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Summary report

**Changing the Game -  
How can Europe move towards zero  
new HIV infections, zero discrimination  
and zero AIDS-related deaths?**

UNAIDS expert consultation

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Executive summary	3
1. Introduction	6
2. Making strategic information fit for purpose	7
Recommendations	10
3. Changing the game	11
3.1. Strategic use of antiretrovirals	11
Recommendations	13
3.2. Re-engagement of communities	14
Recommendations	15
3.3. Role of social media	16
Recommendations	18
4. Making the case for HIV	19
4.1. Making the investment case	19
Recommendations	20
4.2. A new narrative for HIV in Europe	20
Recommendations	21
List of participants	22

## Executive summary

In Europe, HIV prevalence is increasing in key populations at higher risk, especially among men who have sex with men, and in Eastern Europe also among people who inject drugs, their sexual partners and among sex workers. In order to find ways to move towards zero new HIV infections, zero discrimination and zero AIDS-related deaths in Europe, UNAIDS organized an expert consultation 22-23 January at its headquarters in Geneva, Switzerland.

The experts stressed the urgent need to overcome essential data gaps on key populations living in contexts of stigma, discrimination and criminalization. They called for more support to harness the significant potentials of community driven research and sampling by means of community based service delivery, social networks and internet. The experts also highlighted the need to develop meaningful narratives to explain the dynamics and trends of the epidemics, including by strengthening country capacity for triangular and contextual analysis, and by ensuring engagement of key populations throughout the process of data collection and analysis.

A new wave of HIV infections in Europe among men who have sex with men seems primarily to affect men in rural areas, smaller cities and countries in the east with historically low prevalence. The rise in infections may be associated with the rapidly expanding access to online communication, which is providing men in these locations with more opportunities to engage in same-sex encounters. The potential impact of new technologies for HIV transmission and vulnerability is yet to be explored in relation to sex workers, who increasingly are operating online, and for people who gain access to the evolving internet market for new synthetic injectable drugs. At the same time new information technologies bring opportunities for research, peer outreach and interaction, and are fostering a new generation of activism and community mobilization which can radically change the game of the HIV response in Europe.

In the European context, the strategic use of antiretrovirals as a game changer was found by the experts to be hampered by lack of research data on the relative effectiveness of treatment as prevention especially for men who have sex with men. The experts stressed the need to further explore and address the implications of treatment as prevention approaches in relation to prevention messaging, stigma reduction, investment and medicine pricing.

Meanwhile optimized testing and linkage to care and treatment should be pursued as a priority to reduce morbidity and mortality as well as the community viral load. The experts stressed the need to ensure that treatment as prevention is introduced

only as part of a broader package of combination prevention and treatment strategies, including through reinforced condom promotion and other behavioral approaches. Similarly, the engagement of critical enablers such as community mobilization, reduction of stigma and discrimination, decriminalization of key populations, legal and structural reforms should be pursued. Key populations across Europe should be empowered to exercise their rights to access HIV prevention, testing and treatment services and make informed choices on treatment initiation and prevention approaches, including in relation to the reduced transmission risk for people in effective treatment.

The empowerment and engagement of key populations as political voices and partners at all levels remains a critical game changer for the HIV response, and should be reinforced and anchored with a broader strategy for health, equality and inclusion. New innovative strategies for community outreach and mobilization, engagement of new partners, channels and messaging are required to reach new generations.



## 1. Introduction

Since 2001 the number of new HIV infections has declined by more than 33% globally. Western and central Europe saw strong reductions in new HIV infections and AIDS mortality early in the epidemic. However, from 2001 to 2012 the rates of new infections has remained persistently stable at the level of 29 000 to 30 000 new infections per year. In Eastern Europe and Central Asia the epidemic arrived only in the mid-90s, but the annual number of new HIV infections reached an estimated 130 000 in 2012. With today's interventions AIDS-related deaths are preventable, but in Western and Central Europe the annual number of AIDS-related deaths has only slightly declined, from 8 100 in 2001 to 7 600 in 2012. In Eastern Europe and Central Asia, the high annual number of AIDS-related deaths continues to increase, from 76 000 deaths in 2005 to 91 000 deaths in 2012.<sup>1</sup>

These general trends mask great variation in HIV incidence and prevalence between and within countries, and across sub-regions. Across Europe the epidemics remain strongly focused on most at-risk key populations - men who have sex with men, transgender women, people who inject drugs and their sexual partners, migrant communities with origin in high prevalence countries outside of Europe, and most recently sex workers. Moreover, there are concerning indications that epidemics are further expanding within these populations.

In 2012 the estimated 35% coverage of antiretroviral treatment placed Eastern Europe and Central Asia as the region with the second-lowest coverage in the world.<sup>2</sup> In member states of the European Union (EU) antiretroviral treatment is considered to be available for all diagnosed and in need, with the notable exception of irregular migrants in some countries. However, the high rate of later presenters, representing 49% of people diagnosed with HIV<sup>3</sup>, and some studies<sup>4</sup> indicate that stigma remains a significant barrier for full and timely uptake of testing and treatment and for harnessing the prevention dividend of treatment.

Aiming to provide substantive inputs to the development and implementation of policies and programmes in response to HIV in Europe, the consultation brought together experts with a diverse set of backgrounds from the European Commission, EU decentralized agencies, key populations (men who have sex with men, people who inject drugs, sex workers and migrants), service providers, research organizations, governments and United Nations organizations.

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<sup>1</sup> Global report: UNAIDS report on the global AIDS epidemic 2013.

<sup>2</sup> Id.

<sup>3</sup> European Centre for Disease Prevention and Control/WHO Regional Office for Europe. HIV/AIDS surveillance in Europe 2012. Stockholm: European Centre for Disease Prevention and Control; 2013.

<sup>4</sup> Laurel Sprague et al, HIV related Stigma: Late Testing, Late Treatment, 2011.

The experts considered how to take forward the following issues:

- How can strategic information become more fit for purpose and ensure a stronger and timely focus on geographical hotspots and key populations, maximum impact of HIV spending and optimal service provision for those in need?
- What are the game changers in Europe and how can they become engaged to break the trajectories of stable or steadily increasing rates of new infections among key populations, reduce discrimination and address barriers in service delivery?
- How can the narrative of the epidemic and response in Europe be reframed, in order to foster sustained political leadership, community mobilization and resources?

With the goal to encourage 'out of the box'-thinking, the participating experts were asked to observe the Chatham House rules, which allow participants to use the information received, but neither to reveal the identity nor the affiliation of the speakers, nor that of any other participant. The same rules are observed in this report.

## 2. Making strategic information fit for purpose

The experts discussed ways to make better use of existing data and to identify and address data gaps related to the HIV epidemiology and response as well as data gaps related to the legal and social environment. They explored how to speed up data collection and analysis to ensure a stronger and timely focus on geographical hotspots and key populations, maximum impact of HIV spending and optimal service provision for those in need.

At the European level, epidemiological analysis largely relies on reports from countries on diagnosed HIV and AIDS cases, which are regularly collected, analyzed and published by the European Centre for Disease Prevention and Control (ECDC) and WHO Regional Office for Europe. Most countries include information on modes of transmission and increasingly also on CD4 count at diagnosis.

The ECDC/WHO HIV/AIDS surveillance reports enjoy a high level of credibility and are important references for decision makers at European and country levels, guiding political commitment, policy development and resource allocation. As a basis for analysis, however, the experts found that reporting of diagnosed cases of HIV and AIDS is constrained by several flaws and shortcomings, and represents only a subset of the data required to understand and effectively address the current dynamics and trends of the epidemics.

As a true proxy for incident infections, the HIV case reporting suffers from a significant time-lag and reporting delay. Moreover, it is highly influenced by testing patterns and its relevance may become further challenged by increasing self-testing. Few countries are collecting and making available data on recent infections. Poor data on the number of performed HIV tests by key populations makes interpretation of trends difficult.

In countries with high levels of stigma and discrimination related to homosexuality few disclose their sexual orientation to health workers,<sup>5</sup> fewer men who have sex with men may come forward for HIV testing and a substantial part of the many cases reported as 'unknown' and 'heterosexual' may actually relate to male-to-male transmission.

The high proportion of late HIV diagnoses among people who inject drugs<sup>6</sup> may indicate that stigma, discrimination, criminalization and, in some countries, lack of access to substitution treatment and harm reduction services remain barriers to HIV testing and distort case reporting. In some countries health workers are required to report people who are injecting drugs to the police, which may lead to inaccurate reporting of transmission mode.

Data on female and male sex workers are not captured by the current reporting of HIV and AIDS cases and transmission modes.

Complementing the HIV/AIDS surveillance reports, in 2007 the ECDC initiated monitoring of the specific commitments made by WHO European Member States in the 2004 Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia.<sup>7</sup> From 2012, data collection related to the Dublin Declaration and the 2011 United Nations Political Declaration on HIV and AIDS has been harmonized.

This joint monitoring has allowed regular progress reporting on the commitments from a high and increasing number of European countries, including on specific indicators for some key populations of most relevance to Europe - men who have sex with men, migrants, people who inject drugs, sex workers and prisoners. Data on transgender women are not included. According to ECDC data specificity, quality and comparability remain, however, variable, with particularly scant data on sex workers, migrants and prisoners. In relation to people who inject drugs, the involvement of the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) has allowed a more systematic data collection and analysis, which also includes behavioural surveys and prevalence studies, in particular for EU countries.

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<sup>5</sup> EU Fundamental Rights Agency, 2010 EU LGBTI Survey  
<sup>6</sup> Among the 20 countries in 2012 reporting CD4 cell count at time of HIV diagnosis, the proportion of late presenters was 55.3% among people who inject drugs, and 38.4% among men who have sex with men. European Centre for Disease Prevention and Control/WHO Regional Office for Europe. HIV/AIDS surveillance in Europe 2012. Stockholm: European Centre for Disease Prevention and Control; 2013.  
<sup>7</sup> This declaration was adopted by representatives of States and Governments from Europe and Central Asia meeting in Dublin, Ireland, 23-24 February 2004, for the Irish EU Presidency Conference "Breaking the Barriers – Partnership to fight HIV/AIDS in Europe and Central Asia"



Most European countries have not adopted the *UNAIDS/WHO Second Generation Surveillance Guidelines* which recommends regular conduct of behavioral surveillance, including development of size estimates of key populations and surveillance of sexually transmitted infections. For middle income countries in the region this neglect was seen by the experts as reflecting a lack of financial incentives such as those provided by the Global Fund grant requirements in other regions.

Case studies on men who have sex with men and sex workers demonstrated the promising potential of innovative community driven research with sampling through internet and social media. Such methods can increase the size and reach of sampling, enhance the quantity and richness of strategic information and enable the development of meaningful narratives on the dynamics and trends of the epidemics especially among key populations living in contexts of stigma, discrimination and criminalization.

The importance of the internet and social media for sampling and research on key populations was illustrated by the above-mentioned case study on men who have sex with men in Europe. This study presented an analysis rendering probable the potentially huge impact of the expansion of internet and social media on the rise of HIV infections among men who have sex with men, which has occurred in many European countries in the last decade.

For example, Germany has not seen a rise of newly diagnosed HIV infections in the traditional most at risk subpopulation of men aged 30-39 who have sex with men and live in bigger cities. In contrast and strikingly, a rise has been seen among subpopulations of men who have sex with men with previously lower levels of risk, including men living in smaller cities and especially in rural areas; among the young and older age groups. Similarly, at European level the rise of new infections is particularly strong among the previously low prevalence populations of men who have sex with men who are living in countries of central and eastern part of Europe.

The above-mentioned rises in new infections correlate with findings showing that European men who have sex with men meet a large proportion of their non-steady partners online and that seeking partners online is particular frequent in regions with less developed gay commercial infrastructures - in rural areas, eastern and south-eastern Europe. Young men and men with low numbers of non-steady partners find a particularly high proportion of these partners online<sup>8</sup>

The experts suggested that the growth of online communication and tools, and possibly also greater mobility within Europe (e.g. as a consequence of the Schengen area and increased numbers of low cost airlines) may have greatly expanded the size, reach, and density of sexual networks of men who have sex

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<sup>8</sup> The EMIS Network. EMIS 2010: The European Men-Who-Have-Sex-With-Men Internet Survey. Findings from 38 countries. Stockholm: European Centre for Disease Prevention and Control, 2013.

with men. The rise in HIV infections may be explained by the rapidly growing populations with opportunities for same sex sexual encounters, and to a lesser extent by increasing individual risk behaviors. The encounters established through online communication are characterized by more multi-times partners, more sero-status communication, but less risk avoidance than encounters made at traditional gay sex venues.<sup>9</sup>

The experts noted that the impact of internet and social media for dynamics and trends of the epidemics among other key populations is yet to be explored, for example in relation to the already well-established online sex work, and, for people who are injecting drugs, the opportunities to access to new synthetic injectable drugs through the internet.

## Recommendations

1. UNAIDS should work jointly with relevant policy makers, institutions, civil society and other stakeholders on strategies to encourage and support European countries and competent authorities in addressing essential data gaps and developing size estimates, and more specificity in collection of data on key populations in relation to critical indicators such as age, gender identity, country of origin, location, multiple vulnerabilities, condom use, HIV testing, treatment coverage, drug resistance, levels of stigma and other human rights barriers.
2. Such strategies include:
  - Advocacy to strengthen political commitment to conduct research with key populations; development of financial and other incentives for research; provision of technical guidance on relevant indicators, support for cross-regional studies.
  - Guidance, sharing of best practices and support for cross-regional initiatives to strengthen community driven research and sampling by means of community based service delivery, social networks and internet.
  - Guidance, sharing of best practices and support for cross-regional initiatives to strengthen country level capacity to collect appropriate data for triangular and contextual analysis of the dynamics and trends of the epidemics, drawing on multiple sources (including dormant data), and engaging key populations throughout the process of data collection and analysis, especially in the development of meaningful narratives to explain the dynamics of the epidemics.

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<sup>9</sup> Id.

3. Research institutions and other partners should be encouraged to further explore the impact of internet and social media on the dynamics and trends of the epidemics among key populations in Europe, and its implications for the HIV response, with particular attention to groups of key populations living in contexts of stigma and discrimination.

### 3. Changing the game

The experts discussed the role of potential game changers in the areas of policy, programming and research in Europe, and how they can be better utilized to break the trajectory in Europe of stable or steadily increasing rates of new HIV infections in key populations; reduce discrimination; and increase uptake of testing and treatment.

The experts explored in details the following potential game changers i) strategic use of antiretrovirals, ii) the re-engagement of communities, iii) the role of social media.

#### 3.1. Strategic use of antiretroviral drugs

A series of recent research findings has demonstrated effectiveness of antiretroviral drugs in prevention of HIV transmission, including in prevention of mother-to-child transmission, post-exposure prophylaxis, pre-exposure prophylaxis and most astoundingly in the break-through findings of the HIV Prevention Trials Network (HPTN) 052 study in 2011,<sup>10</sup> which demonstrated a 96-100% reduction in risk for HIV transmission among heterosexual serodiscordant couples, when the infected partner received immediate treatment.

These findings are considered an important game changer for the global HIV response, bridging the traditional dichotomy between treatment and prevention, and have given rise to new strategies such as 'treatment as prevention' and 'test and treat'. Following the above-mentioned study, the impact of expanded ARV treatment on community viral load and reduction of HIV transmission has been demonstrated in British Columbia<sup>11</sup> and South Africa.<sup>12</sup> The findings also led to the 2013 revision of the WHO treatment guidelines, which lowered the eligibility threshold for treatment in relation to

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<sup>10</sup> HPTN 052. A Randomized Trial to Evaluate the Effectiveness of Antiretroviral Therapy Plus HIV Primary Care versus HIV Primary Care Alone to Prevent the Sexual Transmission of HIV-1 in Serodiscordant Couples

<sup>11</sup> Montaner JS, Lima VD, Harrigan PR, Lourenço L, Yip B, et al. (2014) Expansion of HAART Coverage Is Associated with Sustained Decreases in HIV/AIDS Morbidity, Mortality and HIV Transmission: The "HIV Treatment as Prevention" Experience in a Canadian Setting. PLoS ONE 9(2): e87872. doi:10.1371/journal.pone.0087872

<sup>12</sup> Frank Tanser, Till Barnighausen, Erolfi Grapsa, Jaffer Zaidi, and Marie-Louise Newell (2013), High Coverage of ART Associated with Decline in Risk of HIV Acquisition in Rural KwaZulu-Natal, South Africa Science 22 February 2013: 339 (6122), 966-971. [DOI:10.1126/science.1228160]

CD4 count and for HIV infected partners in serodiscordant couples.<sup>13</sup>

In the European context, where a large proportion of new infections occurs among men who have sex with men, the experts pointed out that relying solely on treatment as prevention would not be effective. Furthermore, they stressed the need for more research to understand better the relative effectiveness of treatment as prevention among men who have sex with men, as the HPTN 052 study did only include heterosexual couples.

For men who have sex with men who know their HIV positive status and are in treatment with effective viral load suppression, the prevention benefits exist. According to the experts, the increasing trend of new HIV infections among men who have sex with men in European countries with high treatment coverage may, however, indicate an offset of the prevention benefits of treatment by other factors.

A prominent counteracting factor may be the sub-optimal treatment cascade in Europe where a large fraction of people living with HIV are unaware of their HIV status,<sup>14</sup> probably reflecting the persistence of stigma, criminalization of sexual transmission and other social barriers for testing. The list of other possible factors suggested by the experts includes increasing condom-less anal sex related to prevention fatigue and treatment complacency; a large proportion of new infections caused by acute infections; and an increasing population of sexually active HIV positive men as a result of improved survival and life quality. The experts also referred to a particular vulnerability for HIV transmission in relation to anal sex and/or the presence of sexually transmitted infections; less organized gay communities and a weakening of community norms; and, as previously mentioned, the impact of internet and social media greatly expanding the size, reach and density of sexual networks.

At European level there is diversity in eligibility criteria for treatment initiation. France and the Netherlands have already introduced 'test and treat' strategies, recommending immediate access to ARV treatment after HIV diagnosis, and Belgium is considering a similar strategy.<sup>15</sup> The clinical guidelines of the European AIDS Clinical Society<sup>16</sup> issued in October 2013, which serve as an important reference for many European countries, do not, however, reflect the above-mentioned new recommendations of the WHO treatment guidelines, stating to be at equipoise on the question of individual benefits of earlier treatment.

Considerations on the strategic use of antiretrovirals in Europe should also reflect the economic crisis, which in several countries have become the pretext for sharply reduced financing for prevention activities with key populations.<sup>17</sup>

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<sup>13</sup> WHO, Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection, 2013

<sup>14</sup> With reference to foot note 2.

<sup>15</sup> National guidelines for antiretroviral treatment in France and the Netherlands, Belgium HIV plan 2014-19

<sup>16</sup> European AIDS Clinical Society Guidelines, Version 7.0, October 2013.

<sup>17</sup> European Centre for Disease Prevention and Control. Thematic report: Leadership and resources in the HIV response. Monitoring implementation of the Dublin Declaration on Partnership to Fight

In eastern European countries, treatment coverage remains among the lowest in the world.<sup>18</sup> For many countries in Europe the high costs of antiretroviral drugs were seen by the experts as a barrier for increased access to treatment.

## Recommendations

1. UNAIDS should closely follow and promote research on the relative effectiveness of treatment as prevention for key populations, especially men who have sex with men, such as the ongoing international multicenter PARTNER observational study (2010-2014) on the risk of vaginal and anal sex with effective viral suppression.
2. More in-depth consultations should be convened on the role and implications of strategic use of antiretrovirals as a potential game changer in the European context, e.g. in relation to prevention messaging, stigma reduction, investment and medicine pricing.
3. Political leadership and commitment should be mobilized in Europe for:
  - Optimized testing and linkage to care and treatment as a priority to reduce morbidity, mortality as well as the 'community viral load'.
  - Ensuring that treatment as prevention is introduced only as part of a broader package of combination prevention and treatment strategies, including through reinforced condom promotion and other behavioral approaches, post-exposure and pre-exposure prophylaxis, access to clean needles, syringes and substitution treatment for people who inject drugs, and the engagement of critical enablers such as community mobilization, reduction of stigma and discrimination, decriminalization of key populations, legal and structural reforms.
  - Ensuring the rights and empowerment of key populations across Europe to access HIV prevention, testing and treatment services and make informed choices in relation to treatment initiation and prevention approaches, including on the reduced risk of transmission from people in effective treatment.

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HIV/AIDS in Europe and Central Asia: 2012 Progress Report. Stockholm: ECDC; 2013.

<sup>18</sup> Global report: UNAIDS report on the global AIDS epidemic 2013.

### 3.2. Re-engagement of communities

In the 1980s, AIDS activists emerging from the gay movement became the backbone of the global AIDS movement and should be credited for its many successes. At the time the AIDS activism also empowered and provided a political momentum for advancing gay and lesbian rights in Europe and beyond. As the AIDS movement gradually became broader and more inclusive, a similar empowerment and momentum occurred for other key populations such as people who inject drugs uniting in the harm reduction movement and the movement for sex workers' rights.

For the drug user and sex worker movements the HIV response remains a priority and an important platform for advocacy. However, according to the experts a breach has been growing between the AIDS movement, in Europe gradually evolving into professional HIV service organizations, and the LGBTI<sup>19</sup> rights movement. The new LGBTI rights movement prioritizes recognition of same sex marriages, equal rights and social acceptance and has in recent years gained a strong political momentum in many parts of Europe. HIV has, however, long been absent from its political agenda and is no longer seen as a cause unifying the movement. Describing HIV as a particular risk and concern for gay men can be felt as stigmatizing this group and is utilized as such by political opponents. Seen as counteracting the calls of the LGBTI rights movement for social acceptance and equality, HIV has become sidelined along with other health problems such as mental health, alcohol, and drug use. HIV has become a manageable yet serious health condition, but stigma remains rampant also within the gay community, and many gay men living with HIV choose to disclose their status only to a few, if any.

In a situation, where HIV organizations in Europe may be losing political foothold, the experts stressed the potential of the LGBTI rights movement to leverage its momentum and re-gain its role as a strong political voice and force for the HIV response, if HIV advocacy is anchored with a broader agenda for health, equality and inclusion. The experts also agreed that the movement may play an important role in raising HIV awareness and addressing internal HIV stigma within the community.

The LGBTI rights movement represents, however, only a fraction of the population at risk, and was not seen by the experts to be the best intermediary to reach those at highest risk such as the poor, migrants or the counter-subculture of men fetishizing drugs and sexual risk taking. The experts also underlined the need to acknowledge the huge variations in Europe between different regions, legislative frameworks and culture, and the few, weak and outdated structures of LGBTI organizations for example in many parts of Eastern Europe.

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<sup>19</sup> Lesbian, gay, bisexual, transsexual and intersex

As previously mentioned, the population of men with opportunities for same sex encounters may have greatly expanded through online communication and increased mobility, and in countries with strong social acceptance many young people are now living in the 'post-gay' age, where they do not feel the need to 'grab' a gay identity or attend gay venues. Meanwhile the experts found that the development of new skills and approaches for HIV prevention among men who have sex with men seems to have stagnated and not kept pace with the changes. The new generations of gay or post-gay icons, gay business and porn industry, social and other media and apps catch attention and may have potential to serve as partners and channels for messaging, role modeling and influencing community norms. The rise of internet, social media and mobile apps also provides new opportunities for peer outreach and exchange, and is fostering a new generation of connected online activism.

## Recommendations

1. UNAIDS should continue to work closely with and support the European Region of the International Lesbian, Gay, Bisexual, Trans & Intersex Association (ILGA Europe) in its ongoing strategy development for its political agenda and work on HIV as part of a broader strategy for health, equality and inclusion, including by convening a joint consultation for young LGBTI rights activists in 2014.
2. Policy makers and institutions in Europe should promote and convene inclusion of all key populations - people living with HIV, men who have sex with men, transgender women, people who inject drugs and their partners, sex workers, migrant communities and prisoners - as partners at all levels in national HIV responses, ensure support for community empowerment and mobilization and address barriers of stigma, discrimination and criminalization.
3. Civil society organizations in Europe should, with support from health professionals and governments lead the development and sharing of new innovative strategies for community outreach, mobilization and engagement of new partners, channels and messaging for:
  - The 'post gay' generation and the growing populations of men with expanded opportunities for same sex-encounters but little access to HIV services
  - Similar new emerging groups of sex workers, people who inject drugs and migrants which may not be reached through traditional approaches and organizations

### 3.3. Role of social media

The expansion of internet, social media and mobile apps in the new millennium has radically transformed the landscape for the HIV response in Europe. The experts stressed the urgent need to further explore its plausible impact on the dynamics and trends of the epidemic; its huge potentials for community driven research, peer outreach and interaction, empowerment, mobilization and activism; as well as the new challenges in relation to privacy, confidentiality and security.

The world of internet, social media and, most recently, a wide range of mobile apps for location-based search for sexual partners (one such app now have 7 million users worldwide) has greatly expanded the opportunities for same-sex encounters for men, who do not enjoy the same access to HIV information, prevention commodities and services as gay men frequenting the traditional social and sex venues in the big cities. Many app users do not show their face or sexual orientation in their profiles, and openness about HIV can provoke hostile reactions from other users.

This development was found by the experts to pose a series of challenges, for example for young men who are now becoming sexually active much earlier, may not identify as gay and rarely have received any form of sex education matching their needs. In Central and Eastern Europe many gay men do not disclose their sexual orientation<sup>20</sup> and may lack access to tailored information, services and prevention commodities such as condoms and lubricants. They are, however, through online communication exposed to new opportunities for same sex sexual encounters.

According to the experts the expansion and rapid evolution of online-communication has also provided a series of new and empowering tools and opportunities for the HIV response, which can be applied efficiently and at low cost, allowing people to choose their own level of exposure. In the UK more than one in ten diagnosed with HIV is signed up to sites hosting closed fora for people living with HIV. They often gradually become more open in their profile and end putting up photos of themselves. The social media is seen as a very effective platform for community empowerment, as it encourages people to become open and stand up for their rights. Through social media, sex workers staged protests in 38 cities around the world, when a board member of the Swedish sex worker organization and a sex worker in Turkey were murdered last year. People who inject drugs are also taking advantage of online communication to share and learn from good and bad experiences.

Social media has huge potentials as a prevention tool, for example for men who have sex with men that do not identify as gay men. In the UK social media, especially the widely used smart phone apps, has worked particularly

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<sup>20</sup> EU Fundamental Rights Agency, 2010 EU LGBTI Survey



well to reach people of African origin previously seen as hard to reach. For the development and roll out of new campaigns, crowd sourcing is replacing traditional focus groups for advice on content, mobilizing role models and ensuring community ownership. The new technologies can also help to overcome bottlenecks in opening hours and human resources through use of automated but highly sophisticated and personalized responses.

As demonstrated by the 2013 European HIV Testing Week, social media has a huge potential for community campaigns and collaboration at Pan-European and international levels, which can further be exploited through increased cooperation among organizations in Europe, for example to overcome language barriers of mobile populations.

Social media has particular strengths in allowing creation of user driven content and changing the traditional sender-recipient relation to one of exchange and interaction. Contacts can be established through banners on apps linking to websites and use of celebrity fan sites, competitions and free offers. Social media can be effectively used to search for, challenge and tackle expressions of stigma, but this is not possible with the latest generation of mobile apps. Trending apps may represent a window of opportunity for direct advocacy and exchanges with influential people like politicians, journalists and celebrities.

The experts stressed the critical importance of keeping pace with the rapid evolution and changes of online technology, preferred platforms and patterns of use. With its emphasis on exchange and interaction, the harnessing of social media for HIV responses requires adaptation to the social environment, resources and standards for responses and follow-up. There is a particular need to build rapport, find the right voice and avoid nagging users. Equally important, online technology cannot fully replace face-to-face contacts and services, and the need remains to reach people with limited or no access to online communication.

Furthermore, the perceived online anonymity and confidentiality is severely challenged by modern surveillance technology. There are numerous examples of severe security breaches, where social media has been used as an online pillory for individuals, exposing their HIV status, perceived risk taking and personal portraits to the global public, or used for escalating hate crimes and campaigns.

## Recommendations

1. UNAIDS should liaise with the International Telecommunication Union and relevant global business actors in the area of social media and mobile apps for the development and introduction of corporate social responsibilities and standards that promote health and human rights, protect privacy and confidentiality, and ensure optimal security of the users.
2. The opportunities and challenges for the HIV response of the rapid expansion and evolution of online communication should be addressed as a priority in Europe, including by initiatives to:
  - Advocate for the introduction of sex education in schools, online-communication and other approaches that addresses as a matter of priority the urgent needs of the young men who have sex with men for access to tailored, non-judgmental and anti-stigmatizing HIV information, prevention commodities and HIV testing, counselling and care services.
  - Strengthen awareness and political commitment on the need to address the rapidly expanding epidemics among men who have sex with men in central and eastern Europe, including by ensuring access in local languages to tailored, non-judgmental and anti-stigmatizing HIV information, prevention commodities and HIV testing, counselling and care services.
  - Map and address the needs of new emerging groups of people who inject drugs and their partners, sex workers and migrants for access to tailored, non-judgmental and anti-stigmatizing HIV information, prevention commodities and HIV testing, counselling and care services.
  - Convene a Pan-European platform for cross country collaboration and sharing of innovative approaches and best practices on the use of internet and social media in the HIV response, including in the areas of outreach, peer support, customized online information and service provision, community mobilization and empowerment, advocacy, addressing stigma and discrimination.

## 4. Making the case for HIV

The experts discussed how the future narrative of the epidemic and response in Europe can be reframed in the context of the post 2015 agenda to foster sustained political leadership, community mobilization and resources.

### 4.1. Making the investment case

The 2011 UNAIDS investment framework presented a conceptual breakthrough moving from the trajectory of ever-expanding costs of HIV services towards concepts of investment, strategic allocation of resources and ensuring highest returns and impact in terms of averted HIV infections and saved lives. Promoting an optimal match of resources and needs, the framework brought a renewed focus on investing in key populations, basic evidence informed programmes, and critical enablers such as structural reforms, community mobilization and promotion of human rights. It also brought attention to ensuring sustainability through increased domestic funding as well as efficiency in configuration and integration of service delivery.

In other regions many countries are now developing investment cases in support of the national strategic plan as a whole or for specific components. This is a political more than a technical exercise, where success depends on the ability to convene the right match of policy makers, economists and HIV stakeholders around a debate on how to manage the fiscal space, correct mismatch of resources and needs and maximize quality outputs with minimum expenditures. Similarly, the Global Fund is now moving from the notion of grant giving to investment thinking.

Making the investment case was found highly relevant in the current context of the European economic crisis, where financing, public health spending and cost effectiveness are high on the agenda. Promoting smart and cheap investments for example in internet and social media approaches, community-based outreach and service delivery or investing in key population networks in low prevalence countries may work well. The investment argument may also make the case for decriminalization of drug users and harm reduction spending versus high-cost investments in law enforcement drug control approaches. Investment thinking was also considered highly relevant for community based service providers, which often lack skills and capacity for costing, ensuring optimal and efficient resource allocation and mobilizing resources.

In Europe, investment cases can supplement and reinforce arguments on the right to health and human rights of key populations, but they cannot and should not stand alone. Making the case for longer term HIV investment or the difficult to prove cost effectiveness of behavior change may not convince politicians with a traditional short time horizon. HIV investment for sex

workers and people who inject drugs is often conflated as condoning human trafficking and drug trafficking. Thirty years into the epidemic, financing for key populations is in many European countries still allocated on an ad hoc project basis and mechanisms for longer term financing of community based organizations are lacking, likely leading to a considerable waste of resources and capacity.

## Recommendations

1. The development of investment cases for HIV should be supported, e.g. by:
  - Convening sub-regional consultations with policy makers, economists and HIV stakeholders to make the investment case for addressing the needs of key populations in low prevalence countries in central Europe, and in south-eastern Europe
  - Encouraging governments to develop mechanisms and approaches to ensure sustainable financing for community based service delivery
  - Strengthening civil society capacity building in investment thinking
  - Making a strong case against law enforcement approaches which criminalize people who inject drugs and have significant human and financial costs, and for reallocation of resources into effective and evidence informed harm reduction programmes.

## 4.2. A new narrative for HIV in Europe

*"The HIV/AIDS epidemic threatens to become a crisis of unprecedented proportions in our region, undermining public health, development, social cohesion, national security and political stability in many of our countries"*  
(2004 Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia)

As illustrated above, the catastrophic scenario of the 1980s has long remained a dominant theme in the narrative of the AIDS epidemic, also in a Europe with few indications of moving towards a generalized epidemic. The EU communications on HIV/AIDS in 2005 and 2009 differently placed HIV in the center of the European project of peace building, human rights and growth, emphasizing rights of minorities, equal treatment and solidarity, the need to fight stigma and discrimination and stressing the medical and financial costs of the epidemic.

UNAIDS has called for a new narrative of the global epidemic and response around the visionary and long term goal of "Ending AIDS". This new narrative also suggests epidemiological concepts of location, focus and individual but interconnected epidemics; calls for universal access and the right to health; and underline the need to address social drivers of inequity, injustice, stigma

and discrimination; strengthen community based and people centered service delivery and bring key populations and human rights to the center of the response.

The catastrophic narrative of the 1980s effectively launched an emergency response, and made the basis for the remarkable progress of the global HIV response. The ideal new narrative must be equally compelling, provide a long term vision, inspire hope and actions, but be realistic, meaningful and simple whilst maintaining the sense of urgency.

In relation to the political dialogue with eastern European countries, two messages should be key i) the need to scale up evidence informed combination prevention through community-led programmes with key populations, ii) increasing access to treatment.

## Recommendations

1. In developing the new narrative, UNAIDS should consider the following issues:
  - ensure that the message of ending AIDS does not signal that the epidemic is over and that the complexity of ending AIDS is fully understood by the general public and policymakers
  - ensure a stronger focus on empowerment and meaningful involvement of key populations and their right to access all information, services and commodities required to make informed choices
  - reinforce messages on the need to prevent new infections, and better describe the new reality of HIV as a chronic condition, giving voice to people on the financial, social and economic disadvantages of living with HIV
  - bring the new opportunities and tools to the center of the narrative
  - position the HIV response as a catalyst and pathfinder for broader progress on health and social justice
2. European countries and institutions should maintain a strong political dialogue with some Eastern European countries on the need to scale up prevention programmes for key populations and access to treatment, and to address:
  - Anti-gay propaganda legislation and other legislation blocking work with key populations (e.g. ban against opioid substitution treatment, NGOs required to register as foreign agents, criminalization etc.)
  - The need for domestic investment for prevention with key populations
  - Laws and mechanisms for government financing/purchasing of prevention services from NGOs

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