:

'We have so many problems and that problem is a very little problem. They're happy to have medications, any medications, it's not the correct way but it is... you know, because we cannot live like in France and we must deal with it, doctors also must deal with it... with such problems. And I think that patients are not so unhappy because of that. They are happy to have treatment, you know. Any treatment.' 2 SP

A number of service providers however felt that the treatment supply problems were having a significant and detrimental impact on people living with HIV/AIDS:

'I think it has a terrible impact because even in this period of maybe two, two and a half years let's say, they weren't sure that they had the right medicines. They were afraid all the time.' 3 SP.

The insecurity that people experience has a pervasive effect on individuals' lives, worsening an already difficult situation, as one service provider explains:

'So they lose control, they're anxious about it, their fears about future rise, it's very complicated to think how they live, how they manage their lives. Many things about them, their private life, their social life have changed and this moment was something they could count on. They thought: "OK, they are rejecting me. I cannot work in my place, my family is with me or one of the members is, but at least I have my treatment". Now they can not say this.' 10 SP.

### Treatment strategies under the conditions of supply shortages

In the event of a shortage in HIV therapy supplies two strategies of treatment delivery were reported by treatment providers: interrupting treatment until the appropriate therapy was available again; or changing the combination, or regimen of drugs, that individual patients are prescribed.

Structured treatment interruption (STI) was described as a pragmatic strategy to adapt to shortages within treatment supply:

'Because there are some countries where they don't have any treatment; we don't have such a bad experience with patients: sometimes we must stop treatment for three months or for six months if we don't have therapy.' 2 SP.

In 2005 a key medical study in the USA investigating the impact of treatment interruption, the SMART study, was terminated early on safety grounds after it was established that patients in the treatment interruption arm were significantly more likely to experience disease progression or death than those on continuous treatment [6]. Whilst this remains a contentious area, there is increasingly a general international consensus that the interruption of HIV treatment under particular conditions such as the absence of close monitoring, can have negative implications for health and the development of drug resistance. Service providers accounts in this study however have not found that treatment interruption has had a noticeable detrimental effect on patients' health. It is important to note though that due to monitoring supply problems and only very rare resistance testing, the impact of the strategies on the health conditions of patients have not been able to be closely monitored:

'One of the strategies is STI for example, which was proved not to be safe enough but according to our results it is not very unsafe – it's not unsafe at all'. 1 SP

Regimen change is the most commonly utilized strategy to cope pragmatically with fluctuating treatment supplies. This involves the doctors adjusting the patients' treatment combination to the drugs that are available, often changing one drug within the combination or prescribing the closest alternative combination until the original treatment becomes available again:

'You know when some drug isn't available in the pharmacy, instead of that drug we put patients on other drugs. So it means changes are frequent, not every month, but very frequent... There is no other way which can... we can't use any other way to resolve that problem.' 9 SP

Ideally changes in HIV treatment combinations should take place when there is evidence that drug resistance is developing or side effects become too difficult for the patient to manage. In Serbia and in Montenegro treatment changes occur in order to pragmatically manage shortages. Using a variety of combinations with frequent switching between treatments may have implications for an accelerated development of drug resistance. In light of the economic context and the limited treatment options available on the positive list for PLHIV,

this may have serious consequences for the management of their long term health. The transmission of drug resistance to others may also be a public health concern [7].

**One HIV positive woman's impression of the health impact of treatment changes:**  
'Look, for us this is a basic, elementary problem. For us it's a survival problem, because it happened that some people could not get the medicines they needed and they became resistant. A young man would lose maybe two generations of medicines. And he'll take another one and what if he becomes even more resistant - his hopes are smaller'. # 40.

### Monitoring of HIV treatment impact

The decision to change regimen, or less commonly to halt treatment temporarily, is made more precarious by intermittent shortages of monitoring tests. These tests monitor the strength of the immune system (CD4 count test) and the amount of HIV circulating in the blood (PCR test). Ongoing problems with the availability of supplies for CD4 and PCR tests were reported by service providers and PLHIV alike:

'When we haven't reagents for Viral Load or CD4 cell count, we can't perform these analyses, which means that patients' monitoring, which should be done three or four times every year, we usually perform it once or twice a year.' 9 SP.

Without the technical means always available to assess the specific condition of patients, deciding on the appropriate action to be taken in the event of shortages in treatment is very difficult and introduces the risk of treatment failure [8]. Service providers and PLHIV described how decisions made were therefore 'best guesses':

'So it's a big compromise, but it's very important to follow the CD4 cell count. I can't stop treatment to patients when our Institute has no reagents for CD4 cell count because I have patients whose CD4 cell count of 800 drops to 10 or 15 in a few months when we stop their treatment.' 9 SP

Clinic staff are given little notice as to when supplies of reagents for monitoring tests will be made available or for how long. This appears to partly be as a consequence of an ad hoc funding strategy. Reports suggest that supplies are purchased if and when funding, sometimes through donations, are made available:

'Monitoring, that's the first problem; sometimes we can [do it] but it is from donations for some tests for one hundred patients... and after that I don't know what to do.' 2 SP.

The inconsistency of supplies makes it very difficult for doctors to predict and plan how to monitor the conditions of patients and ensure there is an equitable distribution of resources. This was identified as a cause of concern in a number of PLHIV accounts. As one HIV positive person describes:

'At the moment there's not enough for everyone. I think that some kind of organisation could be made, so as not to be in the waiting room in anticipation of whether there'd be enough for me as well. I think that we should share them between us. It's like this: for example two of us are sitting there and she says: "I had a PCR test done 6 times", and I say: "Well, wait, I haven't done it a single time", and then this psychosis starts.' # 28.



## The Clinic

It is important to note before we discuss the impact of HIV treatment shortages on PLHIV, that PLHIV themselves made a distinction between their access to HIV treatment, in the form of HIV therapy and monitoring tests, and the care that they received from the HIV clinic in Belgrade. So whilst they were generally sceptical about the security of sustainable free HIV treatment, they were keen to differentiate between the doubt they had in the broader system and the trust they had in the staff at the clinic.

Participants frequently commented on the quality of care and the commitment of the clinic staff who they felt did their best with the resources available, and spoke of the doctors' frustration that they were not able to provide more for the patients. As well as their technical expertise, for many participants the staff are a significant support and play a key role in the management of their conditions, both medical and psychological:

'I really trust [them] because the doctors who are working with us have really good experience.... Really they give all of their own.... power to help the people here. I mean the doctors do what they can do, with what the systems give to them.' # 19.

For many who have difficulty accessing medical care elsewhere, the clinic represents a safe haven where they can be assured of a kind reception. There were concerns expressed however that the three doctors are supervising 750 or more patients, 570 of whom are on HIV treatment [2], and are overburdened with work. This workload is exacerbated by a significant proportion of patients attending the clinic for all their health concerns, even those unrelated to their HIV. This is because they do not feel able to seek medical treatment elsewhere for fear of mistreatment and discrimination (See Non-HIV related medical care). Participants reported feeling vulnerable because they were so dependent on the three doctors at the clinic, and were anxious that no other doctors were being trained in this area of medicine. Many patients see their own security and health as being interwoven with the clinic and the doctors, and this, for some, increases their uncertainty.

## Impact of treatment supply shortages for PLHIV

Throughout the study most PLHIV reported experiencing general uncertainty about the availability of HIV treatment. Depending on the circumstances at the time their anxiety related to supplies of HIV therapy, monitoring tests for CD4 and PCR or to both.

### **Living with the pervasive uncertainty of treatment supply:**

'It is very depressing you know, very depressing that uncertainty. You cannot be certain for next month, OK for next month, but in six months you cannot be certain that there will be a dose.... The main problem is that you are never sure that you will have medicines next time, next month... We also know there is a lack of tests for PCR and CD4 and we are all involved in such kind of thoughts. 'Oh are there any tests? I have to go quickly, to hurry to catch some tests'. People start to be desperate at that time because somebody who started recently on treatment for four or two years, suddenly they found hope again and when you don't have treatment everything is lost. I fear for treatment, and others are fearing for treatment also. Now we realise that it cannot last forever.' # 16.

PLHIV experienced treatment shortages differently, depending on their treatment combination at the time. For example those on trizivir and combivir reported experiencing supply shortages more frequently than those taking other HIV therapies. However the study



found that all participants, even those who had little direct experience of treatment shortages, felt more vulnerable because of the treatment supply problems. As one participant described, this uncertainty undermines people's belief that HIV can be a manageable chronic illness:

'We all feel closer to death in a way, and the problem is individually in each person how they handle this, how they cope with this'.# 34.

Participants reported that fears around supplies mean that managing their daily lives and even making short terms plans becomes more difficult. For many, it puts them off making any plans:

'Of course sometimes for instance I cannot plan time because it (treatment) must be constant you know and it's difficult when I have to leave somewhere, just say to go for holidays. Then there is the big question of how to manage it... Will you get enough supplies for this period or not? These are problems following problems you know'. # 20.

When therapy is available but monitoring tests are not, participants reported still feeling intensely insecure about their health, as they did not know what effect the virus was having on their bodies:

'[It is] also very bad because it makes them feel even more insecure because they could only guess what their state is. Some bad feeling might be just a side effect or it might be the symptom of something very bad happening. But there is no facility to have regular check ups and then they are suspicious that this might be a little warning sign for something really terrible happening and so on and so on.' 3 SP.

Towards the end of the study, in 2006, participants reported that there were fewer problems with shortages of therapy in Serbia, although inconsistent supplies of monitoring tests nonetheless remained an ongoing reality. Despite decreased occurrences of treatment shortages, the psychological impact of this uncertainty remained prominent. The insecurity that people have experienced, and some continue to experience, appears to have had a lasting impact on PLHIV's trust in the health system. The study found that in the absence of information about treatment supplies, the information vacuum is filled with rumours. The impact that rumours have in exacerbating existing anxiety should not be underestimated, as one HIV positive woman articulates:

'And it's not like I have this pessimistic view, but this condition now with the medicines is really bad and the talk with people who are on therapy and in the media it's always these terrifying headlines like: There Won't Be Any Medicines; or This Or That Donation Will Not Be; There Won't Be Enough Money For HIV Treatment. I feel this also influences the psychological state of people, they fall into depression, they feel they have no future. It's like some kind of extinction'. # 34.

A few service providers also had some doubts as to whether free HIV treatment could be offered in the long term:

'So it's really not good and I think now it's really getting worse and worse because that's what I hear from all the patients. They are so afraid that the amounts will disappear and what then?' 3 SP.

This uncertainty around treatment has had a profound effect on most PLHIV's confidence in the treatment of HIV/AIDS in Serbia and in Montenegro. The study found that a number of

participants, either themselves or those they know, who are distrustful of the continuous availability of free HIV treatment had decided not to start treatment, had stopped treatment or did not take their adherence seriously. A service provider described the rationale of PLHIV who decide not to embark, continue or comply with HIV treatment:

‘This [situation] would make many people decide not to go on treatment at all because they know what is going to happen. It is more problems than things to gain so this would additionally shorten the life expectancy... because why bother when you are not actually planning to do anything so why go to check ups and so on’. 3 SP.

### **Information available to PLHIV**

The lack of information available to PLHIV although evidently not a cause of treatment problems nonetheless intensifies the anxiety that they experience. This relates both to information about treatment supply problems and to an understanding of treatment more generally (treatment literacy).

### **Information about treatment supply**

The study found that a principal factor that affected PLHIV’s experience of treatment supply problems is the lack of communicated information about what is happening. Some PLHIV are constantly anxious about the next problem that may occur and therefore are neither confident in the sustainability of the supplies nor trust that they are given accurate information about the treatment situation. A serious consequence of this is that even when the system is operating well, they remain fearful:

‘All the time people are used to thinking the worst and all the time when you are not sure what’s going on then the story is bigger and bigger and the wolf is scarier and scarier.’ # 28.

When there is a treatment shortage, there is very little information available. A persistent theme in the accounts of PLHIV was their frustration that they were either given inaccurate information about what was happening or none at all. One participant described the effect of not being told the truth about the treatment situation:

‘The pharmacy doesn’t know at all. They’re always telling you it is on the border, it is in the customs, things like that. But it can last for half a year.... At the beginning you trust, but later you don’t trust them because you can not believe a story like that.’ # 16.

This undermines the trust that PLHIV have in the health system and enables rumours to become very powerful sources of information. Both of which amplify individuals’ fears and contribute to an atmosphere of panic:

‘You have to find everything through rumours or on your own.... there is this big uncertainty. It is really a problem but it depends on the person. Some people are more cool if they have more information or if they think that it is not as it seems, then they are more cool, like, OK, we will manage somehow. But if they really believe what’s going on, they’re terrified.’ # 33.

A number of PLHIV spoke about the value of information, as if it is traded like a currency. For example if an individual learnt through social networks that monitoring supplies were available at the clinic they were more likely to be able to access that service before it ran out again. As one participant describes:

‘If you are lucky someone remembers to call you and tell you and then you have to run, run to the clinic! ... It is hard when someone is in a better position because that person

has information and that person should be provided of some service but others who are supposed to be beneficiaries of that services they are in total ignorance... and even not receiving the service they are supposed to receive.' # 33.

In addition, the study found that amongst some PLHIV participants there were also alarmingly low levels of knowledge about their opportunities to access HIV treatment. Some PLHIV, despite their contact with NGOs, had not started HIV treatment because they were unaware that they could access it for free.

### Treatment literacy

Amongst a number of PLHIV, particularly those living outside of Belgrade, there was a low level of treatment literacy and knowledge about HIV prevention. This contributed to the difficulty of managing their HIV treatment and experiencing HIV/AIDS as a manageable chronic illness. If people living with HIV/AIDS are not given appropriate information about their treatment options, the consequences can be serious:

'Some of them were calling: "It's better for me to commit suicide now instead of waiting for the terrible agony which is going to happen in the following month. I have AIDS, there is no treatment for it". Sometimes I realised the person is on treatment without even knowing... Some of them were totally misinformed. I think definitely it has a bad influence... because my impression is that their expectations are really vague and terrible. Like [they think], "something awful is going to happen to me, I'm sure. What, I don't know. Who to ask, I don't know, and maybe it's better not to know." 3 SP.

#### The low level of treatment literacy undermines the perception that HIV with effective treatment is a manageable chronic illness:

'Out of these six years he was on anti-retrovirals for four years and he thinks he is the medical miracle. So what was his vision of his future? And he was told he was a medical miracle because he would live with HIV longer than 3 years. So the official information I was encountering was one to three years of life expectancy once you have been diagnosed as positive in our country. So this is awful, and I am not sure which percentage of positive people in our country really believe this information because some of our beneficiaries I was discussing this issue [with] in detail, they were completely convinced that this is the only possibility. They weren't even aware there is a possibility to live with AIDS.' 3 SP.

Taking HIV treatment is a big commitment and the level of adherence demanded for it to be effective is onerous. Participants felt that there should be more support available, principally in the form of digestible information to help people manage their HIV treatment appropriately. A number of PLHIV reported finding it very difficult to recall all the information they are given by the doctor during their consultation. These are often stressful times for patients and many participants spoke of their anxiety that after the consultation, which was often hurried due to the burden of work on doctors, that there were no other opportunities to discuss their treatment, side effects and adherence strategies. This was also noted in relation to participants' concern about information about their treatment options if they were co-infected with Hepatitis C.

## Coping in the face of uncertain treatment access

The study found that individuals employed a number of different strategies to deal with their concerns around the continuous availability of treatment supplies. We identified five distinct strategies in the accounts of PLHIV: accessing treatment becomes a full time job; taking what is available at the time; purchasing the treatment privately; stopping treatment until the current combination becomes available and secure; and finally avoiding starting or stopping treatment altogether.

### Accessing treatment becomes a fulltime job.

Some participants described accessing their treatment as a 'full time job'. Many participants spend considerable proportions of their time dealing with treatment problems. This is particularly acute for those who live outside of Belgrade and in Montenegro. As discussed, an absence of information around treatment supplies is considered a key characteristic of the treatment experience for PLHIV. A number of participants reported that some patients manage this by spending a considerable amount of time at the clinic to be certain of accessing any available information and supplies. This in particular appeared to refer to accessing monitoring tests.

### Taking what is available at the time.

Amongst the majority who are unable to afford to purchase the treatment if it is not provided by the state, there were many participants who felt that there was little option but to accept what was available and to deliberately try not to think about the consequences too much. As one participant said:

'I suppose that it will stop one day. I try not to think about it, it's too scary. The same will happen to the others.' # 27.

### Purchase the treatment privately.

There were a few participants who coped with treatment shortages by buying their treatment privately, either all the time or just during the months when their treatment combination was unavailable. One participant who is living on a pension of 250 Euros per month described how he was buying treatment privately while there was a shortage of his medication, and that for him this would not continue to be a viable option in the long term.

However the study found that some PLHIV felt the situation was so serious that they have little choice but to intervene in their medical treatment and adopt strategies that often go against medical advice. These strategies may well be harmful to individuals' health.

### Stop treatment until combination available again.

Some participants whose combinations were not available due to supply problems decided instead of changing combination to stop treatment altogether until their combination became available again. This was because they feel that the risk posed by changing treatment and the potential development of drug resistance was greater than not being on treatment.

One participant was offered to change her combination, but with the above view in mind she stopped taking medication for eight months. When, four months after she restarted, her CD4 count was down, the participant attributed the stress of the treatment situation as being a compounding factor:

'I had to change it several times. During this year I have had to change it several times, different combinations because they did not have trizivir. In the end I decided to quit, to stop taking any medication because I could not, my organism could not adapt to those changes.' # 33.

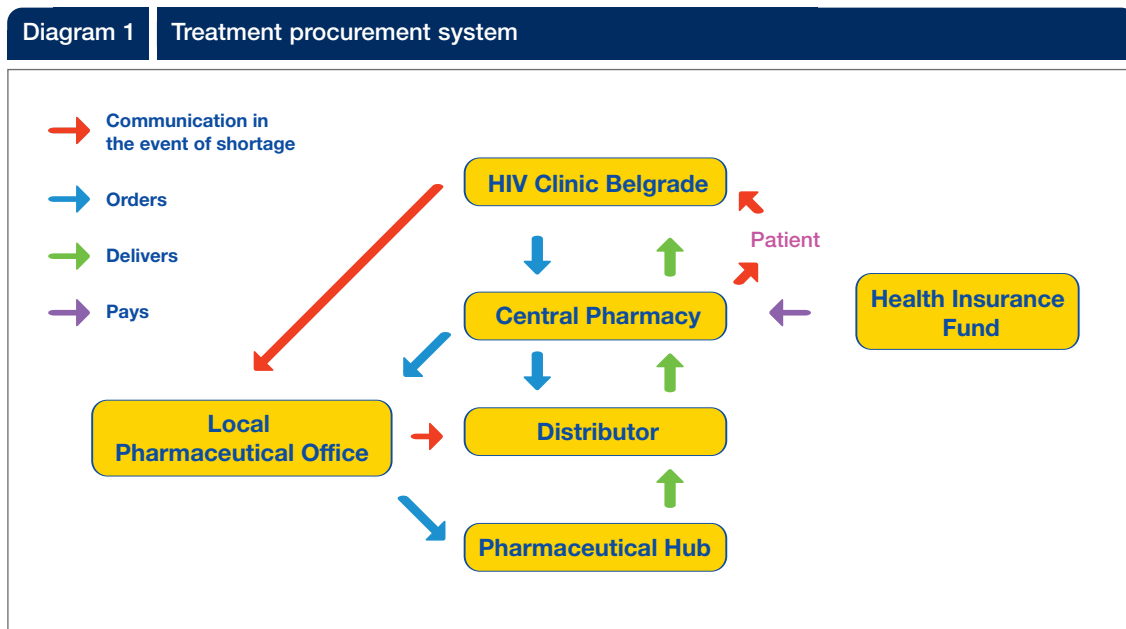
**Stop taking or avoid starting therapy all together.**

A number of participants involved in the study had decided that they would not start therapy because they were so concerned about the sustainability of continuous free treatment. Some had not even started therapy and despite deterioration in their conditions did not want to start. As one participant described:

'That fear that you have, you are in stress all the time, oh what will be? Will they find money for treatment or not. That fear is also very stressful, for people to be in fear all the time. Still there are a lot of people who even did not start to take medicine, they are so devoid of hope, not in whether the medicine will help them or not, but in the whole system. They cannot adapt to the system, to go to check themselves and to start with medicine.' # 16.

**Reasons for treatment supply shortages**

Evidently there are problems with the effective functioning of the treatment system. The study sought to explore the perceptions of the operation of the treatment system through interviewing representatives of all key institutions in the supply chain. Although participation was invited from all key stakeholder representatives within the treatment system not all were able or willing to be involved. The treatment procurement system is outlined in Diagram 1.



Whilst the study identified bottlenecks and areas of leakages within the system, there is a need for a thorough and systematic review of the supply and delivery system. We identified six reasons in interview accounts for treatment supply shortages: finance; management and accountability; poor information sharing; weak communication; institutional importance; and lack of alternative means of procurement.

## Finance

Money is typically characterized as the primary constraining factor behind the shortages of treatment and monitoring supplies. When asked why the shortages occurred, one service provider replied:

'[It's] only money because... there are no other reasons because we have virologists, we have a laboratory with the machine which is sufficient for our patients. There is no problem besides money'. 9 SP.

There were a number of systemic weaknesses identified in the financial planning of treatment procurement. It was felt by some that there is not a sustainable funding plan for therapy or monitoring tests. This appeared to be particularly the case in relation to monitoring tests. Whilst service providers' accounts emphasized that there were sufficient funds to cover the costs of purchasing HIV therapy, concerns persisted as to how HIV therapy could be financed if prices rose:

'So far, yes. We fit just right, last year we at least financed the list, but if prices rise there will certainly be prices [that] we won't be able to follow through.' 12 SP.

In the context of constraint and scarcity there is a need to explore cost-saving opportunities in the treatment system. For example, a service provider gave an example of the kind of innovation that may be required to utilize resources more effectively:

'There is a pharmacy at the Infectious Diseases Clinic where the HIV centre is located. Currently the drugs are distributed via the Central Pharmacy. The problem is that this Central Pharmacy is charging a 12% retail margin which makes it 600,000 EUR per year. This amount could be saved if the distribution of HIV drugs were moved to the pharmacy of the Infectious Diseases Clinic – where no retail margin is charged.' 15 SP.

It is clear that there are systemic weaknesses which contribute to the financial burden of providing fully subsidized HIV treatment. However there are also more macro economic factors which affect the financing of HIV treatment in Serbia and in Montenegro, for example the relatively small size of the HIV treatment market which influences the high prices of HIV therapy and slow registration of new drugs. This is a problem that is also likely faced by other countries in the region.

Additionally, a number of service providers felt that pharmaceutical companies in Serbia had not been sufficiently cooperative in reducing their prices. This had led to the need to impose participation fees, which has added considerable strain to the purchase and delivery of key HIV therapy. A service provider described in his opinion how the small market of the country affected the service that pharmaceutical companies provided:

'They probably do not have interest in that very small piece of cake, you know, so they really do not take care about how the supplies are coming: regularly or irregularly. We are small spenders and this is why they sort of, you know'. 1 SP.

It was also felt that the small size of the market and profit potential reduced the number of pharmaceutical companies interested in investing in the country:

'Well we are not attractive for them. The same is with drug companies. Some of the drugs are not registered in the country because they feel like... it will be very small market, they will not have a profit.... For example some companies like Gilead they are not registering drugs here because we are a small market with few hundred patients so they said it's not interesting'. 1 SP.

## Management and accountability

Some senior figures denied that financial problems are the principal cause of the treatment supply problems, proposing instead that problems arise from a lack of effective management, responsibility and accountability within the system. A key service provider stated that:

'The money is not a problem, everything could be covered by health insurance fund. There is discontinuity and very often we discuss with the Minister where the problem is. Why is it impossible to provide [medication] to the clinic the whole time and definitely the answer is that the people who are responsible for this are not very well organized and don't do their job in the best way....The main problem with treatment here is the people who are responsible for this do not have well developed management skills. The reason for the whole shortages of essential medicines and essential tests, from my point of view, is that it is not a very well organized system for this.' 6 SP.

This opinion was shared by other service providers:

'Everyone says, I do my job, but that person before me is waiting, they are not serious enough, I cannot trust them... So no one takes responsibility: "OK, this is my job. I'll do it, or if I don't, I'll take the consequences."' 10 SP.

We found that blame was shifted around the treatment system, with few people interviewed readily accepting weaknesses in their particular system component. It would therefore suggest that there is a need for a system appraisal, to improve the efficiency of each link within the treatment supply chain and to encourage accountability.

### **An unpredictable treatment supply punctures hope for the future:**

'If the purpose of all this is to improve the quality of life, for these people stress is the cause of bringing this quality a step lower. So all we do to improve some quality of life, it all still keeps going in circles. Why? Because of paperwork, because of someone's laziness. There are enough people who know something, there are enough people who want to do something, there are enough enthusiasts ....it can all be wrapped up nicely. Alright, we can't beat it, we can't get cured, but in a way at least allow people, give them some hope, if that's what we're talking about.' # 40.

PLHIV accounts emphasised that not having information about who is accountable and what is happening reduces their ability to raise complaints and pursue their rights:

'As soon as you don't know where its coming from you don't know who's responsible and then you don't know who to complain to when there aren't any medicines. Then you are just dependent on someone's goodwill....I think that the whole thing is connected with stigma. It's like keep quiet. You've got whatever you get.' # 28.

## Information sharing

The systematic collection of accurate information, required to order supplies and for monitoring current stock, was identified as a system weakness. It was reported that the clinic is asked to estimate the amount of treatment they will need over the following year.



Such long-term forecasting was considered a difficult task by the clinic as new patients are diagnosed and new treatment needs arise for current patients at an unpredictable rate. Problems occur in adapting supplies when there are changes in the treatment needs at the clinic, for example in the numbers of patients or in the drugs that patients are prescribed (due to adverse side effects or the obvious development of resistance). This may cause supply problems:

‘These companies who import the drugs have a plan for the year and then if we spend more drugs than they have planned for they are not able to get any more very quickly. It’s a very slow system.’ 1 SP.

However, there was also criticism directed towards the clinic and pharmacy by a number of service providers who felt that there was insufficient data collected about the precise number of patients on treatment and what therapy they were being prescribed. The clinic’s data system is still paper-based which hinders the efficiency of making accurate calculations and sharing the data with stakeholders within the treatment system:

‘Well basically those (the clinic’s) are not exact data, because even if they, when you ask them at the Infectious Diseases Clinic, they always have different data from month to month. Because I think they are not systematic in their work.’ 15 SP.

It is very difficult to access other data sources about treatment supply. For example the data of pharmaceutical companies are collected for commercial purposes and companies have a vested interest in protecting access to this information:

‘Everything is estimations, nothing is correct. For example from the distributors you cannot get data because they will not tell you how many [other companies] ordered drugs. Also in the pharmacy you have a problem, they will not give you data. I also personally don’t understand that. It should be public data and should be official.’ 15 SP.

In situations when supply does not meet need, the lack of accurate data traceable throughout the ordering and delivery system makes this shortfall more difficult to account for. It is not easily identifiable how many patients need what combinations of drugs, how much has been ordered and how much stock is remaining. It also means that it is difficult to identify at what point the system has broken down. This therefore impedes the identification of how the problem could be resolved and the system improved.

### **Communication**

Whilst there was criticism that data was not adequately collected and shared at the level of the clinic, it was also reported that the doctors at the clinic were given insufficient information about impending shortages, and how long they were likely to continue, from those responsible for treatment procurement and delivery.

Doctors at the HIV clinic get their information about supply stocks from their daily communication with the pharmacy. This form of subsistence information means that they are unable to plan or forecast shortages and are only able to react when and as it happens. This means that alternative plans are implemented on an ad hoc basis. It was reported that as a result of not knowing how long CD4 monitoring supplies will be available for, supplies are often not distributed evenly amongst the patients:

‘We haven’t got any plan [for distributing monitoring supplies]. We can’t have any plan, because we don’t know when reagents will not be available. So when we have reagents we can’t plan how to distribute these tests exactly for every patient.’ 9 SP.



Consequently many PLHIV reported that CD4 tests were given on a first come first served basis. This adds to the uncertainty surrounding the delivery of HIV treatment for PLHIV. Some participants complained that the distribution of resources were unfair as whilst some patients had received CD4 tests quarterly through the year, others had had only one test in the same period. One participant who had been on HIV therapy since 2002 had only had 'two or three tests since then' # 20.

Currently distributors have not signed any agreements which oblige them to notify the Health Insurance Fund and pharmacy if there are going to be any treatment shortages. When these institutions are notified it was reported that notification is given shortly before the event. There is therefore very little time for contingency plans to be designed and implemented. Instead the study found that when supplies of therapy run out it is the doctors who contact the pharmaceutical representatives directly and between them they attempt to resolve the problem. Both patients and some service providers were critical that it was the doctors themselves who are forced to take on the role of chasing up treatments, instead of others within the treatment system. This diverts them from their primary function, which is to treat patients:

'But we have so many problems like this one and we are the whole day on the telephone and calling to get one medication to reach the pharmacies, and so on'. 2 SP.

PLHIV likewise reported that they felt that they were not given enough information about the shortages, how long they were likely to last and what alternatives would be put in place. They also felt that nobody, other than the clinic doctors, acknowledged the problem or took responsibility for resolving the issues. Many PLHIV spoke about how alarming they found the situation and how this was intensified by an absence of information and accountability from those managing the situation. While it was commonly reported that the only people who the patients are able to get information from are the doctors, as one participant said, even they know little:

'I went to my doctor and she said 'I don't know what to do!' She was desperate. I don't know what they are doing, how many telephone calls, trying to help us to find a way. But they cannot do much, we have a Ministry of Health, we have our government, we have I don't know what and they don't want to see about our problems.'

She goes on to say:

'It's really difficult to get an explanation or an answer and as I've said this is psychologically really bad, and even the doctors don't- can't give the right information, they don't even know and the patients don't really know whose job it is to know... Hardly anyone who is really in charge sort of shows up and says something about it'. # 33.

In addition to communication concerns in relation to the clinic, the study found that communication between institutions within the treatment system relied on a few key individuals and was not integrated within the system. This meant that there were relations were poor between individuals, communication between institutions suffered. Service providers identified the Institute of Infectious and Tropical Diseases and the Clinical Centre of Serbia as one such example shows:

'His level of responsibility is to have good communication, connection and cooperation with the heads of clinics.... And when we start talking about this the head of the department for HIV said to us, "Yes, but I have a problem with bad communication with my director and he doesn't have a good communication with the top manager of the Clinical Centre"'. 6 SP.

## Institutional importance of HIV

Several service providers within the health care system felt that a factor contributing to the problems with the continuous supply of treatment was that HIV was not an institutional priority. Accounts emphasised that some of the key figures, amongst the institution's management, are not adequately committed to the provision of HIV treatment and this affects the management of the system:

'[I was told that] the 'infectious diseases are not interesting for the top manager of the centre, we (Institute of Infectious and Tropical Diseases) are the last one in the row'. And because of this the Director of this institution is not as interesting for the top manager as the Director for Neurosurgery or any other.... It is maybe a personal issue I don't know, but definitely it is an explanation, we are not so important for the top management.' 6 SP.

This was not a unique position and other service providers similarly felt that HIV/AIDS was not of sufficient priority to the 'top management' and therefore funding for supplies was inadequate:

'The authorities in the Clinical Centre of Serbia do not see HIV being a major problem... They always said we have much more priorities in surgery, paediatrics, oncology.' 1 SP.

It is acknowledged that balancing needs is inevitably a difficult task. The study identified that there was a tension created by the expense of HIV treatment and the already overstretched health care system, and this constrained both PLHIV and service providers pursuing the state's treatment. As one service provider described their discomfort in discussing supply problems with the Health Insurance Fund:

'They in the Fund know about our problems, you know. Some of them they said: "what do you want more: you have enough; look how much money you spend".' 2 SP.

Whilst both service providers and PLHIV do not expect HIV/AIDS to be resourced to the detriment of other diseases, some felt that HIV was deliberately not perceived as a priority in order to excuse not giving adequate support to PLHIV:

'Well they are not very much interested in the issue of HIV...in general. ... I think they feel that they have done their best by means of spending money for HIV. And they will always say: "Ok, look around you, there are some other diseases which are not covered so effectively like HIV" for example. So they have their alibi.' 1 SP.

In addition to institutional prioritisation we uncovered a strong feeling amongst PLHIV and some service providers that whilst they can rely on the support of the doctors at the clinic, they feel that others in key positions within the treatment and political system are not fulfilling their responsibility to ensure the continuous delivery of treatment. Some PLHIV feel that the political rhetoric about commitment to the provision of HIV treatment does not translate to reality. One service provider described her frustration:

'Maybe just you know to be present at the meetings, but actually to do something and to give the right priority and to really solve the problem, that's a completely different question'. 3 SP.

Subsequently a number of PLHIV spoke of feeling very much alone in managing their health and treatment difficulties.

'You have to care for yourself, either they can't or they don't know what to do'. # 33

## Alternative means of procuring treatment

In the event of treatment shortages many PLHIV tried to resolve such problems on their own by purchasing treatment through alternative channels. Some PLHIV who can afford to have purchased their treatment abroad or privately. However there is very little information available about alternative means of procurement. This makes it even more difficult for individuals to manage the treatment shortages using alternative channels. The study found that there is currently considerable confusion amongst PLHIV about where and how you can privately purchase treatment.

If PLHIV could purchase treatment, and be reimbursed, they could avoid having to either change treatment combination and risk accelerating the development of resistance to their original and new combinations, or avoid stopping altogether:

'It could be done much, much better at least with complete honesty for the patient for them to be able to plan, to organise [it]. Maybe some of them were able [to] and I know some of them were able to borrow the money, to organise with some relatives from abroad instead of waiting for the clock to say the right time. It's much worse that way.' 3 SP.

PLHIV also reported that during periods when monitoring tests are unavailable those who can afford it visit private clinics to have the tests done. This option is extremely expensive and there is scarce regulation of this sector. PLHIV would benefit from there being a private clinic that is recommended by the HIV clinic so that patients can be assured the service that they receive is regulated and supervised.

## Outside of Belgrade

The study found that there were additional problems encountered by PLHIV living outside of Belgrade in relation to accessing HIV treatment and care. Whilst PLHIV living outside of Belgrade encountered difficulties with treatment supply problems as discussed, they also encountered serious problems with accessing HIV care in their local towns. These were identified as the problems associated with needing to get referrals to access HIV treatment and care, and the concerns surrounding the decentralisation of care.

At the time the study was conducted specialist HIV health care was only available in Belgrade. They were unable to access any, or only minimal, specialist HIV care in their own towns. In order to access HIV treatment and care PLHIV need to follow a referral process before they are able to travel to Belgrade for treatment. The bureaucratic procedures were described as strenuous and time-consuming with multiple signatures required. One participant described the steps in the referral process:

'It needs so much paperwork like about ten signatures just to reach the clinic in Belgrade. Here you start by getting a referral with the signatures of three doctors.... So the procedure is that you first go to your GP and then... he refers you to the Clinic for Infectious Diseases and then you get three doctors to approve two sheets of paper and then you go back to your GP with this so he can give you your travel order, and also the referral to go to the hospital in Belgrade and then from there you need to go to the social services before some kind of committee for reimbursement, and then you get three or four more stamps there and then finally you get to the station to buy the tickets; and there's so much paperwork you need to leave five or six hours on each day for three or four days at a time.' # 36.

As well as being exhausting, many felt that the referral procedures to access HIV treatment jeopardised their general ability to manage their illness: as it is so time consuming that it is difficult to retain a job and it increased the number of people aware of an individual's HIV positive status. Therefore although accessing treatment is necessary to maintain their health, the process of accessing treatment increases their vulnerability to stigma related consequences. This is discussed further in the social impact of HIV section. As the same participant goes on to explain:

'It's a really small place, there are around 10,000 inhabitants, it is a part of the town of (...); but everyone knows each other and it's like a village. I even ask my doctor to put the codes down on my health care record and she writes HIV in large letters and these files are shown to- other people can see them and I don't know why that is. The second thing is that my neighbour is a nurse; so she sees these files when she's filling them in and writing the prescriptions so she tells her son, her son tells a friend and that's how it spreads.' # 36.

Once participants have got their referrals, with all the risks this involves, they have a long journey to Belgrade. A participant describes their day travelling from Niš to the clinic and back:

'I start on the bus at 4 o'clock in the morning from Niš. It arrives directly to Belgrade in 3 and a half [hours]... And then I go directly to the Clinic for Infectious Diseases there and wait for an hour or two. If I arrive first thing I go in straight away, and if it's a bit later and I'm not the first then you need to wait for much longer, sometimes even until one! And then again straight to the station, 'cos... you get tired just by waiting in the waiting room, and the trip, and not sleeping, and then again to the station to go back to Niš, and sometimes I get there around 4, 5, 6 in the evening in Niš, and it's... terrible, I'm tired physically. It's exhausting'. # 38.

Some have to travel even further:

Last time there was a man from Uzice! He had to, the poor guy, get up at 3 in the morning in order to make it to the Clinic by 11. And he had to wait for a while, and he was in great panic if he'd make some train or not, 'cos it's cheaper to travel by train than by bus, so it also has to do with expenses, if you ask me totally unnecessary ones.' # 2.

Currently there is no refund available for an escort, so when individuals are unwell, a common reason for needing to attend the clinic in Belgrade, they must undertake the journey without anyone to help them.

However the situation is changing and HIV services are becoming decentralised, with clinics opening in Niš, Novi Sad and possibly Kragujevac. However whilst participants were unhappy that they could not access HIV healthcare in their own area, many are anxious about the quality of care that they will receive in the new clinics. This doubt appeared to stem from a number of concerns. Firstly participants appeared confused about what services would be available to them and how it would affect their relationship with the clinic and doctors in Belgrade. Secondly there appeared to be some concern about the ability the doctors in the local clinics would have to treat the patients, both in relation to their expertise and experience, as well as what kind of equipment and facilities would be available. As a result many participants expressed a desire to continue going to Belgrade. Some PLHIV also spoke about a lack of trust they had in the doctors in their local areas from their past experience with them. One participant described a situation where the doctors charged with caring for PLHIV in the area refused to treat her:

'So my mother took me to the centre for HIV and the doctor said, 'We don't have the legal right to treat HIV patients, this clinic is only for death for Hepatitis and HIV/AIDS'. She told him, 'Give her just one drip', and he told her, 'it's only water, she doesn't need it'. My mother was very mad about that and in the institute for hygiene, they found out what is the matter. But I have to do it through connections. The doctors in our town mean we have very bad treatment here.' # 37.

Despite the risks involved in the referral process, PLHIV emphasised that an advantage of going to Belgrade for treatment was that they had a greater chance of anonymity when accessing care. Some participants felt that their anonymity would be jeopardised by being seen attending the clinic or from the anticipated indiscretion of certain medical staff, who some PLHIV felt did not respect their confidentiality:

'I hate that there isn't some kind of private paperwork for doctors, that it's not kept secret. For example now, you're a doctor from my neighbourhood and this paper came to the Health Centre, you saw it and you will tell your children to be careful of me, and your children will go and talk around town, and that's how it's spread. These doctors don't respect the patients' privacy, it's very rude.' # 13.

This anxiety was fuelled by the experience of some PLHIV who had suffered the consequences of medical staff's breach of confidentiality. One participant described how after their diagnosis the doctors asked them to give them the contact details of all their partners and the consequences:

'They (the doctors) told me give us the numbers of your friends, boyfriends, it will be incognito: but it wasn't incognito. That year, everybody, the whole city... this is a small city, everybody knew that I am positive. And when I pass by somewhere they were talking about me. "Oh, she has AIDS". # 37.

Some PLHIV felt that these same medical staff although working with PLHIV held prejudiced opinions about PLHIV. An HIV positive man went to the doctor with his girlfriend to get advice about prevention:

'And you know what they [the doctor] told her, "You're such a beautiful girl. You can have thousands of guys, what do you need him for?" .... And then they say "We fight discrimination!", and these same people are leading in some (HIV) organisations.' # 39.

This participant was so upset by the attitude of the doctor he will no longer visit them for a referral for Belgrade. As he is unable to complete the bureaucratic procedures necessary to be reimbursed for his travel and treatment at the Belgrade clinic and he is unable to afford it himself he has stopped taking HIV therapy

Despite the poor treatment and the mistrust that some PLHIV have of a few medical staff, participants spoke about their fear to openly criticise the individuals because they are dependent upon them to receive care:

'And if I were to say this, who knows what would happen to me tomorrow, I'm telling you this... They're (the doctors) counting on it. We're in a minority, we keep a low profile, we're scared and we won't raise our voices. There's few of us to do something big, and we're in the situation that we have to listen to them.' # 38.

## HIV Treatment: key points and recommendations

While there have been improvements in the delivery of continuous treatment in Belgrade over the course of the study, with reported treatment shortages becoming less frequent, the study found that PLHIV perceive access to free and sustainable HIV treatment is fragile and remains a significant concern for PLHIV. Amongst service providers there was disparity in the way the treatment system service was viewed. Whilst some considered the situation to be serious for PLHIV, others perceived the system to be functioning appropriately in the circumstances.

Two strategies were employed in the event of treatment shortages: the first was to change components of the combination of drugs that individual patients are prescribed; and less commonly the second was to interrupt treatment until the appropriate therapy became available.

These strategic decisions are made more difficult, and more precarious, by intermittent shortages of monitoring tests. Ongoing problems with the availability of supplies for CD4 and PCR tests were reported throughout the duration of the study.

The study found that PLHIV's anxiety about the unpredictability of treatment supply was exacerbated by a lack of available information.

### Key recommendations:

- There is a demonstrable need for a thorough and systematic review of the treatment procurement and delivery system. This review would need to identify bottlenecks and areas of leakages within the system.
- In the absence of clear accessible information, an information hub is needed where PLHIV and those close to them can access information about treatment. This information hub could be a central access point for information and services relating to other needs of PLHIV, such as information on bureaucratic procedures, access to health care and legal services, and availability of support services.

**For more detailed recommendations see 'Conclusions and implications'**



# Non-HIV related medical care

In addition to accessing HIV treatment, PLHIV access other types of health care. While PLHIV accounts emphasised that they were treated with care and respect at the HIV clinic in Belgrade, most said they felt anxious about seeking care and treatment outside of the clinic. The study found that the majority of participants had encountered negative experiences when attempting to access non-HIV related medical care. There were a few participants who reported no problems.

## Refusal of treatment

Many PLHIV reported that the reactions they received from doctors and nurses throughout Serbia and Montenegro were unpredictable, and often negative. In some cases they had been refused treatment. The study found that accessing care was particularly difficult in the areas of dentistry, gynaecology and surgery. However a number of participants reported that they had had negative experiences due to their HIV status at their primary health care centres. This is particularly acute outside of Belgrade.

This is an example given by a participant who recently tried to arrange to be seen by a gynaecologist. She had encountered difficulty previously and therefore as a precautionary measure had decided to use a personal contact to help her get an appointment. Despite her connections, she was refused an appointment for an examination:

'When I told her that I was HIV positive she said, "I can't treat you, I have to ask my supervisor doctor." I said, "OK, what should I do, should I call you or will you call me?" "Oh we'll be in touch". When I called her in a few days she told me that her supervisor doctor had forbidden her to check me. It was just a normal gynaecological examination, no kind of intervention just an exam. I was shocked, because I expected, I had a connection you know and both these gynaecologist doctors had just finished university and so I expected them to know better. I could not believe it. Always there is some excuse; you can go nearer your home or things like that. But it is only an excuse to send you away'. # 16.

The study found that in prison too, PLHIV encountered some difficulties accessing treatment:

'They wouldn't pull out a tooth in Pozarevac in the Health Centre! They wouldn't pull my tooth out. And then the warden, at the women's prison in Pozarevac, the warden that came over, when he saw it, when I sat on the chair, he says: "We're out of material!" Suddenly like they don't have material.' # 11.

Many PLHIV reported similar stories where medical treatment and care had been refused, either directly or indirectly. They described their experiences of having to search for a doctor to treat them as humiliating and exhausting. In addition to this being a threat to their health these experiences have created a deep sense of insecurity among some PLHIV, who are uncertain as to whether they will be able to access medical care if they need to. The accumulative stress of being refused treatment and denied the human right to medical care was commented upon by a service provider:



'How is it possible to live like that? How many times can they be like, "who's going to reject me? What shall I do when I need a dentist....? When I need care which I can not get [at the clinic] and I must go somewhere else. When I carry this illness, this status as the mark, as something they took away from me, all my rights, all my life I had before". I really admire all those people who can still live like that ... and try to organise their life with dignity.' 10 SP.

If PLHIV do manage to gain access to medical care, they are frequently mistreated by medical staff. One participant recounted an incident in which she had to get a doctor's signature as part of the bureaucratic procedure necessary for a particular referral. The doctor at the primary health centre was not required to examine her but just to give her a referral:

'My doctor was not there, and this other guy was the replacement and he did not want to see me at all. In the end because someone had to see me he cleaned the table and he removed the chair so that I could not sit and talk with him. I was supposed to stand. I asked him just for the referral paper for the other institution and he started to clean the table with alcohol, to wash it again. The main thing he was interested in was how I became ill. I never went to his organisation again.' # 16.

#### **Humiliation in accessing medical care:**

'It happens sometimes even if I am scheduled for an appointment they did not treat me until the end, the very last person. Then after some time I told them please I have to plan my days, if you can tell me to come at the end it would be much easier for me. But they are not honest. "It is not free, that special room on the end it is not free, they cannot do it now". ....After you feel angry, "Why am I different? OK, I can understand technical problems, problems of cleaning instruments. (But) If I am honest with you, why can you not be honest with me?" I feel like they do this on purpose- make me sit the whole day, so everyone can see me. "Oh there's the person who is HIV". They don't care. They are not in my skin; they don't feel what is the problem'. # 16.

#### **Facilitating access to medical care**

As a response to the problems PLHIV have in ensuring access to medical care, participants reported that they often had to rely on the doctors at the clinic to personally facilitate appointments with other doctors who are known to be willing to treat PLHIV. Arranging these appointments, and often calling on personal favours, is seen as the most pragmatic strategy to manage the situation. However it takes up a great deal of the doctors' time, which they can ill-afford:

'They are coming to us and then we are calling our friends or colleagues and making some appointments and something like that... It takes very, very much ...well so much energy, and most of our energy is going to our medication problems'. 2 SP.

There were reports that there are occasions when doctors, who have agreed with the clinic doctors to treat the clinic's patients in the end refuse to. As one participant describes:

'Yes, they tried to find doctors who can be helpful, who are not afraid and who are willing to work with HIV patients but... it is always a disappointment. They find one doctor and after it is not good, that Doctor does not want really to treat us. He just wants to improve his career by saying that he will work, but in the end he will not work'. # 16.

Even when these particular doctors do fulfil their obligation to treat PLHIV, it is still a fragile strategy as PLHIV are then dependent on only a few key individuals for their medical care. The difficulties in accessing non-HIV related medical care mean that many patients visit the clinic for nearly all of their medical needs. Even when PLHIV are given medical treatment the negative reaction they encounter puts them off visiting health institutions outside of the clinic again. As this example of a young man's experience demonstrates:

'When I found out I was HIV-positive, I also had another problem. I has some hernia behind my ear, like an ulcer, and then I went to New Belgrade, where they were supposed to cut it there, drain it and that was it. ... Like the woman [doctor] stepped away, ran away, like: "Oh! How did you get here? Why are you here? You have your own clinic!" like "Hey, you, AIDS person, you have your own clinic!" that's how I understood it: "You people have your own clinic!" And then ok, I asked her like: "How much do you need? Please do this for me, now that I'm here already!" And she didn't ask for money or anything finally she did it and like: "Please go for everything you need to that clinic of yours." So that I never again went to a doctor.' # 13.

This increases the workload of the three doctors at the clinic, as some feel that the clinic doctors are the only ones that will help them:

'We gave the patients [our] telephone numbers and they are calling us on weekends, you know, any time because they don't have other way to do something, if they need some help.... especially outside our Clinic. I mean in our department they can have doctors, but outside of this Clinic it's very hard to get some help'. 2 SP.

## **Medical knowledge and stigma**

It appears that a fear of treating PLHIV persists amongst a large number of medical staff. From reports given by PLHIV and service providers the existence of these negative views is particularly prominent outside of Belgrade. One doctor described conversations he had had with his colleagues about his work with PLHIV:

'Not all of them, but some of them say: "How can you work with them? How can you be like that?" We are working on that to break that fear and it's very hard, very hard. Especially in other cities, in Belgrade maybe it's not ..., you know, but in the country it's very hard'. 2 SP.

There is a low level of knowledge about the risks of examining and treating PLHIV and the opportunities afforded by treatment, amongst doctors and nurses. Again this appears most pronounced outside of Belgrade. However it is reported that the situation is improving and advances are being made through workshops with medical personnel throughout Serbia and personal initiatives of a handful of doctors in their own working environments.

It is clear though that, despite poor knowledge in some cases, the problem is not just one of education, it is also a social problem. Some felt that health care workers had adequate

knowledge about transmission routes and the risks of treating HIV positive patients, and therefore their attitudes were not sustained by ignorance, but instead reflected a more generalised stigmatisation of PLHIV within the population:

‘After that I realised that if the doctor is an OK person he will treat you no matter what. If he’s afraid he will find an excuse no matter what. It’s always like that’. # 33.

Inevitably though the stigmatising attitude held by some health care workers further justifies for the general population their own fears and prejudicial behaviour. It is an influential cycle. As one participant explains:

‘How can other people behave if they hear the health workers themselves are in panic, what else is there to expect from the general population?’ # 29.

The extent of the problem is demonstrated by reports from both service providers and PLHIV who say that doctors who treat HIV positive patients outside of the clinic are often ostracised for doing so by their own colleagues. Some felt that this was because colleagues were concerned that their patients would stop attending the clinic if they knew that HIV positive people were also treated there:

‘So, the only place... where health workers are relaxed and where they communicate normally is the HIV Clinic with the patients. There are some individual cases in Health Centres who see HIV patients with problems, but they’re individuals, they’re not the whole medical personnel. They’re individuals who still... because of seeing them get penalties from their colleagues... that’s a fact! I mean that’s the truth what it’s like.’ # 29.

### **Medical confidentiality**

A number of participants reported that they felt their medical confidentiality was not respected when they visited the doctors. A few PLHIV reported being very uncomfortable in the waiting room and feeling that medical staff were negatively, and unnecessarily, discussing their antibody status in public. The study also found that a number of medical staff enquired unnecessarily about the transmission route of individuals.

‘They don’t want to help you, but they want to talk about this’ # 33.

Many participants described this experience as painful and reinforced their perception that others thought they were in some way guilty and deserving of their illness.

A commonly reported issue was that patients’ files were clearly marked on the outside with HIV positive in red pen. This continues despite calls from key doctors and NGOs to stop this unnecessary practice. In such circumstances, being handed their medical file felt like a transgression of their medical confidentiality and a deeply unpleasant experience:

‘You see what kind of marker HIV’s written with. Well, that’s murder! That, I don’t know how to explain it, it’s as if one was stabbing you with a knife in the heart and another one in the back! And when the nurse goes to take the file I get the shakes! I start shaking, although she’s silent, she’s not saying anything, I know.’ # 5.

For those who need to take copies of their medical documents out of the medical setting for administrative procedures, having their HIV status publicly displayed can cause serious and upsetting problems for them:

'When people should go downtown and have a copy of that particular report and go into a store for copying those documents and those people who work in the store will see the report with HIV plus and they will look at them strangely, saying like I don't know. We had several cases when people hear that an HIV positive person is near to them they say like, 'Get away from me. I don't even want to be close to you or near to you. Why do you want to speak with us?' # 13.

#### Refusal of healthcare and the reinforcement of stigma

'I had a situation when I needed to do some blood tests and I went to the military hospital because that was the only place where I could find the needed tests. And of course I was waiting for the nurse and after half an hour she showed up. She started yelling, 'I told you I don't want to see you again, anyone of you! What if I harm myself and become sick'. It was horrible because there was some other people waiting and in front of them she humiliated me. I started to cry of course because.... imagine how one could react! Some young doctor tried to settle me down and he says to me you can sue her. But of course I didn't have this in mind because I have other problems to think about. Its not the way I want to live, you know. This is just one example, but imagine other people maybe have much harder stories, and they have to face things like this everyday.' # 20.

#### Non-HIV treatment: key points and recommendations

Most PLHIV reported feeling anxious about seeking care and treatment in health care centres outside of the HIV clinic. The study found that the majority of participants had encountered negative experiences when attempting to access non-HIV related medical care. There were only a few participants who reported experiencing no problems.

In addition, a number of participants felt their medical confidentiality was not respected when they visited doctors for non-HIV treatment.

As a response to these difficulties, PLHIV often rely on doctors at the HIV clinic to personally facilitate appointments with other doctors. This increases the workload of the three doctors working at the HIV clinic and does not directly address the discrimination which PLHIV are facing in medical institutions outside of the clinic.

A fear of treating PLHIV appears to persist amongst a large number of medical staff. It appears that this is not just a problem of inadequate knowledge about HIV transmission but is frequently a consequence of social prejudice as well.

#### Key Recommendations:

- There is a demonstrable need for HIV education workshops for medical personnel that have been held around Serbia to continue. Further educational and advocacy work with medical professionals appears to be valuable in addressing knowledge gaps and stigma. A key aspect of education work should include the importance of respecting a patient's right to medical confidentiality.
- An environment of accountability needs to be fostered which encourages doctors to treat all citizens and which penalizes those that refuse treatment to individuals on the grounds of their HIV status.

For more detailed recommendations see 'Conclusions and implications'



# Social impact of HIV

'If you treat someone so that you're the one who needs to put time and energy into getting medicines, to run around all the time chasing papers, that's really stupid... Let alone have a normal life, you're being judged! It's interpreted like: "You got what you deserved!" from now on your life will be a horror film!' # 14.

In addition to HIV treatment and access to medical care, PLHIV reported encountering many non-medical problems related to their HIV status. The social impact of HIV on the lives of PLHIV is pervasive and operates at the level of the individual, the family and structurally at the level of the community. It is important to understand how this wider social context mediates and shapes the lived experience of HIV.

The study found that many PLHIV anticipated or experienced discrimination in their daily lives. In differing ways this was felt at every level of social encounter, in relationships with close relatives and friends to bureaucratic procedures, for example collecting their pension.

## Neighbours yell abuse at an HIV positive man:

'I had terrible stress in April because of that woman downstairs, who shouted from her terrace: "He has AIDS! Get away from him!" And then some bloke from my building when I pass by says: "He should be treated with a stick!" something like that... I didn't react at all, I didn't want to mess around... I was shivering, I had no strength to... I neither had the physical nor psychological strength to confront them, I just kept quiet and smiled, like: "They are fools!" But the people got out on their balconies! She was yelling: "Get away from him! Don't let him touch your dogs! He will infect you, he has AIDS!' # 3.

These experiences cannot be understood in isolation from each other, for they are felt by the individual accumulatively. Stigmatising experiences undermine a sense of self worth. Some service providers commented that they expect PLHIV to participate in efforts to challenge this discrimination, however it is precisely these corrosive experiences that undermine PLHIV's capacity to do so.

Whilst the experience of fragile HIV treatment delivery may directly affect the energy and health of PLHIV, the stigmatising experiences that they encounter in nearly all aspects of their lives influence their capacity, and belief in the benefits of, participating in treatment advocacy to challenge the status quo. Uncertain medical treatment access (both HIV and non HIV) weaken ability to fight stigma: the layered effect of stigmatising experiences undermine the capacity of PLHIV to engage and address both treatment delivery and stigma.

The social response to HIV is complex and multifaceted. We found it to have a pervasive impact on the lives of PLHIV' participants. Within the remit of this report we are unable to map out all the multiple levels in which it operates and the effect that it has. Therefore we will take the family and employment as two examples to show how the social response to HIV is manifested.

## Case example – family

In times of crisis the family is often perceived as a relatively supportive environment. Many PLHIV, despite their fears in disclosing their status, looked to their families for support:

‘The most important thing here is that your family accepts it... they’re your primary strength for everything in life.’ # 22.

However the study found that there were many examples where the support offered by family members is weak and constrained. This restrained support appeared to stem from both the particular social construction of HIV/AIDS and misunderstandings in the basic knowledge about transmission routes. This tension in the support given is reflected in a number of participants’ accounts that family members frequently blamed HIV positive individuals for the social consequences of their illness. One young man, who disclosed his status to his close friends and family, reported being told by his mother:

‘Look what you’ve done?! You made all our friends go away! You ruined your brother’s career! You did the same for your father.’ # 13.

Incomplete knowledge about transmission routes increases the levels of fear about the risks of infection. This influences the behaviour and attitudes of family members to those who are HIV positive. Consequently a number of PLHIV suffered from varying degrees of physical isolation by those with whom they share their home. As the same participant explains:

‘They isolated me in my room right away, I had my own plate, my own fork, my knife, my sheets, my towel for the face, for washing hands, my own glass for water, my soap. "You sit in the armchair there, you can’t sit all around the house". I don’t know, it was isolation in my mother and father’s house like: "We have another son who’s a year older than you, we don’t want him to get infected too..." and they were scared.’ # 13.

Some of the family members reported that it was only much later after learning of a relative’s status did they become aware of the improbability of infection. A woman whose partner is HIV positive, and was present at her husband’s interview, described the conflicting information that they had been given about the risk of transmission and how this had caused her to fear him unnecessarily:

‘Everyone is telling a different story, but simply this fear is inside me. I know it can’t be any other way but through blood, to get infected like this but still... Some people said he should have his own set for eating, his own glass... No one gave us the right information what and how... And everyone said something different. Then simply at the beginning, to be honest now, I was just scared of the children coming near him, I just wasn’t informed. But now it’s different, but the fear still remains in the subconscious.’ # 4 (HIV negative spouse).

Poor knowledge about transmission routes and the fear it creates does not apply only to those around PLHIV, but also to some HIV positive individuals’ themselves who fear the risk they pose to others. For example one HIV positive couple, despite being in contact with an NGO, were unaware that HIV could not be transmitted by touching people. This unnecessarily

meant they were physically segregated from their family in their living space, which seriously impaired their relationships with loved ones, and increased their physical and emotional isolation:

'I watch my grandchildren playing every day... If I could just hold them, hug them like this, I desire it so...We can't touch them like this with our fingers, we can't... They're so scared! I just miss the children so much, I desire nothing else. One day I'll tell them to get a towel, the bathing one, and they can wrap it up around them so I can hold them over the towel!' # 5.

The contradictory nature of the restrained support that the family offers to HIV positive relatives reinforces and feeds the existing social response to HIV which stigmatises the individual.

### Case example - employment

Employment and income are critical to the capacity that PLHIV have to respond to the treatment difficulties that they face. The study found that nearly all PLHIV participants encountered employment problems due to their HIV status, either through losing their job, struggling to keep their job or being unable to get a job. Not having a job profoundly affects PLHIV's capacity to cope with and react to their treatment access problems, both HIV and non-HIV related.

The fact that HIV treatment is perceived as uncertain, yet very expensive, intensifies PLHIV's need to have a secure income so they are able to buy medicines in the event of supply problems. However these employment problems mean that PLHIV's incomes are either insecure or non-existent. They are therefore unlikely to be able to purchase treatment privately (both HIV and non HIV related) and take steps to secure their health. Consequently the anxiety resulting from the risk of treatment interruptions becomes even greater:

'I don't have any income, I can't work, maybe some lighter physical work, but anyone who finds out about my status or my history they take me for a day and when they check they don't want me there anymore so I couldn't afford treatment for myself'. # 25.

A number of PLHIV reported losing their jobs after their employers learnt about their status. This has made them reliant on alternative financial support, which is often of a minimal amount. While a number of participants have turned to their parents or family for help, many have also sought out social welfare. For instance one participant who lost his job as a result of his HIV positive status sold family property and goods to cover gaps in HIV therapy. This has now run out and he is dependent on his pension. He has no further possibilities to purchase treatment in the event of a shortage:

'It's really hard. My mother helped mostly... she sold things and I sold something and afterwards there was nothing left. I'm retired. I have a pension, a small one 250 euros. That's not enough for a normal life and let alone medicines on top of it'. # 26.

The effect of losing a job not only damages capacity for financial independence and the ability to manage treatment problems, but it also undermines self esteem and confidence. Many PLHIV who had lost their jobs as a result of their HIV status commonly reported feeling at a great psychological loss, with people feeling sad, disappointed or empty at not working.



### Stigma, loss of employment and enforced social segregation.

"They called me [and told me], "You cannot work here anymore. You can take some low job or you can go." They told me directly. And I decided to go for the pension, the invalid pension and so from '96 I have lived on pension... At first I was angry because I liked that place, I liked these people. We know each other. It is not like an average job. It is a very interesting life. Its not a big salary, but it's a good job... I felt very sad at that time because I had to leave, but I had no choice... I didn't want to see what happens when everybody knows. What it was like... they said that only homosexuals and junkies get this. This is a curse and you deserve it... I still at that time I remember the films about Nazi and Jewish people and Gypsy people and at that time I could really imagine how they, they live with these Nazi problems. I feel like the same. It is not the same, but for me at the time it was like the same...discrimination." # 23.

Even for those who were not directly forced to leave their jobs, the fear of anticipated reactions meant that many felt that they had little choice but to leave. Amongst many participants the loss of employment is perceived as the point at which they began to retreat from social engagements and relationships, and when their lives became increasingly isolated.

A few of the participants in the study had managed to retain their jobs. Amongst those whose bosses were aware of their status there were some positive reports about supportive managers, although this applied principally to those working in the NGO and health sector. Others though felt their employment was more precarious as a result. One participant worked at a large financial institution in Belgrade. She was on a temporary contract when her boss received an anonymous tip off that she was HIV positive:

'The anonymous call came so I wasn't accepted permanently but for a specified time. Two people were taken on for my workplace, permanently, and they kept me on specified time contracts the whole 15 years. They just prolonged it. I have 3 working cards, so where there should be a year, they would stamp a month. So I was uncertain whether they would prolong my job each month, for the entire 15 years.' # 32.

A few PLHIV involved in the study had managed to continue working, but felt that they had to keep their status a secret. Maintaining this secret and effectively adhering and managing their HIV treatment is very difficult. Many were anxious that they might be found out by their colleagues if they became suspicious about their daily treatment routines in the workplace:

'I'm not saying they're getting suspicious, but I had to come up with a story about the four pills that I'm taking every day. So if I tried to hide it in five working days, maybe I'd manage to hide my taking pills from them on four, but on the fifth someone would see it for sure. There is another thing, we're all having our lunch together, 'cos we're a small office in terms of numbers... So, they have never actually seen me taking my pills, and they don't know what pills they are and how many of them, but I told them a story (...) And they bought it, 'cos they don't know that much about the subject.' # 41.

Even if a job could be secured, participants perceived that the time and energy demanded by the current treatment situation mean that retaining their job is very difficult. The same

participant as above explains the difficulty he had in finding the necessary time during the working week to complete the bureaucratic procedures and travel for his treatment:

'I had to find some excuses to get out, because I obviously had to be away all day. My usual excuse is that I go to another town for the exams, since I'm still a student there, but it's not good enough to stay out of the office all day. OK, it might be fine once or twice, but not if it's once a month, that would be suspicious.' # 41.

He has subsequently stopped treatment in order to retain his job. In his opinion building a career and having an income is a wiser investment in the security of his health in the long term, than losing it in order to be able to take treatment now. The fact that this is a choice he feels he is forced to make demonstrates that whilst the security of access to medical treatment is bound up with secure income, for some PLHIV accessing treatment and maintaining the financial capacity to purchase it privately are in reality mutually exclusive.

### The cumulative effects of stigma

Through the two case examples of family and employment it is clear the layered impact of these experiences, which occur at multiple levels, amount to stigma. This is felt accumulatively at the level of the individual. In extreme cases people feel completely shunned and liken the experience to social death. One old man was left feeling so ashamed of his diagnosis that he tried committing suicide:

'At least everyone would've mourned properly then, and like this who will mourn for me? No one will mourn, they'll just say: "Thank our dear Lord he died!"... I've said a million times: why didn't I get cancer instead of living to experience this! Don't let anyone experience or live through what we have... These are difficult moments, if you understand me, there's nothing worse.' # 5.

For some PLHIV each experience further fuels and feeds individuals' felt stigma. Within this environment openly challenging the situation they face carries great perceived risk for themselves (for example in terms of their social relationships and employability) and those close to them. Almost without exception amongst PLHIV participants the risks of public disclosure are perceived as severe and debilitating. The priority therefore both for themselves and those close to them becomes protecting their status from disclosure. The fear of stigma, experienced or anticipated, undermine PLHIV's willingness to seek help and in many cases demand their rights. In this situation their health can be threatened. Participation is subsumed under other more immediate priorities:

'But always you must live with this possibility that somebody starts to talk and that time everything is changed. It starts to poison you. You start to think about this and you lose energy. You don't think about your health, you think about gossips. It's not good.' # 23.

The stigma which characterises the experiences of most PLHIV weakens the resources individuals can draw on to challenge the medical access issues they encounter. This is exacerbated by the weak legal framework which makes pursuing action against discrimination very difficult. The study found that PLHIV had very limited access to information about their legal rights. For the most part participants knew neither whom they could turn to nor what exactly they should do. Not a single participant had heard of anyone who had taken steps against discriminatory behaviour and succeeded. For some this lack of precedent confirmed their opinion that the legal system was unable to effectively protect them.

The powerlessness that people feel therefore feeds the cycle of not engaging with the legal system. Within a highly stigmatising environment PLHIV and some service providers commented that the current risks of using the legal system were too great and the chances of success too low to encourage anyone to take on this challenge:

'You need to change the whole system. It's too dangerous. It's very difficult. Maybe it will be changed once, from time to time, but you cannot establish here a system which will punish this behaviour. Impossible.' 7 SP.

There were a few participants who had investigated the possibility of bringing discrimination cases to court. One individual describes her reaction after being badly treated whilst in labour. However, unemployed and battered by negatively stigmatising experiences, she was overwhelmed by the emotional obstacles and risks in pursuing her claim. She gave up on the idea of pursuing a legal battle because she felt it would further drain her already meagre resources of energy and wealth:

'I was exhausted then from all of it and I was so... on one hand exhausted and on the other happy that everything was alright with her (her baby), so I said: "Never mind!" I went to the Clinic. I told Jevtovic and the doctors there about it. They were appalled, and they called them and told them off. And after some time went by I didn't feel like starting [a claim]... I should have... I should have because of the others!' # 11.

The study found a rare example where a participant had tried to pursue their legal rights but had themselves been discriminated by the lawyer from whom they were trying to seek help.

**The legal system to challenge discrimination can be in itself discriminatory. An HIV positive woman's experience:**

'When I told her that I'm HIV positive and I would like to know some facts, she threw me away from the office. It was really terrible. I felt really terrible. I could not believe it you know. There was a line of people waiting to step inside and when it was my turn I stepped inside and the door is open. if you are inside or outside the door is open, and I say, "OK I'm HIV positive I would like to know that and that". She said, "Go out!" and I did not at first understand and I said 'Why?' and she was so afraid, terribly afraid.' # 16.

There are a myriad of responses that individuals have to the cumulative effect of stigma and the HIV experience. Amongst the participants, the study identified the following key responses and coping strategies: enhanced engagement with the NGO sector, education or spiritual faiths; pragmatism; fatalism; resignation and withdrawal. The study is particularly interested in how the context in which people are living their lives with HIV affects their engagement with community action and participation. We turn to this next.

## Social impact of HIV: key points and recommendations

PLHIV reported encountering many non-medical problems related to their HIV status. The social impact of HIV on the lives of PLHIV is pervasive and operates at the level of the individual, the family and structurally at the level of the community.

It is difficult to understand socially stigmatizing experiences in isolation from each other, for they are felt by the individual accumulatively. These ongoing stigmatizing experiences undermine individuals' sense of self worth.

In particular, the study found that nearly all PLHIV participants encountered employment problems due to their HIV status, either through losing their job, struggling to keep their job or being unable to get a job. The study found that not having a job profoundly affects PLHIV's capacity to cope with and react to their treatment access problems, both HIV and non-HIV related.

### Key recommendation:

- There needs to be accessible information available about the rights of PLHIV (esp. employment, social welfare and pension rights) and the necessary support to use these opportunities to alleviate the financial problems they face as a result of their illness.

For more detailed recommendations see 'Conclusions and implications'



# Community participation

Poor access to health care reinforces the perception of some PLHIV that by virtue of their HIV status they are marginalised members of society. Crucially, the cumulative effect of the stigmatising experience undermines the opportunity and the motivation PLHIV have to engage with society. The common response is to withdraw and disengage.

Separation from normal life:

'So I gave up, and I said OK I will not work, I will not mix with... I was giving up outside life- normal life, working, having pleasures. It was very, very not good.... I heard somewhere on television about some girl who had AIDS and she said one sentence that is so very, very true. That during the time that people have AIDS the outside world is getting further away all the time. You look from a distance at this world and it is getting further and further away. You are trying to wave or to say, 'oh hey', over time it is going, going. It is slipping away. So you try to make your own little existence.' # 21.

This context severely impairs the ability that PLHIV have as individuals and as a community to challenge the structural discrimination they face and to advocate for improved treatment access. A number of service providers expressed their frustration that PLHIV, with a few notable exceptions, do not participate in community action. They feel that this weakens the efficacy of their efforts:

'You can change the situation very fast with a fight. If you don't fight then you can not. You can organise everything, but if you have no support from HIV positive people you can not fight.' 7 SP.

However the study found that the interlocking factors of fragile treatment access and the highly stigmatised environment are key obstacles to HIV community action and participation. This context constrains both PLHIV's capacity and their opportunity to effectively respond to the situations they face. As one HIV positive person explains:

'People won't come! And now I know why: it's not just the thing if someone will see them or not, if they will give their name, but the thing is that they can hardly survive, have the therapy each month! If we had it for six months, and took it monthly, if I could go each month and say: "Hello, I'm here to get my medicines."... but like this when you're thinking every month about it you can hardly think of self-help groups, some volunteer work, and paid work. You have to understand this.'# 40.

This is potentially a perpetual cycle and one that needs to be broken for positive change to occur.

The NGO community are making important strides in HIV prevention awareness, and there are also a smaller number of NGOs who offer support to those living with HIV/AIDS. The study found that amongst those PLHIV participants who did participate in community action through NGOs and self support groups there were a number who described them as having a very positive influence in their lives. They reported that not only did their involvement give them an enhanced sense of purpose by helping others, but gave them an improved confidence and ability to manage their HIV and HIV treatment. As one HIV positive person volunteering in an NGO comments:

'It gives me strength in life, gives me satisfaction and purpose, that I should do something useful for me and for others. I'm among people, something good is taking place, and I'm not stuck between four walls and if that's something that will help someone, I'll be happy. Let them find the cure even when I'm not alive, but I know that I contributed a little bit to, to come to that. And that means a lot to me.' # 22.

However there are also criticisms of NGOs – reportedly not everyone's needs had been met by the services NGOs provide. This appeared to cause disappointment and has undermined some individuals' willingness to get involved. The study identified a number of factors in accounts that that weaken PLHIV's engagement with the public, voluntary or third-sector HIV community activity in Serbia and in Montenegro. These include: dissatisfaction with the use of funds; a perception that the role of PLHIV is not taken seriously enough by NGOs; and a perceived lack of sustainability in community services and activities.

Some participants felt that the focus and financial expenditure was not sufficiently targeted towards activities that support PLHIV:

'There's a huge number of organisations who deal with HIV-positive people; unfortunately it all stays written in a project and on paper. These are all nice and humane ideas but no one really reaches HIV people and not in the form of giving psychosocial help.' # 34.

Another key issue raised was that some PLHIV feel that those working in NGOs do not adequately listen to and respect the views of PLHIV. There is frustration that some organisations do not include PLHIV in the decision making processes in a meaningful way. A barrier to participation therefore is the distrust that some individuals have about the motivations of particular organisations in their sincerity to help PLHIV. There was no clear uniformity on this however and this was highly contested by other participants. As one individual commented:

'All the time there is the story that there is a lot of money for the HIV field. But some institutions, some NGOs are spending this money on totally wrong purposes. [Many PLHIV] think that other organisations and other institutions are taking advantage of their illness. That is the main line I have heard. "They take advantage of our illness, of our problems," and things like that'. # 33.

Some participants also appeared to be put off by the fluidity of the services offered. The lack of sustainability of the organisations' funding results in beneficiaries feeling disappointed and let down when an activity is discontinued. Some participants spoke about how they are reluctant to become involved because they do not trust it will last. Participants applied this particularly to self-support groups. Whilst they recognised their potential, after a number of failed attempts they are now very sceptical about the chances of self support groups' success. This is a crucial area for community participation and participants expressed concern that inadequate managerial and financial support had been given to groups.

The study also found that there was weak communication and cooperation between NGOs operating in this area. This has negative implications for maximising the use of resources and for ensuring the sustainability of services. In addition, some service providers commented that the

competition between NGOs to attract beneficiaries may contribute to the low levels of collaboration between organisations. This damages the efficacy of services provided which reduces the number of PLHIV willing to become involved in HIV support and community activity. Therefore in an environment where even the public sector is perceived as somewhat unstable, NGOs do not have the reliability that would persuade people to have an active role:

‘When you see some good practice on how to manage things (self-support groups), you think finally someone will do something good. That we can try to improve and work on that. Then when you start to do it and to feel safe and comfortable, then there is nothing, like with the medicine it is a really, really big problem.’ # 16.

### **Community participation: key points and recommendations**

The difficulties of obtaining treatment on a regular basis, as well as socially stigmatizing experiences had a profound impact on the attitudes of some participants to their relationship with other people and themselves. The study found that the most common response amongst PLHIV is to withdraw and disengage from social life and their lives before diagnosis.

Concerns around treatment availability and the risk of social stigmatization are why relatively few PLHIV choose to participate in HIV community, support and advocacy activities.

In addition the study also found that for some PLHIV their engagement in community activity was curtailed by an element of mistrust in NGOs. This was a minority opinion though.

#### **Key recommendations:**

- Genuine and effective steps need to be taken to address treatment availability concerns and widespread prejudicial attitudes towards PLHIV so that PLHIV feel enabled to participate in community participation. This could have a significant impact on further reducing stigma and prejudice.
- Service providers, in particular NGOs, need to enter into a more meaningful communication with PLHIV on the issue of increased participation so that there can be an improved cooperation in providing services for PLHIV.
- The study notes that many self-support groups fail to survive their first year. These important initiatives need to be given more support in terms of training, capacity building and funding.
- In an environment of increasingly sparse funding for HIV/AIDS, existing NGOs to improve communication between themselves and PLHIV to ensure that current resources are utilized with the maximum effect.

For more detailed recommendations see 'Conclusions and implications'





# Montenegro

During the period of the study Montenegro voted for their national Independence. It is likely that this will alter the situation for the delivery of HIV treatment and care for PLHIV in Montenegro and that resources and services will be further concentrated in Podgorica. Whilst the study interviewed a number of participants after this event, little effect was noted as no changes to the delivery of treatment and care had at that time been implemented. The report therefore presents the findings of the situation as experienced by PLHIV in Montenegro during 2005-2006.

## Treatment supply in Montenegro

Whilst the situation improved during the course of the study for PLHIV accessing treatment and collecting their therapy in Belgrade, the situation in Montenegro remained insecure throughout. The study found that participants have serious problems accessing their treatment. In order to describe the problems that PLHIV encounter in accessing their correct treatment in Montenegro, a brief outline of the system will be given first.

The doctors at the Infectious Disease Clinic must submit an order every three months detailing what therapies will be described. This order is made through the Montenegrin Health Fund to Montepfarm, who are the distributors responsible for purchasing and delivering the HIV drugs in Montenegro. These are then delivered to the clinic pharmacy. However it appears that frequently there are gaps in this delivery, where certain drugs have not been obtained. In such instances some patients are without their full combination. There are no private pharmacies which supply HIV drugs and therefore individuals need to travel to purchase the necessary treatment from the Central Pharmacy in Belgrade. Individuals will then be reimbursed for this purchase by the Montenegrin Health Fund. Depending upon the number of drugs missing from the combination one month's supply costs between 300-1,000 Euros. It is likely that an individual starting on therapy will also have to purchase the treatment from Belgrade as their requirements would not have been included in the clinic's quarterly order. In order to be able to purchase the treatment in Belgrade, these drugs must be available in Belgrade and individuals must be able to access funds to cover the costs of travel and the initial purchase of the drugs.

One participant describes their experience of the HIV treatment system:

'Since I started treatment in 2003 there's always been problems. I got the medicine in hand here at the Clinic in Belgrade. But the ones here, it's always buying and reimbursement. I can't buy the medicine. I'm on a break for a month, two, we shouldn't even be doing this, and we all do it, there's no money, there are no medicines. I had to send it through a friend in Belgrade so he can send it on the coach to me, so I wouldn't have to go to Belgrade once a month – I couldn't do it, I don't feel well, and these people here do nothing.' # 42.

PLHIV uniformly characterised the treatment delivery system as fragile and their experience of HIV treatment access as uncertain. However, similar to the situation found in Serbia, there was disagreement between PLHIV and service providers and amongst service providers themselves about the gravity and extent of the problem. Clinic staff presented the situation as comparatively much less serious than it was described by PLHIV and other service providers.

Clinic staff felt that there were very few problems with treatment delivery. Some commented that PLHIV's concerns may be a way to justify their own individual problems with adherence. One service provider described the treatment situation:

'Generally speaking we don't have problems with these patients who are choosing to stop taking therapy. Maybe one or two cases occasionally, but the majority of them are being treated regularly.... [Problems around treatment supply] this is just hearsay, this has nothing to do with the factual state.' 18 SP

There is clearly a discrepancy reflected in the data we collected. This disagreement must be borne in mind when reflecting on the findings in this report.

Amongst PLHIV, HIV treatment delivery is a serious concern and the situation is perceived as alarming. One participant describes their difficult experience in 2005 when there were drugs missing from their combination. Not only were these drugs not available in Montenegro, they were also unavailable in Belgrade.

#### **Purchasing treatment in Germany to maintain adherence:**

'I was [feeling] terrible, in a terrible psychological state. At the infectious clinic they gave me two of the medicines but zigen is gone, the third one, and I say: "You have given me nothing" ...[So]..I quit.... Wherever I turn, I ask pharmacists, I go to ask them myself whether they'd get it for me, but nobody wants to. I mean, why would they get one medicine for 300 euros, it doesn't pay off or whatever. ...And then I got those medicines through some friends from Germany, but it's only temporary. Then I calm down for that month, but perhaps 10, 15 days pass, and it begins again.' # 40.

In the event of a shortage those able to afford the initial costs of purchasing HIV treatment travel to Belgrade. In Serbia the situation improved during 2006 and therefore the treatment is rarely unavailable in Belgrade. However, although the money is reimbursed participants need to have access to the funds to be able to purchase the treatment initially. Participants able to afford to purchase treatment in emergencies expressed concern as they weren't able to continue to do this when shortages lasted for some time. This is especially pronounced for those who, due to their status, are unable to work and have very little income. For some borrowing the money, when they are unable to reveal the purpose, causes its own problems. As one participant explains:

'The problem remains, there's over a thousand euros to get each month for medicines, then I get the money reimbursed. However, a thousand euros is a year's salary here. I can't get to a thousand euros now, and I can imagine what it'd be like borrowing every month I mean... I haven't been working for two years already. Even if I were, we're familiar with the average salary... Even if I earned more, had a better lifestyle, it would be hard to manage each month, although you get reimbursed, but still, you can't keep it from everyone, 'cos you can always borrow money from friends, but the moment will come when they will naturally ask: "What are you doing with all of it, I keep giving it to you all the time?!"'# 14.

The study found that this situation prevented some people from being able to start therapy at all, despite treatment being fully covered by the state:

'I would've started sooner if I'd had the money to go... I thought I'd have some opportunity to borrow money and... so I still haven't started.' # 14.

There are others who have begun therapy but during the shortages stop therapy because they are either unable to access funds to purchase the initial treatment before the reimbursement or do not want to switch to other combinations due to resistance concerns.

A participant, in summer 2006, had been without therapy for three months. Their combination was not available in Podgorica and although they would be reimbursed they could not afford the initial cost of 800 Euros to purchase the month's treatment in Belgrade. The previous year they had been in a similar situation but had been able to get a loan from their employer and the bank. This year they were unable to do this, and when we spoke with them they were waiting, without treatment or monitoring tests, until their treatment became available in Montenegro again. They were offered the possibility to change treatment combination, but one drug in this combination was also only available in Belgrade, so they decided to wait until their original treatment became available again. They did not know whose responsibility it was to resolve the problem, but they were dubious that anyone was genuinely committed to resolving it as the problems had been going on for so long. They were clear though that they felt unsupported and alone in managing this very serious situation:

'It's really terrible. We need to buy medicines and we need to borrow the money. I'm also much more confident when I'm on treatment. As soon as I notice something hurts just a little I get scared, but no one asks me, there are no medicines and... I don't even call the Clinic anymore, really, they took my phone number there, they said they'd call when they got the medicine. If I, God forbid, felt something and that I needed to take the therapy, then I'd look for money and ask. I live from one day to another, it's horrible... And these NGOs and this CAZAS, they try so hard and work so hard, but there's really no progress. I don't see any improvement. It's horrible, I was thinking of whom to go to and ask for help and you really don't have anyone to turn to.' # 42.

PLHIV and service providers reported that they did not know the reason for the treatment availability problems in Podgorica. PLHIV in particular were sceptical towards the explanations they are given about the lack of available supplies and amongst some there is a strong feeling that if there is sufficient funding, the problems occur because they are 'in someone's interest' # 15. Amongst many PLHIV there is a lack of trust in the treatment system, as one HIV positive person comments:

'I still don't trust them! They can say that therapy's available, as many times as it happened I went over there and they didn't have it- nothing. It can happen that they send it, then it's lost along the way.' # 40.

## Referrals and reimbursements

The study found that PLHIV's experience of the referral procedure in Montenegro was that it was difficult and time consuming. The number of signatures required not only made obtaining a referral a tiring task for people not feeling well and trying to deal with many other difficult and pressing problems, but it also increased the number of other people aware of their status. This was one of the reasons participants gave for moving from their hometown to Podgorica or Belgrade, where it is possible for them to be more anonymous within the system.

Participants described the reimbursement procedure as even more arduous and complex:

'I went Podgorica to xxxx (town of residence in Montenegro) to Belgrade, that was my monthly routine. I mean, really – I couldn't take it now, I wouldn't have any more strength for that now. And on top of it I have to go on the coach. I start in xxxx at 7 am and I'm sensitive, I mean being HIV-positive, especially in winter, sometimes I don't feel well and it's a 14 hour drive to Belgrade. No one cares and they keep saying they'll sort it out.... "Just have patience!" and I said: "How much more patience?! What do you mean to do with us, we'll all die like this!" ....But it's been the fourth year of my treatment and nothing's working out.' # 42.

#### A participant describes the process of reimbursement of therapy purchased in Belgrade.

1. Take the prescription obtained from the Belgrade clinic to the GP in Montenegro.
2. If the drugs are not available at the clinic in Podgorica: Call the pharmacy in Belgrade to check that the drugs are available (7 days in advance of purchase)
3. Go to Belgrade to buy the drugs. Ensure that they pick up two papers at the pharmacy: the cash register and the invoice. Recommended to take three other papers: the exchange slip from the bank, the prescriptions themselves and a report from a specialist stating that they need to receive treatment over a long period of time.
4. Return to Montenegro and attend the next Consilium Meeting (once a week- Wed 8-9am).
5. Submit all these papers to one of the state owned pharmacies before 11am on Thursday, so that a certificate can be issued that the drugs are not in stock and that they are on the positive list of drugs (for which reimbursement is allowed).
6. When they have all the paperwork together, submit it to the Health Fund.
7. This is passed on to the Commission who make a decision about it and if there are no discrepancies the money is transferred to the bank within 7-10 days.
8. The money goes through the payment operations system, which means that the money can be collected between 8am-2pm.
9. Reimbursement of therapy happens in one office and travel expenses in another. This is not done at the same speed. This can be problematic for those who do not live in Podgorica.
10. Most people will need to do this monthly, not only because the prescription and invoice dates need to match but also because it is already a serious strain to afford one month's supply of drugs and people do not have the capital to buy more.

Participants felt that there was inadequate information available to guide individuals through the steps involved in the bureaucratic process:

'This procedure was very difficult to find out about. Everyone is telling you a different story. Explanations are scant, you have to go from one institution to another.' # 41.

One participant described how not having access to all the information and therefore not fulfilling all the necessary steps had meant that they had been unable to reimburse one month's prescription. This mistake cost them 800 Euros. Those trying to keep their status a secret, either from family or employers, need to find excuses to justify the time necessary for the frequent trips to Belgrade to purchase treatment, as well as find the money. The study found that to manage this, individuals would try to purchase more than one month's therapy at a time. However they feared that the stringent reimbursement regulations would not allow them to do this:

'I think I might have problems with getting reimbursed now, because I took a double quantity of the drugs last time I went to Belgrade, to avoid the need to go back a month later, and to lie to get out of work... And I might have problems because they demand that the prescription is older than the invoice. Generally speaking, the procedure is terribly complicated'. # 41.

There were mixed accounts of how promptly the money was reimbursed to individuals. Whilst some participants had not encountered any serious problems, others reported that they were often not reimbursed in sufficient time to cover the next month's therapy and therefore individuals needed to find a further 300-1,200 Euros to cover their treatment without interruption.

The study found that PLHIV encountered difficulties with getting reimbursed for other aspects of their treatment critical to their effective management of their HIV. For example one participant described how only one return train trip to Belgrade every three months was reimbursed. However there were instances when therapy changes or test results required an additional visit within the three months in order to respond to these important developments. Participants had found that these were not reimbursed.

In another example some participants had paid for necessary treatment and procedures to be done privately, with their doctor's consent, which the reimbursement committee had subsequently refused to cover. A participant gave an example of having her PCR tested at a private clinic. This should be done four times a year and is a state obligation. Monitoring supplies were unavailable in Belgrade and so, under the advice and approval of doctors at the clinic, they had had this test done privately, which reportedly cost significantly less at a private clinic than through the clinical centre of Serbia:

'I went there, they didn't have reagents in Belgrade. Our Fund pays the Clinic for Infectious Diseases 500 euros per reagent, per test for me. They don't have the reagents and I ask there: "Can I do it in a private laboratory? Does anyone in Belgrade do that?" "They do." "How much does that cost?" "150 euros". Ok, I do it. I pay, because I need to see how my therapy is working. I gave the money.... And I came back, got it all great in writing from Nenad: "The refund is necessary because it's not available, either here or there..." I took it to the Fund and the woman there said: "We won't refund it, prepare a lawsuit, appeal." That's how they also rejected [another] woman. For half a year already she didn't get anything from the Ministry at all, she appealed – nothing.' # 40.

When this participant was asked how this made them feel, the participant responded:

'Furious and really angry! I know now what it is- that I'll write to them, I was angry and I'll try and once and for all sort this thing out, it's not just me. They really got me angry. And if it happened to someone they'd probably feel bad and miserable, they'd go home and say: "Now what?! I should appeal! I should type it out, who'd do it for me, who'd print it out?! How am I to do it? When they see me there... I give up, I won't do it!"' # 40.

The other woman referred to in this example received help from a lawyer affiliated to CAZAS to lodge her appeal. This appeal failed. It was reported by service providers that as the Health Insurance Fund did not have an agreement with the specific clinics involved they did not have an obligation to reimburse patients, despite the referral of the doctors.

## Relationship of PLHIV with the clinic in Podgorica and the treatment system

PLHIV in general were disillusioned with the healthcare system which they felt was not taking adequate responsibility for their needs. One participant articulated her frustration and the consequences of the system's failings:

'I can't believe that the state – and the state is paying for 16, 17 people- they can't provide medication, where they actually can! So, it's not just about the money, but about laziness, and this laziness can cost many of us to become resistant and eventually two, three years less.' # 40.

Some participants described their relationship with clinic staff as positive, but the study also found that tensions existed between some patients and staff at the clinic. This was recognised by the staff at the clinic:

'Even though we do all we can for them. Sometimes they get angry. Sometimes they can get really nasty talking about us as people who don't do the things we ought to be doing for them, although in these cases the money is being refunded to them. Only later, but it's still being refunded.' 16 SP.

Despite the support given by service providers it is clear from the accounts of PLHIV that they feel they are alone in their treatment access crises. Some feel that those who should be supporting them are not doing enough to help them. They also feel that the implications of not having treatment, which they see as resolvable if there was sufficient commitment, is not adequately recognised. PLHIV justified their frustration and anger by arguing that for them, isolated and frightened, having access to continuous and free treatment is a question of survival:

'And if it's someone's problem for life, and if it happens every month, you will put up with it when you go to the dentist or when you have appendicitis or something, you will live, and who knows when you will go next. But this is each month for the rest of your life!... And then they're complaining and getting angry, saying: "Look at these..." – meaning people who have what I have, "They're nothing, what is it with their psychological profile, they're nothing, selfish, always asking for something!" .... It's no wonder they're aggressive, they are like that, I mean, that's not aggressive. They're great compared to what they should be like! Because when you deprive a man of his basic needs it's something that looks like an animal.'# 40.

## Stigmatising environment

The environment that PLHIV are living in Montenegro is one where HIV carries an intense stigma. As in Serbia, a number of participants explained the context of this stigma by reference to 'Balkanism'. The conservative social context means that PLHIV are depicted as shameful and guilty. Participants depicted the confidentiality of medical and administrative systems as porous, where individuals have little control over the disclosure of status:

'But for example now, you're a doctor and you're from xxxx, from my neighbourhood and this paper came to the Health Centre in xxxx, you saw it and you will tell your children, to tell them to be careful of me, and your children will go and talk around town, and that's how it's spread. It's something that... they don't have some... I don't know... these doctors don't respect the patients' privacy. It's very rude.'# 13.



The close knit communities of the relatively small Montenegrin populace intensifies the problems that PLHIV face. Many participants had encountered problems when their status, or rumours of it, had quickly become public knowledge within their community:

'I told a few people who spread the word to everyone in xxxx... The problem turned up when 20 days later we woke up one morning, I don't know if it wasn't written out on our whole house: "We don't want AIDS in xxxx! We don't want HIV in xxxx! AIDS people go away from xxxx!" And then it was like: either I move out, or we all move, or... we lost friends in xxxx, we lost mates, we lost neighbours, we didn't talk to anyone... Everything was ruined because of me.' # 13.

The consequences for this individual and his family were so severe that he moved to Belgrade. Another participant fearful of the porous nature of the 'confidential' administrative procedures, and the effect this would have on his family, left his hometown and moved to Podgorica:

'Because I'm HIV positive, that's why I moved, changed my residence, my ID card, my health insurance ID, because it all goes through the Social Security Office, and people who work there know me... So I personally did not have a problem with that, with the fact that someone in the street could tell me that I'm a faggot, or an AIDS infected scum, or anything... I didn't care. As long as there's no physical violence involved! But I didn't want my family to suffer because of me'. # 41.

The study also found that where there had been high level intervention by key individuals within the government, participants had experienced reduced discrimination and had been able to continue employment.

### **Participation from PLHIV in Montenegro**

Many PLHIV participants explained how the size of communities meant that the consequences of rumours and public disclosure for individuals and their families are serious. As a result PLHIV try very hard to prevent their status becoming known within their community and are reluctant to be associated in any way to an organisation or activity that links them to the disease. It is clear that this is the principal reason why the study found it initially so difficult to recruit people to participate.

The study found that there is, at best, a weakly linked PLHIV community, despite the efforts of the NGO CAZAS, other service providers and a few key HIV positive individuals. This seriously undermines the capacity that PLHIV have to advocate for improved treatment access and greater understanding and acceptance within society. The fear of disclosure is so pronounced that some PLHIV do not feel comfortable to admit their status even to each other. A service provider describes the interaction in the waiting room at the clinic:

'They try to hide their status from one another. For example most of them are coming in on the same day....and they don't feel comfortable admitting they have HIV even in front of their of the other HIV patients. They say "no, no, I'm here for hepatitis", or something else.' 16 SP.

Participants reported that the only spaces where they feel they can openly discuss the issues they face are the Voluntary Counselling and Testing centre and CAZAS. However many PLHIV do not feel able to come even to these spaces. This has a number of effects. One notable one is that PLHIV continue to feel isolated and are not able to benefit from the support that PLHIV can give each other both on a psychological and social level, but also in



the pragmatic sharing of treatment collection etc. A number of participants commented on how few PLHIV understood their rights and felt able to stand up and ask for them. Even those who do know their rights commented that they don't know to whom they should turn to demand them.

Critically though, as one participant explained, and as has been discussed in Section 1, without secure access to treatment the opportunities for interaction and participation become less important when the priority is accessing life-sustaining treatment. The cycle of weak participation in advocacy efforts is fed by poor treatment access.

Arguably this cycle also undermines HIV prevention efforts. Participants felt that without improved anti-stigma efforts, led by PLHIV advocates, and guaranteed access to free and continuous treatment there is currently little incentive to encourage people to get tested for HIV.

### **Montenegro: key points and recommendations**

The study found that participants have serious problems accessing their treatment. Participants were experiencing frequent shortages of therapy. Some participants, unable to afford the initial purchase of treatment from Belgrade (which would subsequently be reimbursed), felt they had no choice but to stop HIV treatment until their drugs became available in Montenegro again.

Participants were anxious about the impact that Montenegro's independence would have upon their HIV care and treatment, and how it would affect their relationship with the doctors in Belgrade.

With a few exceptions, high levels of fear surrounding the risk of disclosure prevents PLHIV participating in any form of HIV community activity such as support networks or advocacy efforts. This is demonstrated both by the study findings and the difficulty the study team encountered in recruiting PLHIV in Montenegro to take part in the study.

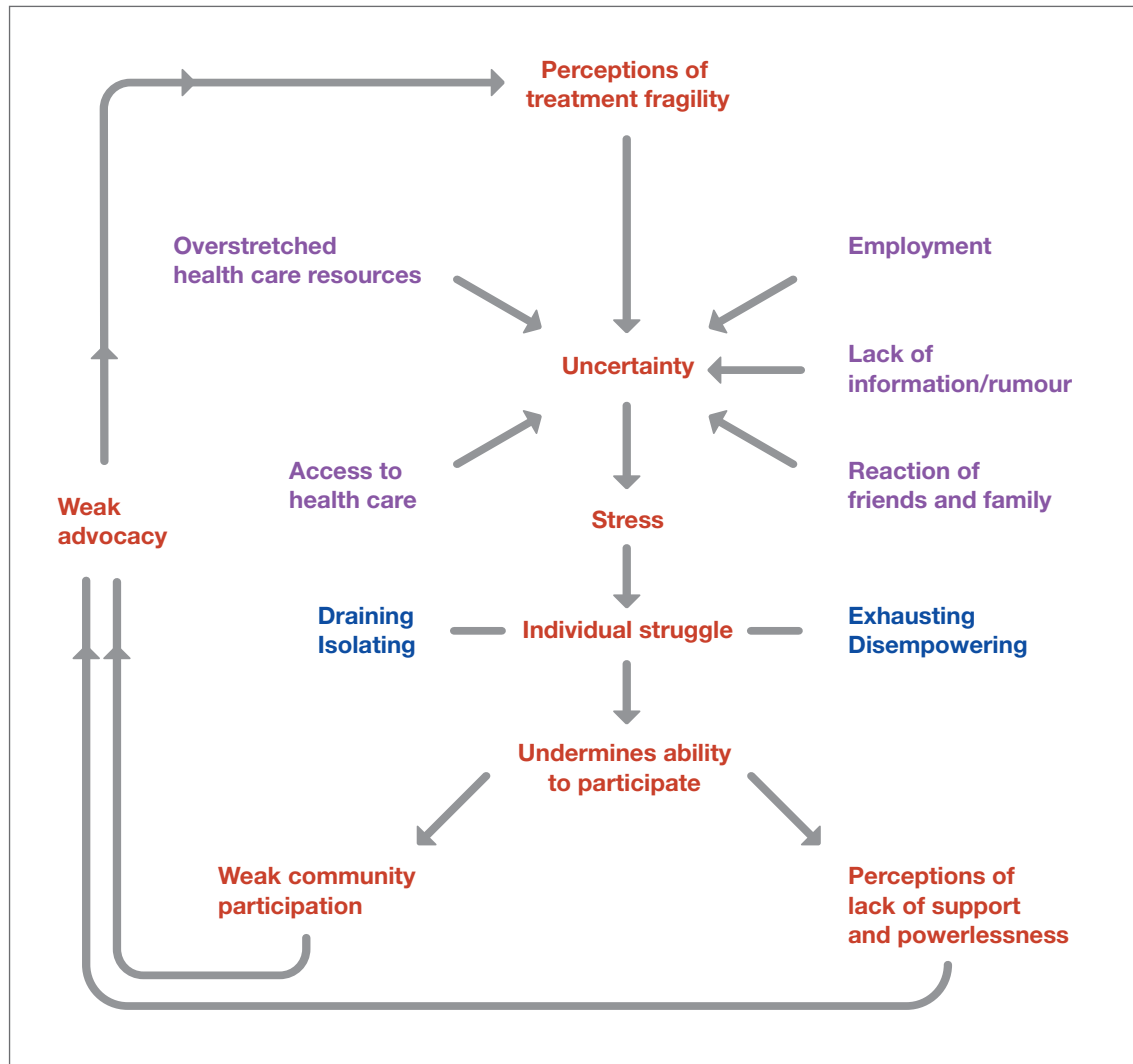
#### **Key recommendations:**

- There is an evident need for a treatment system review to be conducted in Montenegro. This may be timely to inform decisions about the changes in the health insurance and healthcare system likely to be implemented over the next few years.
- Meanwhile immediate efforts need to be taken to address the significant concerns of PLHIV who feel unable to access treatment.
- Steps need to be taken to encourage confidence and trust in the HIV treatment and care that patients will receive at the clinic in Podgorica.

**For more detailed recommendations see 'Conclusions and implications'**

# Conclusions and implications

Diagram 2 Disempowering cycle of treatment fragility



This qualitative study investigated the lived experience of PLHIV in Serbia and in Montenegro. The key finding was that PLHIV perceive there to be fragile access to HIV treatment. This perceived treatment fragility undermines the ability PLHIV have to overcome obstacles to accessing health care as well as other forms of support. Such constraints on access to care and support have a negative impact on the ability PLHIV have to manage living with their illness and weaken their capacity to participate in interventions to address the problems that they face.

## HIV treatment supply

While there have been improvements in the delivery of continuous treatment in Belgrade over the course of the study, with reported treatment shortages becoming less frequent, we found that fragile access to free and sustainable HIV treatment remains the primary concern of PLHIV.

Two strategies were employed in the event of treatment shortages: changing components of the combination of drugs that individual patients are prescribed; and less commonly, interrupting treatment until the appropriate therapy became available.

These decisions are made more difficult, and more precarious, by intermittent shortages of monitoring tests. Ongoing problems with the availability of supplies for CD4 and PCR tests have been reported throughout the duration of the study. Treatment shortages may have negative impact regarding the resistance and long term health of PLHIV [6, 7].

The study found that PLHIV's anxiety about the unpredictability of treatment supply was exacerbated by a lack of available information. Rumour was rife, further fuelling personal anxieties and insecurities. The power of rumour in shaping the perceptions of the treatment situation should not be underestimated. Our findings show that this affects PLHIV's perceptions of HIV being a manageable chronic illness as well as their own treatment literacy and trust in the healthcare system. Crucially, the study also found that treatment fragility can undermine PLHIV's self-confidence and capacity to participate in community action.

PLHIV's experience of insecurity in relation to HIV treatment access may also have implications for treatment adherence. The study found that some PLHIV's commitment to taking their treatment is adversely influenced by the faltering adherence of the state to deliver the necessary HIV treatment continuously. It is possible that fragile HIV treatment delivery may have an impact on HIV prevention efforts as it could undermine people's willingness to get tested for HIV if they are not confident in their ability to treat HIV [9].

- In the absence of clear accessible information, an information hub is needed where PLHIV and those close to them can access information about treatment. This should include information about therapy and monitoring supplies, as well as information about managing HIV treatment and maintaining health. This could be disseminated through trained peer treatment educators, PLHIV treatment workshops facilitated by self-support groups and appropriate and relevant literature.
- This information hub could be a central access point for information and services relating to other needs of PLHIV, such as information on bureaucratic procedures, access to health care and legal services, and availability of support services. This could be based near or within the Belgrade clinic to ensure maximum profile and access for PLHIV and have secure and effective communication with other clinics as well as NGOs throughout the country.

PLHIV evidently face a very demanding situation in relation to the uncertainty surrounding treatment access and the societal attitudes towards PLHIV. The mental health needs of this group are significant. The counselling service currently available within the Belgrade clinic, although considered excellent by both PLHIV and service providers, is unable to meet the mental health needs of all PLHIV who require support and care.

- The study team in close conjunction with the NGO IAN and the study Advisory Group have secured funding from Catholic Agency For Overseas Development and HPVPI to provide for a two year pilot counselling service for PLHIV in Belgrade. Further funding and support are necessary to ensure the sustainability of these services and to provide training and ongoing support to services outside of Belgrade.

There is a demonstrable need for a thorough and systematic review of the treatment procurement and delivery system. This review would need to identify bottlenecks and areas of leakages within the system. Some of the areas which the findings of the study suggest attention should be focused on are:

- analysis of the cost-effectiveness of the delivery system; including a particular focus on the operational costs and retail margins costs within the current system;
- ensuring there are sustainable purchasing plans and communicating resource forecasts to those managing supplies, for example for CD4 tests.
- defining responsibilities within the treatment supply system (to include accuracy of projections, timeliness of delivery, and solving day to day issues);
- improving accountability of each stakeholder in the treatment supply system and their mutual communication;
- setting up systematic collection of accurate and computerised information about treatment needs, orders and deliveries which can be shared so that prescriptions, orders and current stock can be cross checked and monitored
- planning contingency strategies in event of supply shortages
- consider pursuing regional purchasing of HIV treatment to improve scale of market and purchasing power.

## HIV Clinics

The doctors and nurses at the Clinic in Belgrade are a significant source of support to PLHIV. Patients often rely on the three clinic doctors to provide medical treatment, resolve treatment supply concerns and facilitate their other medical care. This dependence on the doctors has created a situation where for some patients their own security and health is inextricably linked to the doctors. This increases the heavy workload of staff at the clinic, but also leaves the patients vulnerable should any of the doctors be unable to continue in their job.

- Alternative strategies need to be identified and implemented so that clinic staff are not alone as the principal figures responsible for patients uninterrupted access to HIV treatment.
- There is a clear need to ensure that there are adequate opportunities available for other doctors to be trained in this specialism, so that the current level of care and expertise at the Belgrade clinic can become sustainable.
- As waiting times are often considerable, improving the facilities in the waiting room and encouraging PLHIV to visit self-support clubs nearby to enhance the experience of attending the clinic and improve peer support opportunities.

The study found that those living outside of Belgrade faced increased problems accessing HIV therapy, monitoring tests and medical care for HIV. This is in part due to the logistical, bureaucratic and financial difficulties of being able to access HIV treatment and care in Belgrade. In general both service providers and PLHIV were confident that the situation would improve when the decentralisation plan of HIV treatment and care to the clinics in Novi Sad, Niš and possibly Kragujevac comes into effect, as there would be a welcome reduced need for referrals and travel. However this is also a source of concern for a number of PLHIV who fear that their treatment will suffer by being treated by doctors who are less experienced than those in Belgrade. In addition problems may arise in the procurement of HIV treatment in regions where structural changes in the administration of the Health Insurance Fund are occurring, for example in Vojvodina.

- Over the next few years there will be significant changes in service delivery outside of Belgrade, and the standard and availability of care needs to be closely monitored. Patients need to be able to feel confident in the treatment, care and services they receive in the newer clinics, and be given clear information about what their relationship will be with the doctors in these clinics and with Belgrade.

### Non-HIV related medical care

PLHIV experience problems accessing health care, both HIV and non-HIV related. The rights of PLHIV to treatment and medical confidentiality are currently not being fulfilled in numerous medical facilities across Serbia and Montenegro. These are the same rights of any citizen seeking medical care. Many participants felt that they had been refused medical treatment, directly or indirectly, on account of their HIV status. The fragility of access to medical care was described as humiliating, exhausting and intensely stressful. These negative experiences contributed to participants feeling stigmatised and marginalised from ‘normal functioning’ society.

The study identified three pragmatic strategies that PLHIV employ to negotiate the barriers to accessing care: the clinic doctors’ facilitate appointments through their own contacts; visiting the clinic for all their health needs (HIV related or not); or not seeking medical treatment at all. Currently this increases the workload of the clinic, both directly and indirectly.

Weak adherence to the codes of medical confidentiality by healthcare personnel is also perceived to be an issue for PLHIV, in particular for those outside of Belgrade and in Montenegro. Many participants reported that they even when a transgression of confidentiality is not explicitly perpetrated, PLHIV objected to having ‘HIV positive’ written on the outside of their medical files. They described this as violating their confidentiality and denoting a negative and discriminatory attitude towards them.

- Access to health care is being managed in the short term but long term strategies focused on behaviour change amongst medical staff need to be given greater priority. There is a demonstrable need for the HIV education workshops held around Serbia to continue and for further educational and advocacy work with medical professionals, including on the importance of respecting medical confidentiality.
- Currently there is inadequate information and support available to PLHIV about accessing non-HIV related medical care. This is necessary to both improve access to medical care and alleviate the burden on the clinic. This could be incorporated into an information hub.
- An environment needs to be fostered which encourages the accountability of doctors to treat all citizens and which penalises those that refuse treatment on the grounds of HIV status. Continued efforts are needed to ensure that medical cards are not marked with ‘HIV positive’ on the front, with all doctors and nurses made aware of the far-reaching implications of unnecessary disclosure.

### Social consequences of HIV

The non-medical consequences of being HIV positive were likened by some PLHIV to ‘social death’. For many, the perceived reactions and attitudes of others towards them were as significant, if not more so, than the uncertain medical prognosis of HIV/AIDS. The stigmatising experience and poor access to health care and treatment mutually reinforce each other to produce an environment in which PLHIV face severe problems and feel unable to speak out about the situations they face.

The study found that the layering of discriminatory experience – in health care settings, in bureaucratic procedures, in employment, in their local community, even amongst their close friends and family – have a significant impact on their quality of life, their relationships and their sense of self worth and identity. Currently PLHIV feel unable to pursue their legal rights, for instance in relation to employment, due to a lack of information, support, confidence, energy and trust. Many people’s lives were shattered by the social implications of being HIV positive, even if for many their fears of mistreatment were not fully realised.

- There needs to be accessible information available about their rights to work and pension options and the necessary support to use these opportunities to alleviate the financial problems they face as a result of their illness. This could be centralised through an information hub.

### Community participation in NGOs and self support

Both the results of discrimination – for example losing a job or being denied treatment – and the emotional effect of the experience, had a profound impact on the attitudes of some participants to others and themselves. The study found that along with treatment anxieties, the feared risk of disclosure and the undermining of self confidence are significant factors in why relatively few PLHIV choose to participate in HIV community, support and advocacy activities.

In addition to this though the study also found that some PLHIV’s engagement was curtailed by an element of mistrust in NGOs. Some PLHIV were disillusioned with NGOs and self-support groups due to a perceived lack of sustainability. Amongst a minority of participants there was also a scepticism about the use of funds intended to support PLHIV and the motivations of some NGOs. From some service providers however there was frustration that PLHIV are not more involved in advocacy efforts, for example in initiatives to reduce stigma.

- Service providers, in particular NGOs need to enter into a more meaningful communication with PLHIV on this issue so that there can be an improved cooperation. For example one way to move forward on this could be to jointly address the treatment issues through advocacy and to implement the findings from a system review, which would both demonstrate that the views of PLHIV are being listened to and respected, and that positive change is achievable.
- The study notes that many self-support groups fail to survive their first year. These important initiatives need to be given more support in terms of training, capacity building and funding in order to foster a sustainable group service which can act as a catalyst for strengthening the PLHIV community.
- In an environment of increasingly sparse funding for HIV/AIDS, existing NGOs need to ensure that current resources are utilised with the maximum effect. It is important to acknowledge that the weak cooperation and communication between NGOs and the tensions arising out of ownership of ideas hinder the effectiveness of the NGO community in supporting PLHIV.

### Montenegro

Montenegro’s recently acquired independent national status means that the situation faced by PLHIV is likely to change considerably. Although a few participants were interviewed after May 2006, little effect had so far been experienced as changes to the delivery of HIV treatment and care had not yet been implemented.

The study found that the treatment situation is very serious for PLHIV living in Montenegro. Participants were experiencing frequent shortages of therapy, and some participants, unable to afford the initial purchase of treatment from Belgrade (which would subsequently be reimbursed), felt they had no choice but to stop HIV treatment until their drugs became available in Montenegro again. Participants were anxious about the impact that Montenegro's independence would have upon their HIV care and treatment, and how it would affect their relationship with the doctors in Belgrade.

With a few exceptions, high levels of fear surrounding the risk of disclosure prevents PLHIV participating in any form of HIV community activity such as support networks or advocacy efforts. Other than the support given by the NGO CAZAS and the Voluntary Counselling and Testing Centre, PLHIV reported feeling isolated and unsupported in relation to the treatment and care situation.

### **Key Recommendations:**

- There is an evident need for a treatment system review to be conducted in Montenegro. This may be timely to inform decisions about the changes in the health insurance and healthcare system likely to be implemented over the next few years.
- Meanwhile immediate efforts need to be taken to address the significant concerns of PLHIV who feel unable to access treatment. Measures could include facilitating the purchase of treatment from Belgrade for all those whose therapy is not delivered to Montenegro, or providing an interest free loan to patients so they can afford the initial purchase of treatment.
- PLHIV are uncertain as to how their relationship with the Belgrade clinic and information about this needs to be made available to PLHIV. Steps need to be taken to encourage confidence and trust in the HIV treatment and care patients will receive at the clinic in Podgorica.
- The highly stigmatised environment makes community participation extremely difficult for PLHIV. Addressing the treatment problems will encourage an environment in which PLHIV are more able to participate and address issues of stigma which currently seriously curtail efforts to support PLHIV and HIV prevention.

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