Right to Health, Right to Life: Why We Need to Act Now on HIV and Human Rights

High Level Meeting
on HIV and Human Rights
in the European Union and neighbouring
Countries

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Abbreviations

AIDS Acquired Immunodeficiency Syndrome

ECDC European Centre for Disease Prevention and Control

EFTA European Free Trade Association

EMCDDA European Monitoring Centre for Drugs and Drug Addiction

EU European Union

GIPA Greater Involvement of People living with HIV

HIV Human Immunodeficiency Virus

NSWP Global Network of Sex Work Projects

TRIPS World Trade Organization Agreement on Trade-Related Aspects of

Intellectual Property Rights

UNAIDS Joint United Nations Programme on HIV/AIDS

UNDP United Nations Development Programme

UNFPA United Nations Population Fund

WHO World Health Organization

Foreword

At this pivotal moment in global health and development, we applaud this opportunity for Member States of the European Union (EU) to unite with neighbouring countries to renew their commitment to put human rights at the centre of the HIV response. We have already made significant progress, and today in Europe and around the world there is an unprecedented opportunity to chart the next steps to end AIDS. This journey to end the epidemic must be signposted with an uncompromising protection of human rights: the right of everyone to a life of dignity and security, to be free from discrimination, to access information, to access services, and to the enjoyment of the highest attainable standard of health.

Thirty years ago, when HIV first emerged, fear and repression triggered calls to "arrest, test, quarantine, isolate". Today, we know that the most effective solution is to do the opposite. People living with HIV should lead the response. When HIV emerged in Europe, fragile networks advancing gay rights were at the forefront of engaging and mobilizing communities in the HIV response. The agenda to advance the rights of lesbian, gay, bisexual and transgender people must remain at the forefront of the HIV and human rights agenda today.

The people most vulnerable to HIV must be mobilized and supported to protect themselves and their loved ones. Human rights, hand in hand with evidence-informed interventions, will get us there. We are fortunate that we now have the tools to end AIDS. Today antiretroviral treatment is enabling people to live healthy lives and contribute to society and economic development, while also dramatically reducing the risk of transmitting HIV to others. We have a comprehensive package of combination HIV prevention services, including harm-reduction programmes.

What we need now are political will and decisive action to provide support to populations that are hard to reach. The EU can demonstrate to the rest of the world how to take courageous action to engage and support the communities that are most marginalized and even hidden – hidden because discrimination and punitive approaches have driven them away from life-saving services, and sometimes into prison, where they are more vulnerable to HIV infection.

We require continued leadership to end the AIDS epidemic, combined with an unwavering commitment to human rights. This means investing in programmes that uproot deeply ingrained stigma and discrimination, and replacing them with legal and social environments that protect human rights. Europe, the cradle of the modern human rights movement, can and should lead the way.

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Executive Summary

In an era where ending the AIDS epidemic has become a realistic vision, the European Union (EU) and its neighbouring countries are at a critical juncture in their responses to AIDS. Although there is potential to attain the vision of "zero new HIV infections, zero discrimination and zero AIDS-related deaths", such progress will be achieved only if there is strong and sustained political leadership to reach people most affected by HIV. Because these populations are often highly marginalized, stigmatized and, in some places, criminalized, this is a human rights challenge and involves a different way of working. Thus, at the highest level, and in line with Europe's position as a global human rights leader, HIV should be addressed as a high-priority health and human rights issue, nationally, regionally and internationally.

All EU Member States and neighbouring countries are party to international and regional human rights treaties that enshrine human rights critical to an effective HIV response, including the rights to life, health and non-discrimination. Moreover, over the years, governments have made a range of HIV-specific political commitments to protect and realize the human rights of all those living with and vulnerable to HIV in their national AIDS responses. In the European context, these human rights obligations and political commitments should be operationalized to infuse, guide and inform every step of the HIV response.

Reaching the unreached requires paying attention to equity in programmatic coverage, overcoming discrimination, replacing punitive laws with protective laws, enabling and empowering people affected, and tailoring services to meet their needs and realities. It further requires strengthening or creating social and legal environments that protect and support all people to come forward for HIV prevention, testing and treatment. Although most EU Member States have made great strides in making antiretroviral therapy widely available, not all groups are accessing such treatment to the degree they should; and in eastern Europe, antiretroviral treatment coverage rates overall remain alarmingly low. With the benefits of treatment well documented both at the individual level and for the wider public health in terms of HIV prevention, this challenge should be addressed urgently.

Other challenges requiring immediate attention include rates of late diagnosis of HIV infection across the region, an increase in new infections in neighbouring countries, underinvestment in HIV prevention, and uneven availability of harm-reduction services in the context of injecting drug use. In many countries, epidemics are concentrated in men who have sex with men, people who inject drugs, and sex workers, and yet these groups are not receiving the political and programmatic attention they need. HIV-related stigma and discrimination remain at high levels across the region.

Sufficient domestic and international financial resources for HIV should be allocated, and investments should be smarter, including programmes that are evidence-informed and focused on key populations at higher risk; that address obstacles to access and uptake; that reduce stigma and discrimination; and that increase access to justice in the context of HIV. Increased policy coherence and strengthened capacity are needed across sectors, including health, justice, trade, education, parliaments and the judiciary. In practice, this means detailing how different sectors contribute to an effective national HIV response. Across all countries, legislation, policies and practices should be reviewed in light of HIV-related human rights obligations and commitments. Punitive laws, policies and practices involving criminalization and mandatory testing, reporting and treatment should be removed. Instead, laws should be put in place and enforced to protect against discrimination and violence and to ensure everyone has access to HIV prevention, treatment and care services.

To make sure no one is left out, disaggregated data collection and monitoring should be expanded. People living with HIV, people who inject drugs and their sexual partners, men who have sex with men, people in prison, sex workers, migrants and transgender people require focused attention and programmes tailored to address their needs. For this, better data are needed, but privacy and confidentiality must be maintained. At every step of the way, people living with HIV and other key populations should be engaged as active partners and catalysts for change. This requires sustained and strong support for active and open civil society engagement in the AIDS response. Finally, there is a need to strengthen collaboration and cooperation across Europe for evidence-informed and human rights-based responses to HIV. Europe can and should remain a leader against HIV and for human rights. The time to act is now!

1. HIV - A human rights priority

It is timely to take stock, identify lessons learnt, and assess how best to move forward decisively with strong and sustained leadership to put an end to the AIDS epidemic in Europe. One key lesson learnt over 30 years of responding to AIDS is that HIV is fundamentally about human rights.

In both the European Union (EU) and neighbouring countries, the number of people living with HIV continues to grow, reaching an estimated total of 2.1 million (range 1.9–2.4 million) people in 2011. While the number of new HIV infections remains stable in the EU,² neighbouring countries are among the few in the world where new infections are on the rise (UNAIDS, 2012a). In addition, increasing numbers of people living with HIV are living longer thanks to treatment. The number of people living with HIV in the EU reached an estimated total of 900 000 (range 800 000–1 million) in 2011, up from 610 000 (range 570 000–680 000) in 2001 (ECDC and WHO Regional Office for Europe, 2012).

Key populations are groups of people who are more likely to be exposed to or to transmit HIV and whose engagement is crucial to a successful HIV response (UNAIDS, 2010). In addition to people living with HIV, key populations often include men who have sex with men, transgender people, people who inject drugs and their sexual partners, and sex workers and their clients.

Given the scarcity of disaggregated data available and methodological differences across countries in gathering data, it is not clear which populations in Europe and neighbouring countries are the most heavily affected by and vulnerable to HIV. In the EU, key populations include men who have sex with men, migrants from countries with a high HIV prevalence, and people who inject drugs and their sexual partners. In neighbouring countries, key populations include people who inject drugs and their sexual partners, and sex workers; there may also be hidden populations of men who have sex with men (ECDC and WHO Regional Office for Europe, 2012).

Today, there is strong evidence of the effectiveness of antiretroviral treatment for both HIV treatment and HIV prevention. When people have access to antiretroviral treatment, they can contribute fully to society and economic development. Effective treatment also reduces

¹ For the purposes of this paper, "Europe" refers to European Union (EU) countries and the neighbouring countries of the Republic of Moldova, the Russian Federation and Ukraine – EU candidate and potential candidate countries, and European Free Trade Association (EFTA) countries.

² This number of new infections reported from EU Member States has stabilized at around 28 000 cases annually, with no declines since 2004 (ECDC and WHO Regional Office for Europe, 2012).

infectiousness up to 96%, and thus it is one of the most effective measures for HIV prevention (Cohen, 2011). Comprehensive packages of HIV prevention interventions are available that are designed to meet the needs of different population groups.³

The critical challenge in Europe, however, is to reach the people among whom the epidemic is concentrated. This is a human rights challenge because these populations are highly marginalized, stigmatized and, in some places, criminalized. Consequently, standard HIV strategies for the general population are not necessarily effective for these populations. For these populations, it is necessary to change course. As a global leader in the promotion and protection of human rights, Europe can and should embrace human rights as a key strategy to end the AIDS epidemic.

2. A snapshot of the epidemiological situation in Europe

This section provides a snapshot of the epidemiological situation in Europe. For a more extensive review of the epidemiology, see ECDC Thematic reports: *Monitoring implementation of the Dublin Declaration on partnership to fight HIV/AIDS in Europe and Central Asia*: 2012 Progress Report. Stockholm: (ECDC; 2013).

2.1 HIV in the EU

The life time risk of becoming infected with HIV for young gay men living in major European cities, hosting prevalence rates of 10-20% in gay communities, is on par with that of young men living in Southern Africa.

Mirandola et al. (2009)

Around half of new HIV infections in the EU are among men who have sex with men (ECDC, 2013d). The next largest groups comprise people who acquired HIV through heterosexual contact (23%). These are followed by migrants from sub-Saharan African countries, where HIV was likely to have been acquired heterosexually (13%), and by people who acquired HIV through injecting drugs (5%) (ECDC and WHO Regional Office for Europe, 2012).

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³ For more information, see Section 4.

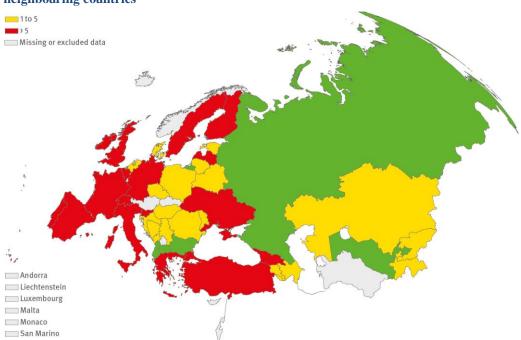


Figure 1: HIV prevalence rates (%) among men who have sex with men in EU and neighbouring countries

European Centre for Disease Prevention and Control. Thematic report: Men who have sex with men. Monitoring implementation of the Dublin Declaration on partnership to fight HIV/AIDS in Europe and Central Asia: 2012

Progress Report. Stockholm: ECDC; 2013. (In press)

Data reported by EU and neighbouring countries indicate high HIV prevalence rates among men who have sex with men (see figure 1 above). The number of diagnosed cases of HIV in men who have sex with men increased by 33% between 2004 and 2010, while the number of people who acquired HIV through other means has remained stable or (in the case of people who inject drugs) declined. Both Greece and Romania, however, reported large increases in HIV cases among people who inject drugs between 2010 and 2011 (ECDC and WHO Regional Office for Europe, 2012; Malliori et al., 2011). Injecting drug use has been recognized as a major driver of HIV epidemics across Europe and central Asia, with 18 countries reporting HIV prevalence rates over 5% among people who inject drugs (ECDC, 2013b). HIV prevalence among people in prison is high in the EU and European Free Trade Association (EFTA) countries where prevalence among people who inject drugs is also high – Estonia, Latvia, Portugal and Spain (ECDC, 2013a).

2.2 HIV in neighbouring countries

The number of people living with HIV in the Russian Federation, Ukraine and the Republic of Moldova increased from 900 000 in 2001 to 1.2 million in 2011. The Russian Federation and Ukraine account for almost 90% of people living with HIV in the 15 countries of Eastern Europe and central Asia (UNAIDS, 2011). The epidemics in these countries are typically driven by unsafe drug injection and by onward transmission to the sexual partners of people who inject drugs. Reported HIV prevalence in people who inject drugs is also high in EU countries, as indicated in figure 2. In Ukraine, people who inject drugs account for a high proportion of people newly diagnosed with HIV infection (38% in 2011) (ECDC and WHO Regional Office for Europe, 2012). HIV prevalence remains high among people who inject drugs in the Republic of Moldova (16% in 2009 and 7.9% in 2012 in the capital city)

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⁴ For estimated numbers of people living with HIV in each country, see http://www.unaids.org/en/dataanalysis/datatools/aidsinfo/. See also UNAIDS (2012b).

(UNAIDS, 2012c), and injecting drug use remains the main known mode of transmission in the Russian Federation (56% in 2011), although the proportion of heterosexually transmitted infections increased from less than 5% in 2001 to 41.4% by 2011 (Russian Federal AIDS Centre, 2012).



Figure 2: HIV prevalence rates (%) among people who inject drugs in EU and neighbouring countries

European Centre for Disease Prevention and Control. Thematic report: People who inject drugs. Monitoring implementation of the Dublin Declaration on partnership to fight HIV/AIDS in Europe and Central Asia: 2012 Progress Report. Stockholm: ECDC; 2013. (In press)

The reported proportion of newly diagnosed HIV infections related to homosexual transmission remains low in the Russian Federation and Ukraine.⁵ In both countries, however, evidence indicates that the HIV epidemic is emerging among young men who have sex with men (Beyrer et al., 2011). Available data also show that prevalence rates are high among sex workers who inject drugs; injecting drug use is likely a key factor in the high rates of HIV prevalence reported among female sex workers in the Ukraine (ECDC, 2013c) (see Box 1).

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⁵ Based on administrative statistics, 1.3% of new cases of HIV in 2011 in the Russian Federation are attributed to men who have sex with men. In the Russian Federation, however, only 3136 of 25 812 467 people were described as men who have sex with men (Russian Federal AIDS Centre, 2012), so these statistics are not representative.

BOX 1

Sex workers

In a World Bank study of 50 countries, female sex workers were found to be 14 times more likely than other women of reproductive age to contract HIV (Kerrigan et al., 2013). Eastern Europe was found to have the second highest prevalence of HIV among sex workers, at 10.9% in four countries. Ukraine had the highest prevalence, at 13.2% across 25 territories.

The World Bank study documents the practice of *subbotnik*, in which police demand sex without payment in exchange for not arresting the sex worker. The HIV implications of such abuse were recently confirmed in the Russian Federation, where *subbotnik* was identified as a significant risk factor for HIV and other sexually transmitted infections. Further corroborating these data are findings from female street youth in four Ukrainian cities, illustrating that over half have reported experiences of forced sex and police harassment.

Sex workers and their organizations play a crucial role in confronting HIV (UNAIDS, 2012d). UNFPA, WHO, NSWP and UNAIDS have recently produced guidelines for the reduction of HIV transmission among sex workers in low- and middle income countries. If implemented, these guidelines will help to enable sex workers to protect themselves from abuse and exploitation and from HIV transmission (WHO et al., 2012a).

3. HIV-related human rights obligations and commitments

All EU Member States, the Republic of Moldova, Ukraine and the Russian Federation are party to various international and regional human rights treaties that enshrine human rights critical to an effective HIV response (see Box 2). These human rights include the rights to life, health, non-discrimination, liberty, information, expression, privacy, association, participation, an adequate standard of living, and access to the benefits of scientific progress.

BOX 2

International and regional human rights treaties include:

- International Covenant on Economic, Social and Cultural Rights (1966)
- International Covenant on Civil and Political Rights (1966)
- Convention on the Elimination of All Forms of Discrimination Against Women (1979)
- Convention on the Rights of the Child (1989)
- European Social Charter (1961, revised 1996)
- European Convention for the Promotion of Human Rights and Fundamental Freedoms (1950)
- Charter of Fundamental Rights of the European Union (2000; applicable only to EU Member States).

The realization and protection of human rights in the context of HIV require a combination of political will, financial resources, legislation, enforcement, access to justice, and access to social and legal services. In addition in the context of HIV particularly, concerted efforts and strategies are required to overcome marginalization and meet specific needs. These efforts and strategies need to be concrete, deliberate and targeted in order to benefit these populations (Office of the High Commissioner on Human Rights and WHO, 2008).

The European Court of Human Rights has consistently asserted that people living with HIV are to be protected from discrimination under Article 14 of the Convention (prohibition against discrimination). Non-discrimination and equality are fundamental human rights principles and critical components of the right to health. Non-discrimination and equality require that States "recognize and provide for the differences and specific needs of groups that generally face particular health challenges, such as higher mortality rates or vulnerability to specific diseases" (Office of the High Commissioner on Human Rights, 2008).

In recent years, EU Member States and neighbouring countries have made HIV-specific political commitments recognizing the importance of human rights in the HIV response, both at the international and the European level. These include, among others, specific commitments to protect the rights of people living with and affected by HIV; to achieve universal access to HIV prevention, treatment, care and support; to remove HIV-related stigma and discrimination; to end violence against women; to review laws to ensure they are supportive of access to HIV services; and to put in place specific programmes to support access to justice in the context of HIV (see Annex 1).

4. The right to health

The right to health is a fundamental part of human rights and of a life of dignity. Although the right to health is to be realized progressively, the undertakings to guarantee non-discrimination and that steps are taken towards its realization are of immediate effect (Office of the High Commissioner on Human Rights, 2008).

In the context of HIV, the right to health involves access to HIV prevention, treatment, care and support (Office of the High Commissioner on Human Rights, 2008). For people living with HIV, access to treatment not only keeps them alive and healthy but also enables them to avoid transmitting HIV to their sexual partners and to their infants. Access to HIV prevention services is essential to enable people to avoid HIV infection and, if living with HIV, to avoid onward transmission of HIV.

HIV prevention comprises HIV information, sexuality and life skills education, services for sexually transmitted infections, provision of male and female condoms, access to male circumcision, prevention of mother-to-child transmission, and services and modalities to reduce the harms related to drug use. HIV prevention services must be tailored, in the right combination and at the right scale, and must include coverage of key populations at higher

⁶ See *Kiyutin v. Russia* (no. 2700/10), Council of Europe, European Court of Human Rights, 10 March 2011. Other relevant cases include *V.A.M. v. Serbia* (no. 39177/05) (denial of access of a mother to her child on the basis of HIV status).

⁷ A comprehensive package for the prevention, treatment and care of HIV among people who inject drugs includes the following nine interventions: needle–syringe programmes; opioid substitution therapy and other drug dependence treatment; HIV testing and counselling; antiretroviral treatment; prevention and treatment of sexually transmitted infections; condom distribution programmes for people who inject drugs and their sexual partners; targeted information, education and communication for people who inject drugs and their sexual partners; vaccination, diagnosis and treatment of viral hepatitis; and prevention, diagnosis and treatment of tuberculosis (WHO et al., 2012b).

risk (WHO, 2011). It is important to reach those vulnerable to HIV with life skills education, HIV and sexually transmitted diseases information and services, and protection from sexual violence (WHO, 2011). Sexuality education should be integrated in all schools; but there are wide variations in the available standards and in the age at which schools initiate sexuality education in both the EU and neighbouring countries (WHO, 2011).

4.1 Antiretroviral treatment

There is a strong push from UN Member States for universal health coverage as an important building block towards the realization of the right to health. The aim is to ensure that all people have access to health services and do not suffer financial hardship paying for those services (WHO, 2005).

EU countries report 81–100% antiretroviral treatment coverage (ECDC, 2013e). The high coverage rates, however, refer only to people tested for HIV and do not capture those people who do not know their HIV status.⁸

Despite some recent successes in ensuring the right to HIV treatment for undocumented migrants (including in the United Kingdom of Great Britain and Northern Ireland and the Netherlands⁹), antiretroviral treatment is available to undocumented migrants in only half of EU/European Economic Area countries (ECDC, 2013f). Denying treatment to migrants is often argued to be a cost-saving measure. This argument may no longer hold, however, due to the economic benefits of international labour migration, the extended productivity of people living with HIV who are on treatment, the fact that treatment reduces the risk of HIV transmission to other people, and the fact that emergency or extended care for people who report with AIDS is much more costly than ongoing treatment. Thus, for reasons of public health, human rights and economics, migrants should benefit from HIV prevention, care and treatment.

BOX 3

Antiretroviral treatment coverage rates

Estimated antiretroviral treatment coverage rates in 2011 were 22–34% in the Russian Federation, 17–28% in Ukraine, and 24–35% in the Republic of Moldova. The average antiretroviral treatment coverage rate in sub-Saharan Africa in 2011 was 56%. 10

As shown in Box 3, antiretroviral treatment coverage rates in neighbouring countries are well below the average in sub-Saharan Africa (56% in 2011), 11 despite recent increases in the number of people on treatment (based on administrative statistics) in the Russian Federation, Ukraine and the Republic of Moldova (ECDC, 2013e). A range of factors hinder access to antiretroviral treatment for people who inject drugs, sex workers, and men who have sex with men, including stigma and discrimination by health workers; lack of access to opioid

⁹ See http://www.nat.org.uk/Our-thinking/Parliamentary-activity/Recent-successes.aspx, and interview with Ronald Brands Soa AIDS Nederlands.

⁸ See Section 4.2.

¹⁰ For more information on coverage rates, see http://www.unaids.org/en/dataanalysis/datatools/aidsinfo/

¹¹ For information on treatment coverage in eastern Europe, see http://www.unaids.org/en/dataanalysis/datatools/aidsinfo/. See also UNAIDS (2012a). For treatment coverage rates in sub-Saharan Africa, see UNAIDS (2012e).

substitution therapy for people who inject drugs (the most affected population in the region); lack of integrated services regarding treatment for tuberculosis, HIV, viral hepatitis and drug dependence; lack of social services and support of peers for initiation and adherence to antiretroviral treatment; and lack of linkages among and between antiretroviral treatment service providers, health services, disease prevention services and prison services (ECDC, 2013e).

4.2 HIV testing

In the EU, the rate of late diagnosis as a proportion of all new HIV diagnoses remains high (35%) (ECDC, 2013e). These diagnoses are often made some 8–10 years after the initial infection with HIV and only after symptoms of AIDS occur. This is too late to achieve optimal health benefits for the individual or achieve a significant reduction in transmission to others.

The reason people are testing for HIV so late is probably due to a combination of ignorance about HIV, lack of sufficient access to testing services, and fear of stigma and discrimination related to a positive HIV diagnosis. Undocumented migrants may fear being identified if they approach health-care providers (European Union Agency for Fundamental Rights, 2012, points 2 and 3). All of these reasons for late testing raise human rights concerns.

The European Centre for Disease Prevention and Control reports that HIV-related stigma (negative beliefs, feelings and attitudes towards people living with HIV or associated with HIV) and discrimination (unfair or unjust treatment based on a real or perceived HIV status) are still widespread in EU Member States (ECDC, 2013g). Where there is stigma, discrimination, mandatory testing and lack of confidentiality, people will be reluctant to test for HIV, use condoms or seek treatment (ECDC, 2010).

4.3 Harm-reduction

Europe has a strong record of spearheading innovative approaches to HIV. Harm-reduction strategies constitute such an example, showing relative success since their adoption in many European countries over the past two decades (EMCDDA, 2010). In the context of injecting drug use, evidence demonstrates the effectiveness of reducing HIV transmission through harm-reduction strategies, including needle–syringe programmes (ECDC and EMCDDA, 2011; WHO et al. 2012b). 12

Unfortunately, coverage levels of needle–syringe programmes remain low in several EU and neighbouring countries (ECDC, 2013b; UNAIDS, 2012a). In the Russian Federation, HIV infections among people who inject drugs continue to increase due to a lack of comprehensive HIV prevention and harm-reduction programmes, including the prohibition of substitution treatment for opiate dependency (Eurasian Harm Reduction Network, 2011).

Nevertheless, there are encouraging reports from the Republic of Moldova and Ukraine indicating that harm reduction is starting to contribute to a reduction of HIV infections among

¹² Many EU/EFTA countries have successfully implemented moderate- to high-coverage HIV-prevention programmes for people who inject drugs. This includes making sterile injecting equipment widely available through different channels, including needle—syringe programmes, pharmacies and dispensing machines. Programmes in such countries have succeeded in distributing more than 100–200 syringes annually to each person who injects drugs. These programmes also provide opioid substitution therapy to more than 30% of people who misuse opiates (ECDC, 2013b).

people who inject drugs (UNAIDS and WHO, 2012). Portugal's efforts against its HIV epidemic, driven largely by injecting drug use, have been particularly successful, due to its solid public health approach involving harm-reduction programmes, the integration of HIV treatment, and the significant lowering of penalties for drug possession for personal use (Hughes and Stevens, 2010).

High rates of imprisonment for people who use drugs have resulted in increased HIV prevalence among prisoners in some EU and neighbouring countries due largely to transmission in prisons through use of contaminated injecting equipment and unprotected sex (Ferris-Rotman, 2010; WHO, 2013). The European Court of Human Rights (2013) has repeatedly asserted the right of people in prison living with HIV to have access to appropriate health care under Article 3 of the Convention.

4.4 Access to medicines

A fundamental component of the right to health is access to affordable good-quality medicines. In this context, the World Trade Organization 2001 Declaration on the Agreement on Trade-Related Aspects of Intellectual Property Rights and Public Health clarified the scope of, and provided interpretive guidance for, the policy flexibilities embodied in the TRIPS that could be used to ameliorate the impact of patents on access to medicines. The perpetuation of monopolies over health products, however, is making access to cheaper generic medicines more difficult for many countries. In Ukraine, generic antiretroviral drugs are, on average, 26 times cheaper than branded drugs; for certain antiretroviral drugs, the generic drug is up to 80.5 times cheaper. There have been five lawsuits against generic competitors effectively suspending the use of certain drugs in antiretroviral treatment (Bivol and Soltan, 2012). The EU has recognized the importance of ensuring policy coherence across the sectors of trade and health and has committed to ensuring that EU bilateral trade agreements avoid clauses that may undermine access to medicines (European Commission, 2010).

The UN Special Rapporteur on the Right to Health¹⁴ has expressed concern about the potential harmful effects of free trade agreements that establish provisions overriding the provisions under the TRIPS Agreement. Those agreements can result in higher prices of medicines (United Nations General Assembly, 2009a). In the context of negotiations for a free trade agreement with the EU, for example, the Republic of Moldova agreed to introduce long periods for data exclusivity, a provision that exceeded the intellectual property protection standards that the Republic of Moldova agreed to during its World Trade Organization accession (Bivol and Soltan, 2012).

5. Creating an enabling environment

To mount an effective and rights-based response to HIV, Europe should continue to prioritize making HIV prevention, treatment and care available and accessible to people living with HIV and other key populations. This, in turn, requires a legal and social environment that promotes access to services and protects people from discrimination, criminalization and violence. People will be more likely to use health services if they are confident that they and their families will not face discrimination or detention; that their confidentiality will be

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¹³ Declaration on the TRIPS agreement and public health, WT/MIN(01)/DEC/2. 2001.

¹⁴ See http://www.ohchr.org/EN/Issues/Health/Pages/SRRightHealthIndex.aspx.

maintained; that they will have access to information; and that they will not be coerced into accepting services without consent.

Although much has been accomplished in the EU and neighbouring States, much more needs to be done, and done differently, to end the AIDS epidemic. A social and legal environment that will enable effective HIV responses requires laws, policies and practices that protect against discrimination; safeguard access to HIV prevention, treatment, care and support, including harm reduction; ensure participation and inclusion of people vulnerable to and living with HIV, including their rights to association and expression; protect against gender-based violence; and provide a supportive and sustainable framework for national HIV responses.

5.1 The social environment

The history of HIV has demonstrated the critical importance of the full participation and inclusion in the response of people living with HIV and people most vulnerable to HIV. This "nothing about us without us" approach has generated strong activism that has galvanized communities and governments alike (Parker, 2011). Participation permits engagement with and ownership of HIV programmes, ensuring they are tailored to address the needs of affected communities. Participation is also a human right: people affected by HIV have the right to participate in the design, implementation and evaluation of national HIV strategies and programmes.

Box 4

GIPA

The core principle of Greater Involvement of People living with HIV (GIPA) was formalized in 1994 in Paris, where countries committed to "fully involve nongovernmental and community-based organizations as well as people living with HIV/AIDS".

(Paris Declaration, Paris AIDS Summit, 1 December 1994)

When HIV emerged in Europe, there were already fragile networks advancing the gay rights agenda in many EU countries. These quickly became engaged in the HIV response and helped to mobilize communities to understand and deal with this then deadly threat. New civil society organizations sprang up to respond to HIV providing outreach, information, services and efforts to overcome HIV-related stigma and discrimination. These civil society organizations continue to support and strengthen HIV responses. For example, the International HIV/AIDS Alliance Ukraine contributed to the Ukrainian HIV response by building and supporting a national network of civil society organizations in delivering HIV and harm reduction services through the Ukrainian health system. ¹⁶

To mobilize effectively, it is essential that people living with HIV and other key populations know their human rights and the local laws relevant to HIV, are able to assert these and are

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¹⁵ For more information on Terrence Higgins Trust, see http://www.tht.org.uk/our-charity/About-us

¹⁶ http://www.aidsalliance.org/linkingorganisationdetails.aspx?id=6

able to seek redress for harms done, through legal means and the justice system. (UNAIDS, 2012f). It is important that laws do not limit civil society's ability to organize, register, associate and engage in the HIV response and related issues. ¹⁷ Such civil society engagement is even more critical where key populations are highly marginalized and/or criminalized, and difficult to reach. 18

National human rights institutions can play an important role in addressing human rights and HIV. For example, the recently created Netherlands Institute for Human Rights, a statutory body with broad authority to hear human rights cases, ¹⁹ has already issued two decisions in favour of victims of work-related HIV discrimination in the few months since it was established.²⁰

Nevertheless, HIV-related stigma remains high across the region and must be urgently addressed with concerted and sufficiently resourced efforts (See Table 1). Public information campaigns, edu-tainment, the engagement of celebrities and sports figures and most importantly people living with HIV are effective ways by which to tackle HIV-related stigma and discrimination. ²¹ Concerted efforts should be made to reduce stigma and discrimination across sectors - health, education, employment, justice- and among the general public (UNAIDS, 2012f). Today, 18 out of 25 EU Member States and Moldova and Ukraine report programmes to reduce HIV-related stigma and discrimination (UNAIDS, 2012f). However, little is known about their quality, coverage and impact.

¹⁷ Civil society organizations indicate decreased access to funding between the 2010 and 2012 rounds (ECDC, 2013h).

¹⁸ As stated in the 2011 Regional Dialogue of the Global Commission on HIV and the Law.

¹⁹ See http://geneva.nlmission.org/organization/departments/political-affairs/human-rights.html.

²⁰ See http://www.mensenrechten.nl/.

²¹ For example, in Germany, a nationwide anti-discrimination campaign implemented by government institutions and nongovernmental organizations to mark World AIDS Day was implemented in 2010 and 2011, calling for greater respect and tolerance towards people living with HIV (see Germany's submission to the 31st UNAIDS Programme Coordinating Board in UNAIDS, 2012k).

Table 1 Examples of stigma and discrimination against people living with HIV				
Area	Key facts	Source		
General stigma	22% of respondents in the United Kingdom were physically harassed over the past 12 months, of whom 54% affirmed that this was related to their HIV status 78% of respondents in the Russian Federation had experienced negative feelings towards them	The People Living With HIV Stigma Index - UK (2009) The People Living with HIV Stigma Index - Russia (2010)		
and discrimination	related to their HIV status over the last year 37% of respondents in Ukraine faced discrimination through unauthorized disclosure of information about their HIV status; 22% underwent mandatory testing or were tested without their knowledge	The People Living with HIV Stigma Index – Ukraine (2011)		
Access to HIV/health services	Many respondents delayed uptake of HIV testing and care services due to anticipated social stigma in Estonia (60%), the Republic of Moldova (31%), Poland (40%) and Ukraine (58%) 17% of respondents in the United Kingdom were denied health services at least once because of their HIV status in the last 12 months	The People Living with HIV Stigma Index - Estonia, Moldova, Poland, Turkey and Ukraine (2011) The People Living With HIV Stigma Index - UK (2009)		
	16% of respondents from Russia had been refused some kind of service by medical institutions in the last 12 months	The People Living with HIV Stigma Index – Russia (2010)		
	In UK, although 88% of people know of organizations they can go to for support, only 29% have sought support from these services	The People Living With HIV Stigma Index - UK (2009)		
Access to social protection and support services	3% of respondents were denied life or health insurance because of their HIV status	The People Living with HIV Stigma Index – Poland (December 2011)		
	25% of respondents in Ukraine faced restrictions in access to social and health care services for reasons related to their HIV status at least once.	The People Living with HIV Stigma Index – Ukraine (2011)		
Discrimination in other sectors	21% of respondents have encountered some kind of discrimination by organisations and institutions in connection with their HIV status. 5% of respondents in the Republic of Moldova were refused employment due to their HIV status	The People Living with HIV Stigma Index – Russia (2010) The People Living with HIV Stigma Index – Moldova (October 2011)		
	4% of respondents with children from Ukraine stated that their children were prevented from attending educational institutions due to their parents' HIV status	The People Living with HIV Stigma Index – Ukraine (2011)		

5.2 The legal environment

An enabling legal environment is characterized by laws that protect rather than punish people living with HIV and other key populations; effective and protective law enforcement, and access to justice in the context of HIV. Although European countries have made significant progress in aligning legal frameworks with their international human rights obligations and commitments related to HIV, much work remains to be done (See Table 1).

In almost all European and neighbouring countries, people who are dependent on drugs face criminal penalties rather than treatment of this health condition (EMCDDA, 2012). Adults who sell sex on a consensual basis similarly face criminalization rather than protection from violence, exploitation and sexually transmitted diseases (Global Commission on HIV and the Law, 2012, Chapter 3.2). Fear of arrest and imprisonment makes sex workers and people who use drugs reluctant to access health services or the police if they are victims of violence or rape (Global Commission on HIV and the Law, 2012). Gay, bisexual and transgender people face limits on their freedoms of association and expression (e.g. Lally, 2013). They also face discrimination, violence and hate crimes with little access to justice. Although the Republic of Moldova has recently lifted discriminatory restrictions on entry, stay and residence based on HIV status (UNAIDS, 2012g), three EU countries²² and the Russian Federation still employ such restrictions (UNAIDS, 2013).

In relation to employment, the International Labour Organization (2010) states that "HIV testing or other forms of screening for HIV should not be required of workers, including migrant workers, jobseekers and applicants". There are positive developments across Europe in this regard, with an increase in the number of countries (from 43% in 2010 to 60% in 2012) that report having a policy or law prohibiting pre-employment HIV testing (ECDC, 2013a,b,c,e,f,g,h). Similarly, although life insurance was often previously denied to people living with HIV (making it difficult, for example, to buy a house), there are some positive developments, such as in France and the Netherlands, where it is now unlawful to deny life insurance to applicants based on their HIV status.²³

Legislation can protect the human rights of people living with and vulnerable to HIV (Global Commission on HIV and the Law, 2012). Recent positive developments are laws that protect equality and freedom from discrimination across sectors. Sweden's Discrimination Act 2008,²⁴ for example, combats discrimination with respect to sexual orientation and drug dependence, and specifically refers to health services. The United Kingdom's Equality Act 2010 includes HIV infection in its definition of "disability", thereby protecting people living with HIV from discrimination and harassment.²⁵

On the other hand, after North America, Europe has the highest number of prosecutions for HIV exposure or transmission, with three European countries representing more than half of the total known convictions in Europe ²⁶. UNAIDS and many HIV experts have long been concerned about the overly broad application of the criminal law to HIV non-disclosure, exposure and transmission. Not only do these prosecutions often involve miscarriages of justice that destroy people's lives, but also they make people fearful of being tested for HIV or disclosing their status, because of fear of prosecution. Moreover, there may have been selective enforcement focusing disproportionately on people from ethnic minorities, migrants

²² Cyprus, Lithuania, Slovakia.

²³ See http://www.hivnet.org/downloads/pdf/life_insurances_international_analysis.pdf.

²⁴ See http://www.government.se/sb/d/3926/a/118187.

²⁵ See http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf.

²⁶ Sweden, Austria and Switzerland

and men who have sex with men, thus adding to the discrimination and stigma faced by these groups. Fortunately, the tide may be turning. A number of countries are revisiting their approach to focus only on truly blameworthy cases involving the intent to transmit and actual transmission.²⁷

5.3 Investing in programmes that support an enabling environment for effective HIV responses

Programmes that enhance access to justice in the context of HIV should be included and significantly expanded in national responses to HIV so that people living with and vulnerable to HIV know their rights and can use them to make concrete demands. UNAIDS has identified seven key programmes that both increase access to justice and work to critically enable basic HIV programmes in the national response. These programmes include the following: rights and legal literacy; legal services; sensitization of judges and law enforcement on HIV; training of health-care workers on non-discrimination and medical ethics; law reform; stigma reduction; and reducing harmful gender norms and violence against women. The roll-out of these programmes was endorsed in the 2011 Political Declaration on HIV and AIDS (United Nations General Assembly, 2011).

The Ukrainian Government, for example, has agreed to develop curricula for advanced training courses for prosecutors, judges and health-care workers on HIV (UNDP, 2013). This follows an earlier successful initiative whereby legal aid services were incorporated into harm-reduction services, drawing people into the latter when seeking legal support.²⁹ In the Republic of Moldova, legal aid has been offered since 2010, and strategic litigation has been instrumental in removing HIV-related travel restrictions and amending the legal framework (IDOM, 2012).

Despite the economic crisis, EU Member States have increased domestic funding for their HIV responses (ECDC, 2013i). This increase, however, is due largely to the increased provision of antiretroviral treatment rather than HIV prevention. Unfortunately, there is limited investment in programmes that support enabling of social and legal environments (UNAIDS et al., 2013). Some eastern European countries continue to depend to a high degree on external funding, with about half or more of their funding coming from international sources, particularly from the Global Fund to Fight AIDS, Tuberculosis and Malaria (UNAIDS, 2012c,i,j). In the context of scarce resources, an investment approach to HIV that prioritizes programmes that are evidence-informed and focused on key populations should be used (Schwartlander et al., 2011). This approach incorporates programmes that adress legal and social obstacles to access and uptake.

6. Conclusion

Much has been accomplished in the EU and its neighbouring countries against HIV. Countries have put in place HIV responses, and the people who have been willing and able to come forward for HIV prevention, testing and treatment have done so. However, significant pockets of marginalized populations continue to be highly affected by HIV. It will take hard work and

²⁹ For more information on such services, see International Development Law Organization and UNAIDS (2009).

²⁷ For more information on legal reform of laws that criminalize HIV non-disclosure, exposure and transmission, see UNAIDS (2012h).

²⁸ See also UNAIDS (2012f).

a different kind of work to reach these populations. This work is largely related to human rights – ensuring equity in coverage, overcoming discrimination, replacing the punitive with the protective, enabling and empowering people affected to participate and fashion effective responses, differentiating services to meet the needs and realities of people affected, and reaching them where they are.

The following steps are suggested for further action and reiteration in Europe and beyond:

- Exercise strong political leadership to address HIV as a high-priority health and human rights issue, nationally, regionally and globally, in line with Europe's position as a global human rights leader.
- **Foster a human rights culture** of respect, inclusion and diversity, including with regard to people living with and vulnerable to HIV.
- Strengthen efforts to **collect disaggregated data** on people living with HIV, people who inject drugs and their sexual partners, men who have sex with men, people in prison, sex workers, migrants and transgender people, while ensuring that their privacy and confidentiality are maintained.
- Allocate sufficient domestic and international financial resources for HIV.
- **Apply an investment approach**, investing in programmes that are evidence-informed and known to work, focus on key populations, and address obstacles to access and uptake, reduce stigma and discrimination, and increase access to justice in the context of HIV.
- Make available and expand access to the full range of HIV prevention and harm-reduction services.
- Engage and support people living with HIV and other key populations as active partners and catalysts for change.
- **Provide sustained and strong support for civil society** engagement in the AIDS response, with sufficient core funding and free and open space for operation.
- Critically review and monitor existing legislation, policies and practices, and remove punitive laws, policies and punitive practices, such as criminalization and mandatory testing and treatment.
- Strengthen or create social and legal environments that protect and support people to come forward for HIV prevention, testing and treatment to maximize health and prevention benefits.
- Take action against violence against women, including against female sex workers, women who use drugs and transgender women.
- Build the HIV and human rights capacity of the three branches of government and across sectors health, justice, education, parliaments and the judiciary.
- Ensure the use of intellectual property rights does not conflict with the TRIPS Agreement.
- Enhance collaboration and cooperation among EU Member States and neighbouring countries for an evidence-informed response to HIV based on human rights.

Annex 1:

HIV-related human rights commitments made by EU Member States and institutions and neighbouring countries

HIV-related human rights commitments made by EU Member States/institutions and			
neighbouring coun	Document Tries	Commitment	
Area Rights of people	UN General Assembly -Political Declaration on HIV and AIDS (2011)	"Reaffirm that the full realization of all human rights and fundamental freedoms for all is an essential element in the global response to the HIV epidemic."	
living with HIV	Statement of the EU and its Member States on World AIDS Day (2011)	"Protect people living with HIV or AIDS from discrimination, stigmatization and deprivation of their rights and freedoms"	
	UN General Assembly -Political Declaration on HIV and AIDS (2011)	"Commit to redouble efforts to achieve, by 2015, universal access to HIV prevention, treatment, care and support"	
Universal access to HIV services	Statement of the EU and its Member States on World AIDS Day (2011)	"The EU underlines the importance of paying special attention towards key populations"; "Ensure a wide access to carefully tailored programmes, services and commodities for prevention"	
	European Parliament resolution of July 8 2010 on a rights-based approach to the EU's response to HIV	"Calls on the Commission and the Council () [to facilitate] "universal access to health care, whether with respect to HIV/AIDS-related prevention, treatment, care and support, or to other non-HIV/AIDS-related medical provision"	
Women and Girls	UN General Assembly -Political Declaration on HIV and AIDS (2011)	"Commit to ensuring that national responses to HIV and AIDS meet the specific needs of women and girls, including those living with and affected by HIV, across their lifespan, by strengthening legal, policy, administrative and other measures for the promotion and protection of women's full enjoyment of all human rights and the reduction of their vulnerability to HIV"	

	IIN Canaral Assamble	"Commit to support their access to IIIV
Migrants	UN General Assembly -Political Declaration on HIV and AIDS (2011)	"Commit to support their access to HIV prevention, treatment, care and support"
Travel restrictions	UN General Assembly - Political Declaration on HIV and AIDS (2011)	"Encourage Member States to consider identifying and reviewing any remaining HIV-related restrictions on entry, stay and residence in order to eliminate them"
Enabling legal and social	Dublin Declaration on Partnership to fight HIV/AIDS in Europe and Central Asia (2004)	"Combat stigma and discrimination of people living with HIV/AIDS in Europe and Central Asia, including through a critical review and monitoring of existing legislation, policies, and practices"
environment	UN General Assembly –Political Declaration on HIV/AIDS (2006)	"Commit ourselves to intensifying efforts to enact, strengthen or enforce, as appropriate, legislation, regulations and other measures to eliminate all forms of discrimination against and to ensure the full enjoyment of all human rights and fundamental freedoms by people living with HIV and members of vulnerable groups."
	European Commission Communication: "Combating HIV/AIDS in the European Union and neighbouring countries, 2009 -2013"	"Support activities that aim at (1) decreasing HIV-related stigma, (2) promoting respect for the human rights of all people living with HIV and (3) addressing all forms of HIV-related discrimination and support the social inclusion of people living with HIV"
	UN Human Rights Council, Resolution A/HRC/RES/12/27 (2009)	"Urges all States to consider taking the steps necessary towards the elimination of criminal and other laws that are counterproductive to HIV prevention, treatment, care and support efforts"
	EU statement for World AIDS Day (2010)	"Support removal of restrictions on entry, stay and residence for people living with HIV as well as decriminalisation of homosexuality, and to remove other barriers, including punitive laws"

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