

### HIV/AIDS in Europe: The basics

In 2016, 36.7 million people globally were estimated to be living with HIV/AIDS, while approximately 1 million people died from AIDS-related illnesses that year.<sup>1</sup> The disease has previously been considered to predominantly affect men; however, this is no longer the case. According to WHO/UNAIDS' latest global estimate, women over 15 years of age make up over 50% of the people infected with HIV, rising to 59% in eastern and southern Africa.<sup>2</sup> Globally, HIV is the leading cause of death and disease in women of reproductive age.<sup>3</sup> HIV incidence peaked globally in 1997, with an estimated 3.3 million new people becoming infected each year; subsequently annual incidence dropped sharply until 2005 where it has stabilized at between 2.5 and 2.6 million per year.<sup>4</sup>

HIV has become a growing health concern for women in Europe. It represents an important challenge in Eastern Europe, where one of the steepest rises in HIV rates among women in the world has occurred, particularly among young women (those aged 15-24).<sup>5</sup> The proportion of women living with HIV has been increasing over the past two decades. In 1990 women made up just under 45% of all individuals living with HIV, a share which the World Bank estimates rose to 51.5% in 2016.<sup>6</sup> Gender inequalities are cited as a key driver of the epidemic in women.<sup>7,8</sup>

Annually, over 55,000 people are diagnosed with HIV in the EU and neighbouring countries (the WHO's European Region).<sup>9</sup> Between 2000 and 2009, the number of individuals with HIV in Eastern Europe has nearly tripled. Currently, 940,000 people are estimated to be living with HIV in Eastern Europe, compared with 651,000 in Western Europe.<sup>10</sup> In the ten years since the turn of the century, the rate of new HIV infections from heterosexual contact has increased by 150%.<sup>11</sup> While sex between men is still the most common mode of transmission of the virus, across the WHO European Region, 45.8% of new HIV diagnoses resulted from heterosexual sex, a figure which rises to 65.2% if we consider only the countries in the east of that region.<sup>12</sup>

According to the World Health Organization's 2015 *HIV/AIDS Surveillance Report*, just under 30,000 diagnosed cases of HIV infections were reported in 31 EU/EEA countries, a rate of 6.3 per 100 000 population<sup>13</sup>. This number is likely to be higher due to the delay in reporting HIV diagnoses in a number of countries.

### What is HIV/AIDS?

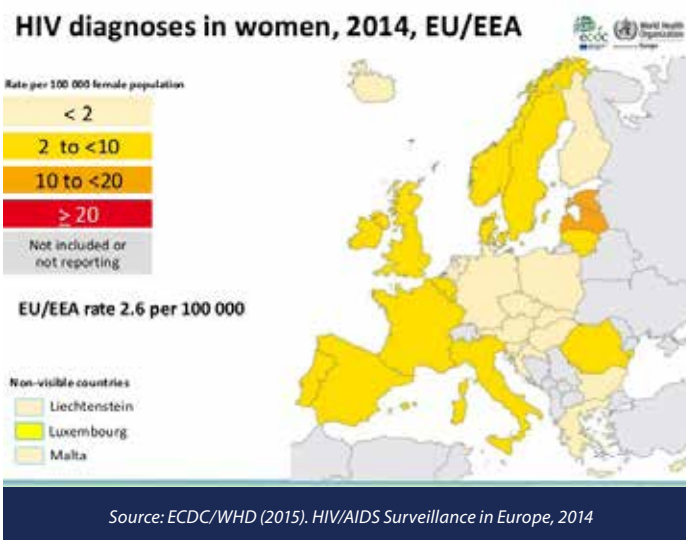
The Human Immunodeficiency Virus (HIV) attacks the immune system, weakening the body's ability to fight off infections and disease, leading to a progressive failure of the immune system and leaving the body vulnerable to life-threatening opportunistic infections. The last stage of HIV is Acquired Immune Deficiency Syndrome (AIDS); it can take years for HIV to progress into AIDS. While there is no cure, many medications have been developed to slow the progression of the disease.<sup>14,15</sup>

The modes of transmission include unprotected vaginal or anal sexual intercourse (the chances of contracting the disease through unprotected oral sex are extremely low), sharing of needles and syringes for injecting drugs, transfusion of contaminated blood or its products, and mother-to-child transmission (MTCT). It is important for women to understand that the virus can be spread from mother to child during pregnancy, childbirth or breast-feeding.<sup>16,17</sup>

### HIV/AIDS: why gender matters

Their biological make-up and society's gender norms, make women and girls more susceptible than men to sexually transmitted infections, including HIV. According to a WHO report, gender inequalities in HIV are a key driver of the epidemic in several ways:<sup>18,19,20</sup>

- Gender norms related to masculinity can encourage men to have more sexual partners and older men to have sexual relations with much younger women. In some settings, this contributes to higher infection rates among young women (15-24 years) compared to young men.
- Homophobia stigmatises men having sex with men, and makes them and their partners vulnerable to HIV.
- Norms related to femininity can prevent women, especially young women, from accessing HIV information and services. Less than 30% of women have accurate, comprehensive knowledge of HIV/AIDS according to the 2013 UNAIDS global figures.<sup>21</sup>



- Violence against women (physical, sexual, psychological, and emotional) is experienced on average by 35% of women worldwide.<sup>22</sup> This figure varies by region, rising as high as 60% in Oceania.<sup>23</sup> Such violence increases vulnerability to HIV. Forced sex can contribute to HIV transmission due to tears and lacerations resulting from the use of force. Women who fear or experience violence often lack the power to ask their partners to use condoms or to refuse unprotected sex. Fear of violence can prevent women from learning and/or sharing their HIV status and accessing treatment.
- A main risk factor for women in Europe for HIV transmission presently is the undisclosed risk behaviour of their male sexual partners.

**Table A: Characteristics of new HIV diagnoses reported in the WHO European Region, the EU/EEA, and West, Centre and East of the WHO European Region, 2015**

	WHO European Region	West	Centre	East	EU/EEA
Reporting countries/Number of countries*	49/53 (50/53)	23/23	14/15	12/15 (13/15)	31/31
Number of new HIV diagnoses	55 230 (153 407)	27 022	5297	22 911 (121 088)	29 747
Rate per 100 000 population**	7.6 (17.6)	6.3	2.8	20.6 (47.5)	6.3
Percentage age 15–24 years	9.8%	10.3%	14.6%	8.2%	10.8%
Male-to-female ratio	2.3	3.2	5.3	1.5	3.3
<b>Transmission mode</b>					
Sex between men	25.6%	43.4%	29.9%	3.6%	42.2%
Heterosexual	45.8%	33.0%	27.5%	65.2%	32.0%
Injecting drug use	13.0%	3.3%	4.4%	26.4%	4.2%
Mother to child transmission	0.9%	0.8%	1.0%	1.1%	0.8%
Unknown	14.5%	19.3%	36.9%	3.6%	20.2%

\* No data received from Bosnia and Herzegovina, Russia, Turkmenistan, Uzbekistan. All data presented were reported to ECDC/WHO through the European Surveillance System (TESSy), except for data for Russia which were obtained through the Russian Federal Scientific and Methodological Center for Prevention and Control of AIDS [1]. Russian data are included in the numbers in parentheses for the European Region and the East.

\*\* EU/EEA rate is adjusted for reporting delay (Annex 5), the corresponding estimated number of new diagnoses adjusted for reporting delay is 32 483

Source: WHO. 2015. HIV/AIDS surveillance in Europe. [http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0019/324370/HIV-AIDS-surveillance-Europe-2015.pdf](http://www.euro.who.int/__data/assets/pdf_file/0019/324370/HIV-AIDS-surveillance-Europe-2015.pdf)

## HIV testing and women

Strategies for HIV testing vary across Europe, but widespread, unacceptably high rates of late diagnosis among women suggests that current testing strategies are not adequately reaching the female population.<sup>24</sup> Research has found, for example, that women miss chances for HIV testing more than men and are more impacted by the potential negative effects of HIV testing such as the disclosure to partners. The targeting of women by policymakers and stakeholder is therefore crucial if we are to ensure that HIV is diagnosed and – crucially – diagnosed early on.

## The biological dimension

Some studies suggest that HIV/AIDS varies between women and men. The rate of disease progression can vary and the standard predictors of disease progression such as viral load are not always as accurate for women as they are for men. A man and woman may have the same viral load, yet the disease may progress at a faster rate in women.<sup>25</sup> Further research is required as the reasons for these differences are not yet fully understood.<sup>26</sup>

Women generally are more susceptible to sexually transmitted infections (STIs) than men. This includes HIV infections. Women are twice as vulnerable to HIV infection by heterosexual vaginal intercourse as are men.<sup>27</sup> Pre-existing infections of Herpes (HSV-2), chlamydia, and the Human Papilloma Virus (HPV) increase the risk of HIV transmission.<sup>28,29,30</sup> Young women, particularly those below the age of 24, appear to be much more vulnerable to HIV. This increased susceptibility occurs because their genital tracts are not yet mature and may be more prone to tears and abrasions during sexual intercourse.<sup>31,32</sup>

Age also impacts HIV transmission susceptibility. Post-menopausal women have an elevated risk of HIV infection due to a thinned uterus lining and increased vaginal dryness. When controlling for other factors, women with HIV live longer than HIV positive men. Although ageing women are making up an increasing proportion of the total HIV positive population, little data exists on older women with HIV. Studies that include ageing women do not have a large enough sample size to draw useful conclusions.<sup>33</sup>

## HIV/AIDS and pregnancy

Most HIV infection in children results from mother-to-child transmission (MTCT). However, only 1.5-2% of MTCT occurs through the placenta during pregnancy. In addition, if the expectant mother remains healthy such transmission is less likely to happen. Most MTCT transmission happens during labour and through breastfeeding.<sup>34,35</sup>

If pregnant women with HIV do not receive drug treatment during pregnancy, delivery, and postpartum, it is estimated that in 25% of cases, their infants will acquire HIV. However, with a multi-care approach to pregnancy and delivery, the likelihood of HIV transmission to the infant is reduced to less than 2%. Specifically, the risk of HIV transmission during childbirth is 10-20% if no prevention is undertaken. Approximately 15% of babies born to HIV-positive women will become infected if they breastfeed for 24 months or longer.<sup>36,37</sup>

Currently, steps can be taken to prevent MTCT. During pregnancy women with HIV are treated with a drug regimen developed specifically for them. It is critically important that women with HIV should tell their doctors about the medicines they are taking as some anti-HIV medications may cause issues during pregnancy such as birth defects that develop during the first few months of pregnancy. In addition, the long-term effects of some medications on babies are unknown. Pregnancy registers then are useful safety tools to ensure the health of mothers and their babies. During childbirth, HIV-positive pregnant women receive intravenous AZT as well as oral tablets. After delivery, babies are treated with liquid AZT for 6 weeks.<sup>38</sup>

**Various factors increase the risk of MTCT transmission. The most common ones are listed below:**<sup>39</sup>

- Stage of HIV
- Labour and childbirth issues
- Breastfeeding
- Smoking
- Substance and drug abuse
- Malnutrition
- Vitamin A deficiency
- Other infections, including STIs

One of the key strategies of the WHO European Action Plan for HIV/AIDS 2012-2015 is to eliminate MTCT through HIV testing and counselling of all pregnant women. Pregnant women who are HIV positive must be provided with antiretroviral therapy (ART) during/after pregnancy and their vulnerable infants must be given ART as well. Access to safe infant formula must be ensured in order to tackle the risk of transmission through breastfeeding. Access and support, in particular, for HIV-positive women with unintended pregnancies is needed to effectively tackle the MTCT and to ensure that HIV positive women remain healthy throughout their pregnancy.<sup>40</sup>

### **Gender inequality, discrimination and stigma**

According to WHO Europe, high-risk populations in Europe face many obstacles to access HIV services, including discrimination, stigma, and barriers within the healthcare system. Disadvantaged and vulnerable population groups often do not have access to or are not reached by health services to prevent, diagnose, and treat HIV infection. It is estimated that one-third of people living with HIV in the EU and more than 50% in Eastern European countries do not know they are infected with HIV due to both limited access to and low utilisation of HIV testing and counselling.<sup>41</sup>

Throughout Europe, high-risk individuals, who are often socially marginalised and in need of HIV treatment, are the least likely to receive treatment. Antiretroviral therapy (ART) access rates in some European countries are the lowest in the world with only 19% (half of the global average) of adults needing ART in low-and middle-income countries in Europe receiving it. These inequalities in access throughout the WHO European region persist; ART access in Western Europe is one of the best in the world, but in Eastern Europe access drastically lags behind. For example, a majority of people with HIV are injection drug users; however only 25% of these drug users are receiving ART in Eastern Europe.<sup>42</sup>

It is crucial therefore that rapid testing be targeted at high-risk population groups, including pregnant women. The health needs of female injection drug users, of the women whose partners inject drugs, and of sex workers throughout the region, especially in Eastern Europe, need to be targeted by HIV healthcare services.

Support must be given to end sex- and gender-based violence, which often is associated with the transmission of HIV to women.<sup>43</sup> Poverty frequently impedes HIV treatment as such therapies are expensive. Women with limited financial resources are therefore especially susceptible. In comparison to men, women are more likely to be excluded from health plans and women often put the needs of their families over their own health needs, which again negatively impacts effective treatment.<sup>44</sup>

### **HIV and female sex workers**

Sex workers are among the groups most vulnerable and seriously affected by HIV/AIDS due to the nature of their work, a high number of sexual partners, an unsafe working environment, an inability to negotiate condom use, as well as not having access to health services.<sup>45,46</sup> Laws, regulations, and policies criminalise or stigmatise sex workers which in turn increases their vulnerability and leaves them at greater risk of infection<sup>47</sup>. A 2012 study covering 50 countries found that female sex workers had a risk of contracting HIV that was 14 times greater than that of other women.<sup>48</sup> A review published in 2013 on the HIV risk among female sex workers in Europe shows that HIV infection rates are low for those sex workers who don't inject drugs, (consumption of intravenous drugs is the primary risk factor for them).<sup>49</sup> HIV in female sex workers is highest in Eastern European countries. Additionally, female sex workers are vulnerable to various forms of violence which, as has been discussed above, is linked to HIV infection.<sup>50</sup> Interventions for HIV prevention should be included in strategies that address the social welfare of sex workers, highlighting the need to target the social determinants of health and inequality, including regarding access to services, experience of violence, and migration.<sup>51</sup>

### Women in HIV/AIDS drug trials

Globally, almost half of women living with HIV/AIDS are women. However, historically, women have been underrepresented in clinical trials for HIV/AIDS medications, making it difficult to draw conclusions on sex- and gender-based differences with regard to HIV treatment efficacy and effectiveness. Lack of scientific research makes fighting HIV more difficult in women than it is in men. For example, in the 18 randomised controlled trials of new HIV drugs submitted to the Food and Drug Administration (FDA) from 2000 and 2008, only 15% of patients enrolled were women. Underrepresentation of in trials is particularly pronounced for women from minority and ethnic groups.<sup>52</sup>

Due to this lack of systematic scientific research, much is unknown how HIV treatments impact on women. More information on drug absorption, drug toxicology, and side effects in women is urgently needed. In future, treatment studies need to explore the impact of biological factors such as hormone variation (from menstruation, pregnancy, and menopause) on drug absorption and efficacy. HIV medication interacting with other medication taken by women, such as birth control pills and hormone replacement therapy (HRT), also requires further study.<sup>53,54</sup>

Women encounter various barriers to enrolling in drug trials. In particular, such trials often require a significant time commitment and potentially demand unpaid time off work. Often, pharmaceutical companies and hospitals do not provide child-care services or compensation of expenses, which can in part explain any reluctance to enrol in such studies. Women are also often reluctant to disclose their HIV status to employers, which can be necessary in order for them to take time off from work. Women have also been kept from drug trials due to their pregnancy potential, something which has important implications for the treatment of young women, a group among which HIV rates are increasing. Finally, many women often lack the necessary socio-economic support to enable them to participate in a drug trial.<sup>55</sup>

### WHO European Region—the East-West Divide of HIV/AIDS

Just over 2 million people were living with HIV at the end of 2015 in the WHO European Region (53 countries), and the numbers continue to rise.<sup>56</sup> Alarmingly, the WHO estimates that around a third of those people with HIV do not know that they are infected. HIV represents a growing threat for women in the eastern region of Europe. Despite some progress in achieving access to HIV prevention, treatment, care, and support, the response to the HIV epidemic still faces many challenges such as unknown HIV status, late treatment initiation, poor access to treatment, co-infection with tuberculosis, and hepatitis.<sup>57</sup>

The rate of new HIV diagnoses per 100,000 population is estimated to have more than doubled in the region since 2000.<sup>58</sup> The HIV epidemic is fastest growing in the eastern part of the WHO European Region; 79% of the newly diagnosed infections were located there. According to WHO estimates, new HIV infections are more than 3 times higher in the east than in the west of Europe.<sup>59</sup> While reported AIDS cases declined by 54% in the West, the number of people newly diagnosed with AIDS increased by 113% in the eastern part of Europe from 2006 and 2012.<sup>60</sup> For the same period, reported deaths among people with AIDS decreased by 14% across the Region as a whole, but increased by 58% in the East. HIV testing and counselling, as well as early diagnosis, need to be stepped up to allow for earlier treatment with ART.<sup>61</sup>

The number of new HIV infections acquired through heterosexual contact has rapidly increased over the past fifteen years. Women comprise of up to 50% of new cases in some Eastern European countries. In Russia, for instance, women aged 15-24 are contracting HIV at twice the rate as men of the same age.<sup>62</sup> According to Dr Jean-Elie Malkin, the UNAIDS Regional Director for Eastern Europe and Central Asia, *“Women [in Eastern Europe] are especially at risk of HIV due to multiple factors such as economic vulnerability, fearing or experiencing violence, and difficulties in negotiating for safe sex.”*<sup>63</sup> The vast majority of the rise in HIV transmission in Eastern Europe is due to injection drug use and heterosexual intercourse.<sup>64</sup> Although the majority of HIV-positive drug users are men, this affects their female partners.<sup>65</sup>

In Western Europe, the spread of HIV remains concentrated among men who have sex with men as well as among migrant populations—both men and women—especially those from countries with HIV epidemics.<sup>66,67,68</sup> In 2015, it was estimated that 4 out of every 10 people diagnosed with HIV in Europe were migrants.<sup>69</sup> While it is important to be concerned with the diagnosis and treatment of migrants who have acquired HIV in their country of origin, the majority of migrants in Europe living with HIV acquire the disease in their new country.<sup>70,71,72</sup> It is the social exclusion that migrants and refugees suffer from that places them at greater risk of HIV infection after their arrival in Europe, and this must be addressed if these individuals are to receive the necessary treatment for diseases like HIV.<sup>73</sup>

The focus of any interventions will have to vary according to the mode of transmission and also be adapted to target marginalised populations, in particular migrants who make up a substantial share of new HIV diagnoses in Europe. This represents a particular challenge since in all countries these marginalised groups are made up of precisely those individuals that often lack access to proper health care, information, and prevention services.

HIV is a serious threat to public health in Europe. The EU urgently needs to address the expanding HIV epidemic in its neighbouring countries, including the former members of the Soviet Union, by developing a clear plan of action to support these countries in the fight against this and other infectious diseases.

**Existing European strategies for HIV treatment and prevention**

**Commission communication on combating HIV/AIDS in the EU and neighbouring countries:** The 2009 document identifies policies to help reduce the rate of new HIV infections and improve the quality of life for people living with HIV/AIDS throughout Europe. The EU policies support stakeholders in EU and neighbouring countries to improve access to prevention, treatment, care and support; to reach migrants from countries with a high prevalence of HIV and to improve policies targeting the populations most at risk.<sup>74</sup>

**WHO European Action Plan for HIV/AIDS 2012-2015:** The Plan's vision and goals for the European Region are **zero new HIV infections, zero AID-related deaths, and zero discrimination** in a world in which people living with HIV are able to live long, healthy lives. The Plan aims to eliminate new HIV infections, discrimination with regard to diagnosis and treatment, and to reduce AIDS-related deaths in Europe. It targets national authorities of ministries' of health and other related services, such as justice, education, and social welfare, throughout Europe.<sup>75</sup>

**WHO European Region: New Consolidated Guidelines for ART:** In June 2013, WHO published new consolidated guidelines on the use of ART. These guidelines call on all countries to initiate treatment in adults living with HIV when their CD4 cell counts fall to or below 500 cells/mm<sup>3</sup>: while their immune systems are still strong. Implementation of the new guidelines needs to be encouraged to make more people in the Region eligible for ART, to prevent more people from developing AIDS, and to further reduce transmission of HIV infection. With the right therapy, started at the right time, people with HIV can now expect to live long and healthy lives. This therapy also protects their sexual partners and infants, as the risk of transmitting the virus is greatly reduced.

**Joint Action on HIV/AIDS Prevention (2013-2015):** Following the strategy for combating HIV/AIDS in the EU and neighbouring countries, the Joint Action uses a public health approach to ensure more effective HIV/AIDS prevention in the EU and neighbouring countries. The Joint Action focuses on vulnerable populations. It aimed to increase the effectiveness of HIV prevention using quality assurance and improvement tools. Importantly, it will train at least 60 experts in participating countries to provide capacity building and technical assistance to programmes/projects applying these tools, ensure that experts have the skills for providing technical support, and develop, adopt and disseminate a Charter for Quality in HIV Prevention.<sup>76</sup>

**Action Plan on HIV/AIDS in the EU and neighbouring countries (2014-2016):** This initiative constitutes a prolongation of the *Commission Communication and Action Plan for combating HIV/AIDS in the European Union and neighbouring countries, 2009-2013*. It represents an interim solution allowing for the continuity of prior EU work within the existing policy framework beyond the 2013 deadline of the original action plan.<sup>77</sup> One of its key aims is to keep HIV/AIDS high on the political agenda at national- and EU-levels.<sup>78</sup>

**The European Commission has set up two groups that meet twice annually to encourage cooperation:**

**HIV/AIDS Think Tank:** This group is comprised of representatives from EU Member States and neighbouring countries to exchange information on HIV and to strengthen cooperation throughout Europe with regard to HIV/AIDS diagnosis, treatment and care.

**HIV/AIDS Civil Society Forum:** The Forum consists of experts, including major European networks and NGOs that make recommendations on HIV/AIDS policy formulation and implementation.<sup>79</sup>

## Steps for policy action

### 1. Improve existing EU data collection on HIV/AIDS.

Currently, HIV/AIDS data collection throughout Europe remains limited. Annual data about incidence and prevalence should be improved, particularly with regard to Eastern Europe, to better understand the full scope of the HIV/AIDS epidemic. The interaction and influence of major risk factors disaggregated by gender and age must be included in order to fully understand HIV trends. More data on hard to reach high risks groups is needed.

### 2. Implement policy, programmes, and interventions that target women, especially socio-economic disadvantaged women, drug users, sex workers and migrants.

It is imperative that women's unique vulnerabilities to HIV are considered in prevention, support and treatment programmes. Diagnosis, treatment and care throughout Europe, especially in Eastern Europe, need to be stepped up to reduce HIV in women. Programmes and interventions must be tailored to the unique needs of women to enable them to have better control over their own bodies and lives. Since migrants make up an important share of new diagnoses of HIV in Europe it is important that interventions be tailored to reduce their social isolation and vulnerability, and to facilitate their access to testing and treatment.

### 3. Ensure that clinical trials include sufficient numbers of women to allow for safer antiretroviral medicines use in women.

Women continue to be underrepresented in clinical trials with regard to HIV/AIDS treatments. Trials need to be designed to support and encourage female participation to improve our knowledge about the efficacy and effectiveness of treatment in women. More research is needed to understand the interaction of HIV treatments with other medications, such as birth control, HRT and the impact and safety of these treatments in pregnant women.

### 4. Support and develop policy and programmes for pregnant women with regard to HIV/AIDS.

Ensure that pregnant women with HIV/AIDS receive the proper support during pregnancy, delivery, and postpartum to eliminate mother-to-child-transmission of HIV/AIDS in Europe.

### 5. Reduce the burden of HIV/Aids in Eastern European countries by improving HIV testing, diagnosis, treatment and care.

Strategies for HIV testing vary across Europe and current HIV testing must be improved to reduce the unacceptably high rates of late diagnosis among women in Eastern Europe. Health services must be strengthened to allow for faster diagnosis and treatment to prevent the spread of the HIV epidemic. Interventions to prevent HIV in female sex workers should be included in strategies that address their social welfare and also target the social determinants of health and inequality.

### 6. Support the revised ART Guidelines to step up access to HIV prevention, testing, treatment and care for all population groups throughout the European Region to avoid the HIV epidemic spreading across the borders to the European Union.

Infectious diseases do not stop at the borders. It is in the interest of EU governments to protect their citizens by actively supporting the fight against HIV/AIDS in neighbouring countries.

### 7. Fully implement the Dublin Declaration as the key European policy document whose implementation is monitored by the European Centre of Disease Control and Prevention (ECDC).

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