Evaluation of the implementation of the Commission Communication

'Combating HIV/AIDS in the European Union and the neighbouring countries, 2009–2013'

Main report

J. Hofman, J. Exley, T. Bienkowska-Gibbs, S. Castle-Clarke, M. Morgan Jones, V. Van Dyck, S. Gonzalo, J. Corbett, F. Lejeune, E. Nolte

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Contact: Paolo GUGLIELMETTI

E-mail: SANTE-CONSULT-C3@ec.europa.eu

European Commission
B-1049 Brussels

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Preface

The European Commission Communication 'Combating HIV/AIDS in the European Union and the neighbouring countries, 2009–2013' follows the Communication on combating the human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) of 2005, which formed the basis for European Union (EU) action to address HIV/AIDS at a European level during 2006–2009. The 2009 Commission Communication sought to gear up the policy profile of the EU fight against HIV/AIDS until 2013, with a view to renew the policy to further strengthen EU policy in the area of HIV/AIDS prevention and control. To inform options for medium- to long-term action at the EU level in the field of HIV/AIDS in the EU and neighbouring countries, the European Commission (EC) commissioned RAND Europe, in partnership with Van Dijk Management Consultants, to conduct an evaluation of the second Communication and the accompanying Action Plan (hereafter referred to as the Communication). The overarching aims of the evaluation were to assess the implementation of the Communication, including the European added value of the Communication and its Action Plan at the Member State and EU levels, and to identify areas for improvement. The evaluation was conducted between September 2013 and April 2014.

This document reports on the findings of the evaluation, which used a combination of methods, including document review, key informant interviews, and surveys at the national and pan-European levels relating to the development and delivery of action on HIV/AIDS, both across countries and within targeted case studies of specific country experiences (Bulgaria, Latvia, Spain and the United Kingdom) and areas of action (EU-funded research).

Key observations point to the importance of the Communication in bringing together various stakeholders and activities and ensuring that issues related to HIV/AIDS remain high on the political agenda. These observations also explain the role of the civil society as well as of research and public health funding in contributing to the Communication's objectives. Based on these findings, we provide recommendations for future policy development at the European Commission level in the field of HIV/AIDS in Europe. RAND Europe is an independent not-for-profit policy research organisation that aims to improve policy- and decisionmaking in the public interest, through research and analysis. Van Dijk Management Consultants is a consultancy firm with expertise in conducting performance monitoring and evaluation studies. This report has been peer-reviewed in accordance with RAND's quality assurance standards.

For more information about RAND Europe or this document, please contact Joanna Hofman (jhofman@rand.org).

Abstract

HIV/AIDS and associated infections remain a significant public health issue in Europe. The most recent policy instruments at the European Union level to address HIV/AIDS in Europe are the European Commission Communication 'Combating HIV/AIDS in the European Union and the neighbouring countries, 2009–2013' and its associated Action Plan.

The Directorate-General for Health and Consumers commissioned RAND Europe, in partnership with Van Dijk Management Consultants, to assess the success of the 2009–2013 Communication, to identify areas for improvement, and to inform the further development of the EU policy framework on HIV/AIDS.

The three core objectives of the Communication were to reduce the number of new HIV infections; to improve access to prevention, treatment, care and support; and to improve the quality of life of people living with, affected by, or most vulnerable to HIV/AIDS in the EU and neighbouring countries. Yet, relevant data that would allow for a robust assessment of the extent to which these objectives have been achieved is as yet lacking.

However, this evaluation found that the Communication was seen by stakeholders to have provided the necessary stimulus, continuous pressure and leverage for various stakeholders to advocate for and take actions against HIV/AIDS in Europe. The evaluation indicated that the Communication added value in a number of areas: it helped focus efforts and resources on priority regions and groups, it empowered the civil society in advocating for HIV/AIDS, it facilitated exchange of experience among countries and it enabled funding of collaborative projects in the areas of research and public health.

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Summary

The policy context for HIV/AIDS in Europe

Despite considerable progress in the understanding of HIV/AIDS and associated infections and of modes of prevention and treatment of the infection, the disease has remained an important public health issue in Europe. HIV disproportionally affects populations that are marginalised, such as migrants, and people whose behaviour is either socially stigmatised, such as sex workers and men having sex with men (MSM), or illegal, including prisoners and people who inject drugs. These behaviours are frequently linked to difficulties accessing services for the prevention and treatment of HIV/AIDS. In the World Health Organization's European Region, HIV remains concentrated in these populations; however, the relative importance of mode of transmission varies across counties, illustrating the wide diversity in the epidemiology of HIV in Europe. The continued challenge posed by HIV/AIDS highlights the need for effective policy interventions to promote HIV prevention, diagnosis and treatment, as well as care and support for people living with HIV/AIDS.

This challenge has been recognised at the European level by means of a series of commitments setting out strategies to combat HIV/AIDS, including the 2004 Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia, the 2004 Vilnius Declaration on Measures to Strengthen Responses to HIV/AIDS in the European Union and in Neighbouring Countries, and the 2007 Bremen Declaration on Responsibility and Partnership – Together Against HIV/AIDS.

The European Commission (EC) has a long history of engagement in HIV policy, and these commitments form the backdrop against which the EC has formalised its strategy to address HIV/AIDS. The most recent policy instruments are the Commission Communication 'Combating HIV/AIDS in the European Union and neighbouring countries, 2009–2013' and its associated Action Plan.

The overarching objectives of the Communication were:

(i) To reduce the number of new HIV infections in all European countries by 2013

(ii) To improve access to prevention, treatment, care and support

(iii) To improve the quality of life of people living with, affected by, or most vulnerable to HIV/AIDS in the EU and neighbouring countries.

The Action Plan that accompanied the Communication identified six areas of action to be taken by stakeholders to achieve the objectives set out in the Communication, namely, (i) politics, policies and involvement of civil society, wider society and stakeholders; (ii) prevention; (iii) priority regions; (iv) priority groups; (v) improving knowledge; and (vi) monitoring and evaluation.

Developed in cooperation with the HIV/AIDS Think Tank, the Civil Society Forum (CSF) and other external stakeholders, actions identified as necessary were meant to be supported through a range of funding instruments, including the Seventh Framework Programme

(FP7); the EU Health Programme 2008–2013; the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM); EU structural funds; the Development Cooperation Instrument; and the European Neighbourhood and Partnership Instrument.

The time span covered by the Communication came to an end in December 2013, and the Directorate-General for Health and Consumers (DG SANCO) has commissioned this evaluation to assess the success of the Communication and to identify areas for improvement to inform the next EU policy framework on HIV/AIDS.

Our approach to the evaluation

The terms of reference (ToR) for this evaluation set out 18 evaluation questions (EQs) that can be broadly categorised into five thematic areas:

(i) Changes in the HIV epidemic and access to key services

(ii) Role and impact of the Civil Society Forum

(iii) Contribution of EU-funded research and public health projects

(iv) Funding to combat HIV/AIDS

(v) Coordination and monitoring of EU HIV policy.

The broad requirements set by the evaluation activities were to be accomplished within a limited time frame. These constraints necessitated using an approach that would balance the breadth and depth of the evaluation and that would also capture the range of activities that have occurred across countries, while ensuring in-depth analyses of selected priority areas to provide sufficient granularity to inform future policy development. We therefore used a combination of methods, including desk research, key informant interviews, surveys and a series of case studies (see Table 1).

Table 1. Summary of data collection approaches used in the evaluation

Data collection method	Description

Desk research	• Targeted review of documents to understand:
	  • Changes in the incidence of new infections of HIV/AIDS in Europe
	  • The role and functioning of the CSF
	  • The state of implementation of the Health Programme projects and any immediate outputs and outcomes resulting from these projects
	  • The level of HIV funding in the EU
	  • In-depth country case studies
	  • In-depth research case studies

Surveys	• Think Tank survey:
	  • Representatives from 28 Member States and 11 non-EU countries were invited, of whom 17 responded
	• CSF survey:
	  • Representatives from 35 organisations were invited, of whom 14 responded
	• *ImpactFinder* survey:
	  • In total, 77 individuals (principal investigators [PIs], work package leaders and technical scientists) from the selected FP7 projects were invited to take part, of whom 30 responded

Key informant	• European-level interviews:

interviews	• Four representatives from the Think Tank were invited, two participated • Four representatives from the CSF were invited, four participated • Five officials from the EC and European agencies were invited, five participated • Two representatives from international organisations (i.e. the Joint United Nations Programme on HIV/AIDS [UNAIDS] and World Health Organization [WHO]) were invited, two participated • Country case studies: • Nine interviews were conducted with representatives of relevant national authorities, civil society organisations and academia • Research case studies: • Five interviews were conducted with selected project coordinators and independent stakeholders
*Case studies**	• *Country case studies (Bulgaria, Latvia, Spain and the United Kingdom):* • *The Member State case studies drew on the above three mechanisms of data collection (desk research, surveys, key informant interviews)* • *Research case studies (EuroCoord and microbicide development):* • *The research case studies drew on the above three mechanisms of data collection (desk research, surveys, key informant interviews)*

NOTE: * Case studies represented an analytical method and served as a data source to address individual evaluation questions.

Limitations of this evaluation

The depth of the evaluation was constrained by its breadth: the large number of countries that were to be covered, including 28 EU Member States, non-EU countries represented in the Think Tank and CSF forum, as well as countries from the wider WHO European Region; the need to engage with a wide range of stakeholders, involving academics, Think Tank members, CSF members and representatives of European Institutions and international organisations; and a time frame of eight months within which to conduct the work.

These restrictions were further exacerbated by challenges encountered during data collection. Thus, the evaluation drew on a wide range of data, some of which are routinely collected as part of ongoing monitoring activities at the European level, including data from European Centre for Disease Prevention and Control (ECDC) surveillance reports, the Directorate-General for Research and Innovation (DG RTD) and DG SANCO. Yet, the ability to fully address all evaluation questions was restricted by the timeliness of data (the most recent data were typically available to 2012 only, so covering only parts of the period covered by the Communication and its Action Plan); a lack of comprehensiveness (e.g. data on CD4 cell count at diagnosis); uncertain quality (e.g. amount of national-level funding on HIV); or lack of specificity (e.g. number of new HIV diagnoses as a proxy for incidence).

Primary data collection involving surveys and key informant interviews was constrained by comparatively small sample sizes and suboptimal response rates. Because of response rates of, respectively, 40 per cent (14/35 CSF members) and 44 per cent (17/ 39 Think Tank members), the generalisability of the findings of the CSF and Think Tank surveys remains uncertain. For both surveys, we attempted to minimise the impact of self-reporting bias by consulting additional stakeholders who had no vested interest. The response rate to the *ImpactFinder* survey that was used to inform the evaluation of the impact of EU research was at 43 per cent (30/77) also leaving some degree of uncertainty as to the robustness of the results. Also, the survey was limited to six FP7 projects and thus may not have captured all of the potential impacts of FP7 research. Similarly, the number of key informants interviewed

for this study was relatively small, as shown in Table 1. This means that the data have to be interpreted with caution.

Finally, it is important to highlight the challenge of attributing observed effects to the Communication and its Action Plan. For example, policies that were implemented before the Communication and Action Plan of 2009 may have contributed to the outcomes observed in this evaluation. Also, it may be that much of the impact of the Communication and Action Plan on the HIV epidemic in Europe occurred indirectly, as a result of its impact on the actions of Member States. Furthermore, because the evaluation was undertaken at the end of the period covered by the Communication, it is conceivable that selected impacts may occur at some later stage, in particular where funding instruments such as the FP7 or Health Programmes are concerned, with many projects ongoing at the time of writing.

Changes in the HIV epidemic and access to key services

We sought to understand the extent to which the Communication and its Action Plan have contributed to reducing the number of new HIV infections, improving access to key services, and improving the quality of life for people living with HIV (PLWHIV). We also sought to explore the barriers to better outcomes in HIV prevention and challenges of implementing HIV-related policies.

It is difficult, on the basis of available data, to provide firm conclusions on changes in the HIV epidemic in the European region during 2009–2013.

Data on new infections are not systematically collected at the European level, and only two countries are currently able to provide estimates for HIV incidence at the national level. Current approaches to HIV surveillance in Europe rely primarily on proxy measures of incidence, such as the number of new diagnoses of HIV (and AIDS) and the number of individuals accessing HIV-related treatment and care services. New diagnoses are a poor proxy for new infections, however, because they include both recently acquired and long-standing infections. An observed change in the number of newly diagnosed cases will thus reflect a change in HIV transmission (i.e. new infection) or a change in testing of undiagnosed infections, or both.

Available data on newly diagnosed infections suggest that across the European Union/European Economic Area (EEA) region, the rate has decreased from 6.2 per 100,000 population in 2009 to 5.8 per 100,000 in 2012, a decline of 7 per cent. The rate of new diagnoses remained highest in the eastern part of the European region and lowest in the central part. The most common route of transmission in the EU/EEA as a whole continued to be through MSM, although heterosexual contact became increasingly important, while in the East transmission tends to occur among people who inject drugs (PWID) and their sexual partners.

In order to better understand the HIV epidemic in the European region, it will be important to collect data on HIV incidence more systematically. The ECDC has developed a framework and technical guidance for coordinating and strengthening HIV incidence surveillance activities across the European Member States through the integration of the Recent Infection Testing Algorithm (RITA) as part of routine HIV surveillance. Such an approach would provide insights into current transmission patterns and dynamics of HIV infection within

and across countries and thereby better inform HIV prevention and health promotion efforts, in particular with regard to targeted interventions for those most at risk.

The available data on access to key HIV services point to some improvement across the region, but problems in access to and uptake of HIV testing and treatment persist.

Data on the number of HIV tests performed are not collected on a routine basis across the region, and those reported by the ECDC are based on estimates compiled from a number of sources, which are only available for about half of the EU/EEA countries. Data that are available suggest an increase in the number of tests performed in the EU/EEA during 2009–2012, but there was considerable variation among countries.

Evidence on access to and uptake of HIV testing as inferred from the proportion of those diagnosed who present late (as measured by CD4 cell count at the time of diagnosis) points to persisting problems. Late presentation was most frequent among those who had acquired the infection through heterosexual contact and PWID and lowest among MSM. Key informants and survey respondents reported that reductions in late diagnosis had been achieved in those countries where services had been set up to target specific at-risk groups.

Likewise, there is little systematic data collection on access to antiretroviral therapy (ART) and ART coverage at the European level. The number of persons with HIV receiving ART has increased across the WHO European Region since 2009, but this does not necessarily equate to an increase in ART coverage. As noted by key informants, it is difficult to know whether the increase in the number of people receiving ART reflects an increase in treatment coverage or whether it results from an increase in the number of individuals newly diagnosed with HIV.

Access to treatment can also be inferred from the number of AIDS cases and deaths, and an observed decline in the rate of newly diagnosed AIDS cases in EU/EEA countries from 1.3/100,000 in 2009 to 0.9/100,000 in 2012 suggests improved access to treatment. Conversely, the number of recorded new AIDS cases increased in non-EU/EEA countries over the same period (from 1.1/100,000 to 1.3/100,000). This was mostly driven by an increase in AIDS cases in the eastern part of the WHO European Region, although this trend was reversed in 2011. This illustrates that although improvements in access to treatment have been achieved, ensuring adequate ART coverage remains a concern.

Reported barriers to uptake of HIV testing and treatment included lack of awareness and knowledge of HIV, entitlement status and (perceived) stigma.

Drawing on a combination of surveys among Think Tank and CSF members, key informant interviews and in-depth country case studies, we identified a range of factors that were perceived to act as barriers to accessing HIV services. The factors that act predominantly at the individual level include perceived lack of risk and knowledge of HIV (such as understanding of the risks of acquiring HIV and awareness about the availability of testing and counselling options and treatment); entitlement status, which is particularly problematic for migrants, especially undocumented migrants; and (perceived) stigma, such as fear of isolation and social exclusion in case of a positive diagnosis. The factors that act largely at the provider level include 'normalising' HIV testing (and treatment) as part of regular health

service delivery; making appropriate information and guidance accessible to providers in order to enable delivery of appropriate services; eliminating negative attitudes of healthcare staff and the wider system to ensure provision of appropriate services for hard-to-reach groups; and providing counselling and support to facilitate access to and uptake of services by those at risk.

Reported barriers to implementing HIV-related policies, activities and programmes included lack of resources, both human and financial, and lack of capacity.

The Think Tank and CSF members who responded to the surveys placed different weights of importance on a range of pre-identified barriers to the implementation of HIV-related policies, activities and programmes. The majority of respondents to both surveys highlighted lack of resources, both human and financial, among the key obstacles, while views on the relevance of political commitment and resistance to harm reduction were more mixed. Lack of capacity was cited by respondents to both surveys as a particular challenge in central and eastern parts of the European region, impeding the scale-up of HIV services. A lack of financial resources is seen to be acting as a key driver of shortages, not only in relation to human resources, but also in relation to service infrastructure and equipment. The respondents expressed concerns about the long-term sustainability of HIV services in areas where the number of PLWHIV is rising. Other barriers that were cited by respondents to the CSF and Think Tank surveys included legislative, regulatory and policy issues more broadly, mainly those that exclude certain at-risk populations from accessing HIV services. These legislative, regulatory and policy issues were linked to ineffective anti-discrimination laws and suboptimal service coverage provisions, affecting undocumented migrants in particular.

The role and impact of the Civil Society Forum

The Civil Society Forum is an advisory body that brings together non-governmental organisations (NGOs) and networks, including those that represent PLWHIV, at the European level. It advises the HIV/AIDS Think Tank, which is a forum for the exchange of information among the European Commission, Member States, EU candidate countries and European Economic Area countries.

We sought to understand the impacts of CSF activities in relation to the development of programmes to address stigma and discrimination, improve access of key populations to important HIV-related services and prevention programmes, the monitoring of new infections, and the development and implementation of national/regional HIV/AIDS policies. We also looked at the effectiveness of CSF communications and the financial resources for CSF activities during 2009–2013.

The CSF was seen as an important actor in combating HIV/AIDS in Europe, but it is difficult to directly link observed changes in HIV/AIDS services, programmes and policies to CSF actions.

The CSF was considered to have facilitated discussions on relevant HIV/AIDS issues, thus providing to its members and to Think Tank members information on developments of HIV polices, enabling the exchange of good practices and experience, and informal collaborations

between different players. Through its meetings, the CSF was seen to offer a platform for planning and implementing coordinated follow-up to support advocacy and to influence HIV/AIDS policies and initiatives aimed at an increased representation of the interests of people at risk or those who live with HIV/AIDS. There was a general perception among key informants and survey respondents that the CSF had helped to bring about some change in national HIV/AIDS policies. CSF survey respondents in particular provided examples of successful action by the CSF at the national level in relation to addressing stigma and discrimination and to the uptake of key HIV services by vulnerable populations (MSM and PWID). It remains unclear to what extent these developments were solely attributable to CSF action.

The regular interactions of the CSF with its members and with the HIV/AIDS Think Tank, alongside the CSF's communication, were judged as helpful.

The communication and the information disseminated by the CSF were judged as helpful by key informants and survey respondents in raising awareness of meeting participants and of Think Tank members on developments in HIV/AIDS at the EU level. Respondents suggested a range of improvements to optimise the flow of information in the intervals between meetings and also a more targeted approach.

Available data on CSF resources suggest that, at present, available funds broadly meet the CFS's needs.

We further found that the financial resources allocated to the running and management of the CSF were rated as being sufficient, at present, to carry out its mandate and the activities it is currently implementing.

Contribution of EU-funded research and public health projects

We sought to understand the extent to which EU funding instruments, such as the Framework Seven programme (FP7) and the 2008–2013 Health Programme, contributed to the Communication's objectives, including improved education and knowledge about and awareness of HIV. We focused on two HIV/AIDS research streams funded under FP7 so as to provide a lens through which to examine the impacts of EU-funded research, namely, the development of microbicides and HIV progression and the long-term effects of antiretroviral therapy (EuroCoord). We also aimed to assess the extent to which FP7 projects and the Health Programme facilitated exchange of experience between countries in the area of HIV.

Available evidence on FP7 projects related to HIV is not yet sufficient to enable assessment of their contribution to the objectives set out in the Communication.

EU-funded research in the area of microbicide development has yet to lead to the development of novel preventive tools, and work in this area is still in the early stages of development, reflecting the global situation regarding research into microbicides. Conversely, the cohort studies on clinical management (explored through the EuroCoord case study) were shown to have contributed to HIV surveillance methods, national surveillance strategies, the type of data that are collected across Europe, research

infrastructure and policy and treatment guidelines. There is also the potential for other projects to impact on surveillance as they move further down the different stages of product development.

Recognising the aforementioned challenges in measuring HIV incidence, we note that it is difficult to assess the contribution made by EU-funded research projects to changes in the number of new infections. However, evidence collected as part of the evaluation points towards a contribution to improved public awareness and education programmes, which ultimately may contribute to a reduction in new HIV infections. It was not possible, in the context of the present study, to assess the contribution of these projects to that end.

This evaluation yielded little evidence on the contribution of FP7-funded projects to improving access to key services and the quality of life of people living with HIV. At the same time, the knowledge generated by the EuroCoord project has the potential to impact on patients in terms of advances in patient management.

FP7-supported HIV/AIDS research projects explored in this evaluation supported activities to improve education and knowledge about and awareness of HIV/AIDS, but their impact is difficult to measure.

The evaluation provides evidence that EU-funded research projects explored within this study contributed to activities raising awareness around HIV prevention and treatment. These projects reported impacts on educating and training future researchers and decisionmakers and improving education programmes on HIV/AIDS, as well as public understanding and awareness of HIV and associated issues. However, it is difficult to generalise from the evidence we collected to the overall impact of FP7-funded projects on the level of awareness of and knowledge about HIV/AIDS, or, indeed, to establish causal effects. This is particularly the case given that a contribution to education, knowledge and awareness was not the main aim of these projects and should rather be considered as a spill-over effect.

The contribution to the Communication's objectives by HIV-related projects supported by the Health Programme is only emerging.

There is some evidence suggesting that the outputs arising from actions funded through the 2008–2013 Health Programme were aligned with the objectives of the Communication and its Action Plan. However, at the time of writing the majority of the Health Programme projects were still ongoing and their preliminary findings have only just started to contribute to the objectives set out in the Communication.

The main type of outputs produced by the HIV prevention actions funded through the Health Programme included eight situation analysis reports produced between 2009 and 2011, as well as training packages, guides and tools for the support of health professionals and community organisations.

The available evidence points to the EU-supported programmes contributing to sharing experience in the area of HIV/AIDS.

Data collected as part of the evaluation supports the notion that EU-funded programmes have facilitated the establishment and development of research networks and have promoted

collaboration and exchange of experience among countries. However, the evidence from the survey with Think Tank and CSF members suggests that the results of EU-funded research related to HIV/AIDS may not be well recognised and that more could be done to disseminate the findings of this research to a broader range of stakeholders across Europe.

Funding to support HIV prevention, treatment, care and support

The evaluation sought to describe EU funds allocated to HIV/AIDS and to priority groups within that funding area; the EC's contribution to the Global Fund; and national spending on HIV/AIDS and co-infections by Member States. We also sought to explore options for how the EU could support NGOs in their role. Finally, we explored the effects of the global financial crisis on HIV/AIDS in Europe.

Available data suggest that the EU has spent approximately €150 million on HIV prevention, treatment, care and support during 2009–2013.

It was not possible to determine the precise amount of money spent by the European Commission on HIV/AIDS because such data are not monitored in a centralised way across the different EC services. Available data also provided limited insight into EU-level (as opposed to Member State–level) spending on identified priority groups, including MSM, migrants, PWID and prisoners, or on priority regions. Such disaggregation was only possible for HIV projects funded through the European Health Programme for the years 2009–2013. We found that during 2009–2013, a total of €12.3 million was spent on HIV prevention, treatment, care and support in the context of the Health Programme. Of this amount, €5.5 million (45 per cent) targeted specific priority groups, including MSM (33 per cent), migrants (22 per cent), PWID (9 per cent) and prisoners (7 per cent). The remaining 29 per cent of the €5.5 million related to priority regions (€1.6 million).

The EC contribution to the Global Fund to Fight AIDS, Tuberculosis and Malaria during 2009–2013 was approximately USD 683.7 million (~€510 million).

The EC contribution to the Global Fund represents 4 per cent of the total donor contributions. This share fell during the assessed period, from around 4.6 per cent in 2009 to 3.7 per cent in 2013.

During 2009–2013, the Global Fund to Fight AIDS, Tuberculosis and Malaria provided financial support to two EU Member States (Bulgaria and Romania) and to the three European Neighbourhood Policy (ENP) countries, Belarus, Moldova and Ukraine, that have participated in the implementation of the EC Communication and Action Plan. The EC pro-rata contribution to the GFATM in those countries corresponded to a total of USD 16 million (~€12 million), or 4.1 per cent of the total EC contribution to the GFATM.

Available data on national-level spending on HIV/AIDS are patchy. For the 11 EU Member States for which there are data, the estimated spending during 2009–2011 was €2,115 million.

This evaluation was unable to identify comprehensive and complete data on national-level spending on HIV/AIDS during 2009–2013. Available data collected by the ECDC as part of their Dublin reporting mechanisms provide only partial insight. Among the five countries for which data were available for each year between 2009 and 2011, Bulgaria, Poland and Portugal reported successive increases in overall spending on HIV/AIDS over the entire period, while Latvia and Romania saw a decline from 2009 to 2010, followed by an increase from 2010 to 2011. However, when we consider spending on HIV prevention, Romania was the only country among those that did report relevant data that documented a year-on-year increase in spending. There was little change in spending on HIV prevention over time in Belgium, the Czech Republic and Poland.

Options for the EU to help NGOs facing the phasing out of the Global Fund include supporting the involvement of civil society organisations in policy development and supporting access to European structural funds, capacity building and participation on EU-level projects on the part of those NGOs.

Bulgaria and Romania were the only two EU Member States that received support through the Global Fund to Fight AIDS, Tuberculosis and Malaria in the period under consideration in this evaluation. However, GFATM budget reductions for HIV/AIDS in these countries during 2009–2013 meant that, in Romania, funding for prevention interventions targeting vulnerable populations was not secured and NGOs had to discontinue their activities because of lack of funding. The future sustainability of HIV activities was also flagged as an area of concern for Bulgaria. While both countries continue to be eligible for (some) support through the GFATM in the foreseeable future, the uncertainty and funding shortfall means that they will have to engage in efforts to plan for transitioning when they may no longer qualify for GFATM funding. These efforts will be particularly important to ensure sustainability of the work and services currently provided by NGOs in these countries, with shortfalls in funding likely to undercut preventative efforts targeting vulnerable groups in particular, as experienced in Romania.

While sustaining financial support is key, it will be equally important to support strengthening capacity among NGOs to enhance their involvement in national policy development and decision-making and their participation in EU-level projects. The EU could take an important role in supporting such efforts. Options identified include funding such activities as training or mentoring schemes between organisations that help build the capacity of NGOs, simplifying the process of applying for and managing EU-funded projects, and ensuring that different funding streams encourage participation of NGOs.

It is difficult to establish causality between the global financial crisis and changes in HIV services where these occurred.

Data on the impact of the 2008 global financial crisis on HIV prevention, treatment, care and support are not readily available. A small number of country-specific studies have

highlighted challenges related to the crisis, with HIV outbreaks reported among injecting drug users in Greece and Romania, and these have been associated with cut-backs in prevention and treatment programmes for illicit drug use. There was variation among countries for which national-level data on year-on-year spending on HIV were available for the period 2009–2011, suggesting that overall spending on HIV may have remained fairly stable, but that countries appeared to have reduced spending on HIV prevention, with implications for sustaining preventative activities. Countries generally reported maintaining the provision of testing, treatment, care and support services, although some experienced cases of service disruption or a redefinition of eligibility for services, which had the effect of reducing the number of people accessing HIV services. Overall, it remains challenging to establish direct links between the financial crisis and changes in HIV prevention, treatment, care and support where these occurred.

EU HIV policy coordination and monitoring

We sought to understand (i) the relation of the Communication to other EU policy areas and (ii) the indicators that are necessary to monitor the process of the implementation of the Communication.

The evaluation found that the Communication was aligned with other EU policies, although closer links could be sought.

The Communication and its Action Plan are in line with other EU policies, including EU policies on research, development, cooperation and drug control. However, there are areas where coordination with other policies could be further strengthened (e.g. the area of public health and HIV issues is somewhat underrepresented in the fields of fundamental rights, migration and the European Neighbourhood Policy). However, a number of key informants thought there was room for improvement in a number of areas, including human rights, affordability of medicines and the operational aspects of EU funding to combat HIV. Providing leadership in the internal monitoring of the Commission's efforts to implement the Communication and its Action Plan and providing an adequate platform for this activity could help further improve collaboration and coordination around EU policies for combating HIV/AIDS.

Given the existing reporting burden as it relates to HIV, additional and process-driven indicators to monitor the uptake of EU policy at the national level might not add further value.

The current monitoring and evaluation framework that the ECDC developed provides limited insight into the implementation process and the uptake of the policy at the level of the Member State. Given the complexity and breadth of HIV reporting that is required from Member States, the scope for EU added value lies in continuing and reinforcing efforts to reduce, harmonise and streamline existing indicators, rather than in developing new indicators.

Exploring changes to the European Surveillance System (TESSy), the evaluation found evidence that suggests that HIV surveillance data collection has improved across Europe

since 2009. However, the data collected are insufficient to unambiguously attribute these changes to the Communication.

Finally, some key informants suggested that further improvements were still possible.

What this evaluation adds: Recommendations for the further development of an HIV/AIDS policy framework at the EU level

Based on the evidence compiled as part of the evaluation, we developed a series of recommendations that the European Commission may wish to consider.

Considering **changes in the HIV epidemic and access to key services**, barriers to access and uptake of HIV services and barriers to the implementation of HIV/AIDS policies and programmes, we recommend that the European Commission considers:

- **Adopting a new European policy framework on HIV/AIDS** in order to ensure that HIV/AIDS remains on the policy agendas and to reinforce stakeholders' commitment to implement policies and programmes to address HIV/AIDS prevention, treatment, care and support at the national and regional levels. The evaluation showed that while activity at the EU level is unlikely to directly impact on trends in HIV infections (except where the EU directly funds related activity) the 2009–2013 Communication has formed an important political backdrop against which to help stimulate activity at the national level, in particular with regard to the most at-risk populations.
- **Supporting activities to strengthen the primary prevention of HIV/AIDS**. While based on limited data from key informants, the evaluation confirmed that there is a continued need to enhance both the awareness and understanding of HIV among key population groups, and the options for HIV testing at the community level This enhanced awareness and understanding would contribute to reducing the number of undiagnosed cases – and the proportion diagnosed late –as well as improve prognosis and, through ensuring timely treatment, reduce transmission.
- **Supporting activities targeting the most at-risk populations**, in particular working with relevant stakeholders to address the needs of migrants and developing guidance on the financing and delivery of prevention, treatment, care and support services for this group. Considering the particularly vulnerable situation of migrants, in particular those with uncertain legal status, support action at the European level, bringing together the European Commission, the HIV/AIDS Think Tank and the Civil Society Forum, may be particularly suited to help improve countries' responses to enhancing access to information and key services for this group specifically.

Considering the **role and impact of the Civil Society Forum**, we recommend that:

- **The European Commission considers continuing to support the CSF** to further enhance the involvement of civil society in the development of HIV/AIDS policies, programmes and activities across Europe and to strengthen advocacy for at-risk populations and people affected by HIV/AIDS, in particular where civil society advocacy is not (yet) well established. The evaluation found that the legitimacy awarded by the European Commission in the 2009–2013 Communication to the CSF was seen to be crucial to empower stakeholders involved in combating HIV/AIDS. It empowered them by increasing their knowledge and informing their actions at the

national level and by influencing perceptions of stakeholders on the added value of the civil society perspective on the development of HIV/AIDS policies at the EU level.

- **The CSF considers focusing its work on the sharing of experience and transferring of good practices among countries** to combat HIV/AIDS in Europe. The evidence showed that, through its activities and website (the clearinghouse), the CSF has facilitated access to good practices that might be transferred to other countries. The CSF (or, indeed, the Think Tank) might serve as a platform where these opportunities could be pro-actively and more effectively exploited. This could be effected by involving a wider group of stakeholders in dedicated sessions or working groups focused on the transfer of knowledge and the review of evidence on what works, for whom and under what conditions.

Considering the **contribution of EU-funded research and public health projects**, we suggest that the European Commission:

- **Continues to develop mechanisms that facilitate communication between scientists and practitioners** and that better address the translation gap between basic and applied research. Mechanisms may include continuing funding streams that (i) systematically require the collaboration of basic science and applied research to ensure that research is translatable into practice; (ii) incentivise the conduct of implementation research alongside studies that develop strategies for HIV/AIDS prevention, treatment, care and support, so providing insights into the scalability of 'good practice'; or (iii) specifically focus on developing (and evaluating) research dissemination formats that effectively communicate HIV research findings to different audiences, including vulnerable population groups. Other mechanisms include the systematic involvement of key stakeholders representing HIV surveillance and monitoring, public health agencies, social services and other stakeholders in the further development of the HIV/AIDS research agenda across the relevant EU agencies (DG SANCO, DG RTD and the Directorate-General for Development and Cooperation [DG DEVCO]).
- **Considers establishing mechanisms within the new Health Programme** that enable access to EU-funded interventions by organisations, such as NGOs, that are currently unable to meet the matched funding requirements and to so encourage their participation in pan-European projects.

Considering **funding to support HIV prevention, treatment, care and support**, we emphasise the reported limitations of the data, which prevent the assessment of EU-level spending on HIV/AIDS. We therefore recommend that the EC consider introducing a centralised system to record and monitor information on the amount of EU funds that are spent on HIV/AIDS by various Directorate-Generals (DG) and EU agencies. Work currently undertaken by the ECDC to monitor national expenditures on HIV/AIDS might enable the EC to follow the trends at the EU and national levels with greater accuracy.

With regard to civil society, we further suggest that the European Commission considers:

- **Continuing facilitating access by NGOs to EU structural funds and EU-funded programmes**, by providing capacity-building components and by further simplifying rules and regulations
- **Prioritising health investments through EU-level funds**, in particular in the European Social Fund (ESF) allocation for social inclusion

- **Supporting training for or mentoring of schemes between organisations** that help build their capacity in the areas of advocacy, fundraising and project management.

Finally, considering **EU HIV policy coordination and monitoring,** we suggest that the European Commission considers:

- **Strengthening coordination between HIV policy and the areas of justice, human rights and non-discrimination** to more effectively address the issue of stigma and the situation of migrants in the EU.
- **Improving coordination of HIV funding among different EU programmes**, including EU-funded scientific research, the Health Programme, the European Neighbourhood and Partnership Instrument, and other instruments, to ensure greater continuity of funding.
- **Further advancing existing mechanisms to monitor the implementation of the Communication and its Action Plan by the EC and EU agencies** in order to take corrective action and/or resolve coordination issues when required. The Inter-service Group on HIV/AIDS in Europe, chaired by DG SANCO, could provide a suitable forum for reviewing the effectiveness of the implementation at the EU level.
- **In collaboration with the ECDC, continuing efforts to harmonise and streamline HIV reporting** to reduce the burden on national authorities and the civil society, who continue to report to multiple funders and organisations on progress in combating HIV.
- **In collaboration with the ECDC, developing actions to further improve completeness, comparability and availability of TESSy data.** While it was outside the scope of this evaluation to assess the existing surveillance system and therefore the evidence we collected to support these recommendations is limited, our evaluation did reveal a number of areas in which improvements seem possible.

Reflections on the evaluation: Lessons learned and implications for the further development of HIV/AIDS policies at the EU level

The Communication provided political backing and strategic leadership in combating HIV/AIDS in Europe.

As illustrated in this evaluation, the Communication and its Action Plan were seen by stakeholders to have provided the necessary stimulus, continuous pressure and leverage for various stakeholders to advocate for and take actions against HIV/AIDS in Europe. While such actions did not automatically translate into new policies at the national level, in the current economic context it was important that issues related to HIV/AIDS remained high on the political agendas. For this reason it will be important that the Commission retains the momentum and seeks to develop a renewed policy framework addressing HIV/AIDS in Europe for the coming years.

Given the at times rapidly changing context, both in terms of economic or societal context and in terms of scientific advances in HIV research, it appears necessary to consider a mechanism that builds an element of 'flexibility' into the time horizon for a new policy framework and that thus would permit greater responsiveness to change.

The Communication's objectives preceded developments in HIV surveillance systems.

Of crucial importance for the systematic monitoring of the impacts of any policy development at the EU level is the availability of data that are aligned with the objectives of the given policy. The three core objectives of the 2009–2013 Communication were to reduce the number of new HIV infections in all European countries by 2013; to improve access to prevention, treatment, care and support; and to improve the quality of life of people living with, affected by, or most vulnerable to HIV/AIDS in the EU and neighbouring countries. Yet, relevant data that would allow for a robust assessment of the extent to which these objectives have been achieved are as yet lacking. This is in part because of challenges inherent in measurement, such as, for example, measurements of the incidence of HIV or the quality of life of PLWHIV. However, other indicators are more amenable to routine collection, such as the number of HIV tests performed or data on CD4 cell count at diagnosis.

It is against this background that it will be important for the Commission, in collaboration with the ECDC, to define future surveillance priorities and develop a sustainable and systematic approach to collecting epidemiological and behavioural surveillance data at the EU level. This may require, as part of a renewed HIV/AIDS policy, incorporating mechanisms suitable to support countries that currently lack the capacity for data collection, in order to enhance the comprehensiveness and comparability of data across the region. Any policy objectives set for combating HIV/AIDS in Europe should also consider the time frame within in which it will be realistic that desired outcomes, such as the reduction of new infections, can be achieved and, more importantly, set targets against which to judge success.

Identified areas of high added value build on key competencies of the EU.

The evaluation found that the Communication was perceived to have added value in a number of areas, including focusing efforts and resources on priority regions and groups; strengthening civil society in contributing to the setting of the policy agenda on HIV/AIDS at the European and national levels; facilitating collaboration and exchange of experience among countries; and supporting collaborative projects in the area of research and public health.

Building on these key areas of activity and competency, it appears to be important for the EC to focus on the following areas for developing further HIV/AIDS polices at the EU level:

- **HIV research**: Building on a small number of recommendations presented in Section 8.1, there is an opportunity for the EC to revisit its approach to the funding and organisation of HIV research in order to strengthen the cohesiveness between research areas and to continue to promote the combination of basic science and applied research to enable swifter translation of research findings into practice.
- **Primary prevention of HIV**: There is considerable opportunity to strategically focus available (research) funding to increase awareness of and knowledge about HIV/AIDS among at-risk groups and to systematically communicate findings among key stakeholders involved in HIV/AIDS policies and practice, in order to facilitate cross-national learning. Given the competencies of the EU in the field of public health in particular, there may also be a role for DG SANCO, in collaboration with other directorates – such as the Directorate-General for Justice (DG JUSTICE), the Directorate-General for Home Affairs (DG HOME) or the Directorate-General Employment, Social Affairs and Inclusion (DG EMPL) – to consider supporting a joint campaign on stigma and discrimination against people living with HIV. Such a

campaign would crucially require involvement of the CSF and the Think Tank to ensure that messages are culturally sensitive and acceptable.

- **Health security**: The EC, in cooperation with the Think Tank, could further explore if and how the Decision on serious cross-border threats to health could be used to support EU Member States in combating HIV/AIDS.

The evaluation presented in this report was prescriptive and task-driven.

The commissioning of the evaluation presented in this report was guided by a set of pre-specified evaluation questions that covered a large number of topics to be explored within a comparatively short time frame. While the answers to these evaluation questions provided a broad overview of a range of issues of importance in relation to the Communication, this broadness will inevitably have to be traded off against a lack of depth.

Also, underpinning this evaluation was an assumption that relevant stakeholders are aware of and understand the objectives of the Communication and its Action Plan. However, as we have shown, this does not unequivocally appear to be the case. Some key informants and survey respondents found it difficult to link the Communication and its Action Plan with the mechanisms intended, including the CSF and Think Tank platforms and EU-funded research, as well as activities of the EC and ECDC. There also appeared to be a lack of clarity about the geographical reach of the Communication and its Action Plan, with representatives from neighbouring countries not considering the Communication to be applicable outside the EU.

This indicates that a renewal of the HIV/AIDS policy at the EU level would benefit from a clearer formulation of the intended outcomes and the definition of causal pathways that are thought to result in the desired outcomes ('theory of change'). Such an approach would clarify the roles and responsibilities of individual stakeholders tasked with the delivery of the objectives set out in the policy; this clarification, in turn, should also aid in the communication of the policy. Considering the evaluation of the renewed policy, it may be important for the EC to consider reducing the scope of the policy or commissioning a series of studies that explore particular aspects in more detail, thereby providing a level of granularity that was not possible to deliver in the context of this evaluation. Furthermore, there is a persuasive argument to reconsider the approach to evaluation towards one that builds on the monitoring and evaluation framework for the Communication and that is informed by theory. Such an approach would set out the different elements of the 'intervention' logic, from inputs, processes, outputs, and outcomes to impacts, and would seek to understand how and why the desired change is expected to come about. This would facilitate both the implementation process (by considering contextual factors, assumptions and risks) and the future evaluation of the next framework.

The information and views set out in this study are those of the author(s) and do not necessarily reflect the official opinion of the Commission. The Commission does not guarantee the accuracy of the data included in this study. Neither the Commission nor any person acting on the Commission's behalf may be held responsible for the use which may be made of the information contained herein.

Abbreviations

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
cARV	Combination antiretroviral therapy
CSF	Civil Society Forum
Chafea	Consumers, Health and Food Executive Agency (formerly Executive Agency for Health and Consumers [EAHC])
EC	European Commission
ECDC	European Centre for Disease Prevention and Control
EEA	European Economic Area
EMCDDA	European Monitoring Centre for Drugs and Drug Addiction
ENP	European Neighbourhood Policy
ESF	European Social Fund
EQ	Evaluation question
EATG	European AIDS Treatment Group
EU	European Union
FTE	Full-time equivalent
DCI	Development Co-operation Instrument
DG	Directorate-General
DG DEVCO	Directorate-General for Development and Cooperation – EuropeAid
DG EMPL	Directorate-General for Employment, Social Affairs and Inclusion
DG HOME	Directorate-General for Home Affairs
DG JUSTICE	Directorate-General for Justice
DG RTD	Directorate-General for Research and Innovation
DG SANCO	Directorate-General for Health and Consumers
FP7	Seventh Framework Programme 2007–2013

GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
HIV	Human immunodeficiency virus
MS	Member State
MSM	Men having sex with men
PMTCT	Prevention of mother-to-child transmission
PLWHIV	People living with HIV
PWID	People who inject drugs
RITA	Recent Infection Testing Algorithm
STI	Sexually transmitted infection
TESSy	The European Surveillance System
ToR	Terms of reference
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

1. Introduction

The advent of effective highly active antiretroviral treatment (HAART) and its wide deployment in Western Europe after 1995 was a turning point in the HIV epidemic that had been spreading across Europe since the early 1980s. The average life expectancy for someone who is diagnosed as HIV positive today is close to that of the general population, provided the person receives early diagnosis and treatment. HIV is now considered to be a chronic disease [1]. However, despite progress in treatment, human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) and associated infections remain a significant public health issue in Europe.

The most recent policy instruments at the European Union (EU) level to address HIV/AIDS in Europe are the European Commission Communication 'Combating HIV/AIDS in the European Union and the neighbouring countries, 2009–2013', and its associated Action Plan (hereafter referred to as the Communication). The Communication and its Action Plan complement the 'European Programme for Action to confront HIV/AIDS, Malaria and Tuberculosis through External Action (2007–2011)' [2]. In March 2014, the European Commission (EC) launched an enhanced Action Plan for 2014–2016, which builds on the Action Plan for 2009–2013 [3]. The further development of the EU policy framework on HIV/AIDS is currently under consideration [4].

The Directorate-General for Health and Consumers (DG SANCO) commissioned this evaluation to assess the success of the 2009–2013 Communication and to identify areas for improvement, in order to inform the further development of the EU policy framework on HIV/AIDS. RAND Europe and Van Dijk Management Consultants conducted this evaluation over a six-month period during 2013 and 2014. This report presents the approach to, and the findings, conclusions and recommendations of, this evaluation.

1.1. Context of the evaluation

The development of policies aimed at combating HIV/AIDS in the European Union has taken place against the background of a series of declarations and commitments at the European level [5-9] and global initiatives [10-13]. These initiatives call on national governments, international organisations and non-governmental organisations to commit to action on HIV/AIDS. Commitments range from the provision of universal access to HIV treatment, care support and prevention services, to investment in research and development on new preventive and therapeutic tools, to support for people living with HIV (PLWHIV) and the most at-risk populations, to the involvement of PLWHIV and civil society organisations in the design and implementation of HIV/AIDS policies.

The EC's Communication and its Action Plan on HIV/AIDS (2009–2013) [14] follow the EC's previous Communication and Action Plan (2006–2009) [15], which formed the basis of the EU's actions to address HIV/AIDS at the European level from 2006–2009. The most recent Communication and Action Plan (2009–2013) sought to strengthen the EU's policies

on HIV/AIDS for the period 2009–2013, with a view to renewing the commitment at the end of this period [14].

The overarching objectives of the Communication (2009–2013) were [14]:

(i) To reduce the number of new HIV infections in all European countries by 2013

(ii) To improve access to prevention, treatment, care and support

(iii) To improve the quality of life of people living with, affected by, or most vulnerable to HIV/AIDS in the EU and neighbouring countries.

The Communication and Action Plan (2009–2013) targeted [14] all EU Member States, EU candidate countries, potential candidate countries, European Free Trade Agreement (EFTA) countries, European Neighbourhood Policy (ENP) countries and the Russian Federation. It invited these countries to contribute to achieving the objectives of the Communication and stressed the importance of sustaining efforts to prevent HIV transmission, promote the human rights of PLWHIV and affected communities and deliver high-quality treatment and care to those in need. The Communication also emphasised that the HIV epidemic and its future trends in the European region could most effectively be addressed by scaling up the implementation of prevention strategies, supporting an effective response to the epidemic in priority regions and developing the means to support those most at risk of, and most vulnerable to, contracting HIV/AIDS across Europe.

In line with its overarching objectives, the Communication formulated a set of expected outcomes to be realised by actions undertaken across Europe. The expected outcomes of the Communication (2009–2013) were [14]:

- *'A decrease in HIV infections*
- *A real improvement in the quality of life for people living with HIV and most at risk populations*
- *Strengthened solidarity towards an unambiguous response to HIV/AIDS*
- *Improved education, knowledge and awareness on HIV/AIDS*'.

The Action Plan (2009–2013) that accompanied the Communication outlined how all stakeholders were to achieve the objectives set out in the Communication. It identified six areas for action [16]:

- Politics, policies and involvement of civil society, wider society and stakeholders
- Prevention
- Priority regions
- Priority groups
- Improving the knowledge
- Monitoring and evaluation.

These actions were to be funded through the Seventh Framework Programme (FP7); the EU Health Programme 2008–2013; the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM; hereafter referred to as the Global Fund); the EU structural funds; the Development Cooperation Instrument; and the European Neighbourhood and Partnership Instrument [3].

The EC developed the Action Plan in cooperation with the HIV/AIDS Think Tank, the Civil Society Forum (CSF) and other external stakeholders [14]. The HIV/AIDS Think Tank is a

forum for the exchange of information among the European Commission, Member States, candidate countries and European Economic Area (EEA) countries [17]. The CSF is an advisory body that brings together non-governmental organisations (NGOs) and networks, including those that represent PLWHIV. The CSF advises the HIV/AIDS Think Tank on the issues discussed by the Think Tank [18]. For each of the actions, the Action Plan specifies organisations that are responsible for their realisation, the *'partners involved in realisation'*: the European Commission, European Presidencies, the CSF, the Think Tank, National AIDS Coordinators, the European Centre for Disease Prevention and Control (ECDC), surveillance institutions in neighbouring countries, the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA), international organisations, Member States, European Neighbourhood Policy countries, national and regional authorities, academia, research institutions, industry, medical associations, migrant organisations and ethnic minority organisations [16].

Requirements for the monitoring of HIV/AIDS in the European Union are set out in the 'Decision of the European Parliament and Council 2119/98/EC' and subsequent amendments, describing provisions for the surveillance and control of communicable diseases [19]. Since 2005, HIV/AIDS surveillance at the European Union level has been coordinated by the European Centre for Disease Prevention and Control (ECDC), as set out in Regulation (EC) No. 851/2004 [20]. The ECDC produces an annual epidemiological report on HIV/AIDS; monitors implementation of the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia; and produces evidence briefs, thematic reports and other publications related to HIV/AIDS in the World Health Organization (WHO) European Region.

The most recent Communication (2009–2013) and accompanying Action Plan were the subject of the ECDC review 'Monitoring implementation of the European Commission Communication and Action Plan for combating HIV/AIDS in the European Union and neighbouring countries, 2009–2013', which was published in 2013 [21].

1.2. Evaluation objectives and questions

The overarching objective of this independent evaluation was to explore the extent to which the Communication and its Action Plan (2009–2013) have achieved the expected outcomes described above. The terms of reference (ToR) for this evaluation [22] are set out 18 evaluation questions (EQs), which are outlined in Table 1.1. Prior to the commencement of this evaluation, the objectives and wording of each of the evaluation questions were clarified with the project's steering group. This evaluation focused on 28 EU Member States. It also included non-EU countries represented in the Think Tank and CSF forum, as well as countries from the wider WHO European Region, subject to data availability.

Table 1.1. Evaluation questions

ToR	Evaluation question
EQ 1	To what extent has the Communication contributed to (1) reducing the number of new HIV infections; (2) improving access to key services, including early combination antiretroviral (cARV) treatment; and (3) improving quality of life for PLWHIV?
EQ 2	What are the relevant indicators that enable monitoring the process of implementation of the Communication?
EQ 3	What is the European added value of the Communication?
EQ 4	What is the relation of the Communication to other EU policies?
EQ 5	To what extent have the EU programmes facilitated an exchange of good practice among the EU Member States in the area of HIV/AIDS?
EQ 6	To what extent has the CSF contributed to (1) the development of programmes to address stigma and discrimination; (2) the improvement of access by key populations to important HIV-related services and prevention programmes; (3) the monitoring of new infections; (4) the development and implementation of national/regional HIV/AIDS policies and plans?
EQ 7	How effective was the CSF in providing interested parties, including NGOs and the Think Tank, with relevant information on HIV/AIDS issues and policies?
EQ 8	Are the resources allocated to the CSF commensurate with its objectives or needs?
EQ 9	(1) To what extent has EU-funded research on HIV/AIDS led to outputs in terms of novel preventive tools and therapeutic options, and surveillance methods? (2) To what extent have these research outputs contributed to the expected objectives set out in the Commission Communication?
EQ 10	Is there evidence of improved education, knowledge and awareness of HIV as a result of EU-funded projects?
EQ 11	To what extent have actions funded through the Health Programme (HP) led to outputs that have contributed to the attainment of objectives set out in the Commission Communication?[1]
EQ 12	(1) What is the exact amount spent on HIV prevention, treatment, care and support by the EU since 2009? (2) What is the proportion of funding of the Global Fund to Fight AIDS, Tuberculosis and Malaria in the Member States that is directly attributable to the EU budget contribution?
EQ 13	How have the EU funds been spread across the main target groups?
EQ 14	(1) What are the consequences of the financial crisis on national responses to HIV? (2) How could these consequences be addressed by the EU?
EQ 15	How can the EU help NGOs to continue their work on HIV that is no longer supported by the Global Fund?
EQ 16	What is the proportion of national funding that is spent on HIV/AIDS and co-infection treatments in the EU Member States?
EQ 17	What are the most prominent problems in implementation of HIV-related policies, activities and programs?
EQ 18	What are the major obstacles that exist today to obtain better outcomes in HIV prevention, as aligned to the EC, WHO and UNAIDS [the Joint United Nations Programme on HIV/AIDS] objectives?

SOURCE: Adapted from the terms of reference for this assignment (unpublished)

The evaluation questions can be broadly classified into five thematic areas, and in the following, we report the findings of the evaluation in line with each of these themes rather than by individual research questions in order to optimise the value of data collected and minimise repetition. The five broad themes are:

(i) Changes in the HIV epidemic and access to key services (Chapter 3)

(ii) Role and impact of the Civil Society Forum (Chapter 4)

[1] We have operationalised this question as 'Which outputs funded through the Health Programme can be identified to have contributed to the attainment of objectives set out in the Communication?'

(iii) Contribution of EU-funded research and public health projects (Chapter 5)

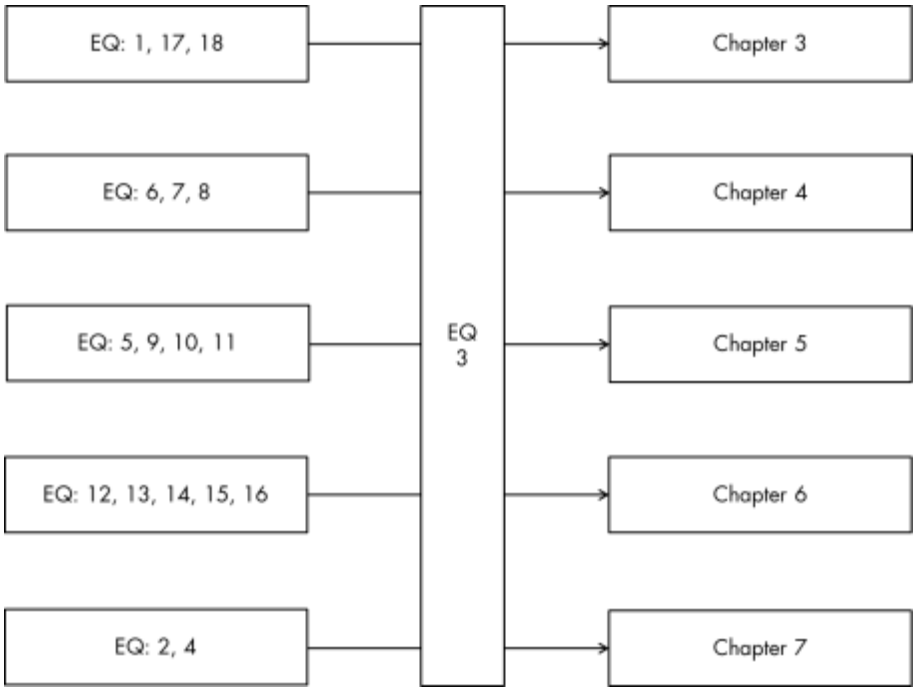
(iv) Funding to support HIV prevention, treatment, care and support (Chapter 6)

(v) EU HIV policy coordination and monitoring (Chapter 7).

1.3. Structure of the report

Following this introduction, Chapter 2 describes the methods used to conduct this evaluation and Chapters 3 to 7 present the core findings of the work, organised according to the five themes outlined above. Multiple evaluation questions feed into each of the above themes, while some evaluation questions cut across themes, as shown in Figure 1.1. At the end of each chapter, the European added value is highlighted and a summary of the thematic area and relevant evaluation questions is provided.

Figure 1.1. Report structure in relation to the evaluation questions



Chapter 8 presents a summary of the results of the evaluation in relation to the wider policy context, in order to develop recommendations for a future policy framework on HIV/AIDS in Europe.

2. Methods

The broad requirements of this evaluation, as described in Chapter 1, and the limited time frame available to carry out the evaluation necessitated the development of a targeted approach that balanced the breadth and depth of the evaluation while capturing the range of activities that have occurred across countries and ensuring in-depth analyses of selected priority areas to provide sufficient granularity to inform future policy development. A combination of methods were used to carry out the evaluation, as shown in Table 2.1, including document review, key informant interviews, surveys and a series of case studies (country case studies and research case studies).

Table 2.1. Summary of data collection approaches used in the evaluation

Data collection method	Description

Desk research	• Targeted review of documents to understand:
	  • Changes in the incidence of new infections of HIV/AIDS in Europe
	  • The role and functioning of the CSF
	  • The state of implementation of the Health Programme projects and any immediate outputs and outcomes resulting from these projects
	  • The level of HIV funding in the EU
	  • In-depth country case studies
	  • In-depth research case studies

Surveys	• Think Tank survey:
	  • Representatives from 28 Member States and 11 non-EU countries were invited, of whom 17 responded
	• CSF survey:
	  • Representatives from 35 organisations were invited, of whom 14 responded
	• *ImpactFinder* survey:
	  • In total, 77 individuals (principal investigators [PIs], work package leaders and technical scientists) from the selected FP7 projects were invited to take part, of whom 30 responded

Key informant interviews	• European-level interviews:
	  • Four representatives from the Think Tank were invited, two participated
	  • Four representatives from the CSF were invited, four participated
	  • Five officials from the EC and European agencies were invited, five participated
	  • Two representatives from international organisations (i.e. the Joint United Nations Programme on HIV/AIDS [UNAIDS] and World Health Organization [WHO]) were invited, two participated
	• Country case studies:
	  • Nine interviews were conducted with representatives of relevant national authorities, civil society organisations and academia
	• Research case studies:
	  • Five interviews were conducted with selected project coordinators and independent stakeholders

*Case studies**	• *Country case studies (Bulgaria, Latvia, Spain and the United Kingdom):*
	  • *The Member State case studies drew on the above three mechanisms of data collection (desk research, surveys, key informant interviews)*
	• *Research case studies (EuroCoord and microbicide development):*
	  • *The research case studies drew on the above three mechanisms of data collection (desk research, surveys, key informant interviews)*

NOTE: * Case studies represented an analytical method and served as a data source to address individual evaluation questions.

The evaluation grid, present in Appendix A, provides further detail on how each of the evaluation questions was addressed. The evaluation grid provided the analytical framework that was used for this study; it details data collection methods used to answer the evaluation questions.

2.1. Desk research

Desk research informed all of the evaluation questions. Our general approach involved a targeted review of the published evidence, drawing on the principles of a network search that builds on a non-keyword-based reviewing approach. The only exception was our approach to address evaluation question 1, which sought to map the evidence on new HIV infections in Europe. Here we used a protocol that followed the principles of a rapid evidence assessment in order to capture the emergent evidence on monitoring HIV infections. We describe these approaches in turn.

Desk research also informed the country case studies (Bulgaria, Latvia, Spain and the United Kingdom [UK]) and the research case studies (EuroCoord and microbicide development). For additional detail on the case study methods, please refer to Section 2.4.

2.1.1. Evaluation question 1

Drawing on the principles of rapid evidence assessment, we identified peer-reviewed publications from the bibliographic database PubMed, using the following search terms ('/' indicates 'OR'): 'surveillance/monitoring', 'new infections/incidence', 'HIV' and 'Europe', restricted to the mention of these search terms in the title or abstract of the identified references. This search was supplemented by country-specific searches, replacing 'Europe' for each of the case study country names (Bulgaria, Latvia, Spain and the UK) (Section 2.4.1). We further adapted the search strategy used in the 2013 review by the ECDC of monitoring recently acquired HIV infections in Europe [23]. That review considered studies published up to 2010. We used it to complement our searches by adding the years 2011 to 2013: 'HIV' and 'incidence' and 'recent/incidence/incident/STARHS/RITA' (Recent Infection Testing Algorithm). References from selected studies identified through searches were followed up. No language restrictions were applied. The titles and abstracts of the identified references were screened against the following exclusion criteria:

- Study was not conducted in Europe
- Study reported on data collected before 2009
- Study did not address HIV, measures of HIV incidence or new infections
- Study did not provide estimate(s) of incidence or new infections.

Within the time and resources available for this study it was not possible to formally assess the quality of the studies and documents identified for review, although where appropriate we comment on potential limitations of the available evidence base.

2.1.2. Evaluation questions 2 to 18

We conducted a targeted review of the published evidence for each of EQs 2 to 18, drawing on the principles of a network search that builds on a non-keyword-based reviewing approach. Searches used PubMed and the Google search engine to identify academic and grey literature, such as institutional and governmental documents, including ECDC surveillance reports, EMCDDA scientific monographs on harm reduction,[2] UNAIDS reports and national surveillance reports. Reference lists of included documents were followed up [24]. In addition, and where appropriate and relevant, we sourced further documents through key informant interviews (see Section 2.3).

Also here, within the time and resources available for this study it was not possible to rigorously assess the quality of the studies and documents identified for review, although where appropriate we comment on potential limitations of the available evidence base.

2.2. Surveys

Three separate surveys were conducted with (i) members of the Think Tank; (ii) members of the CSF; and (iii) principal investigators (PIs), work package leaders and technical scientists representing selected FP7 projects (*ImpactFinder* survey). We briefly describe these below.

2.2.1. Think Tank and CSF surveys

The surveys of members of the Think Tank and those of the CSF aimed to capture their perspectives on HIV policies and surveillance and on changes that have occurred during the implementation of the Communication and its Action Plan. They also aimed to capture perceptions of the extent to which these changes may be attributable to the Communication.

The surveys were designed by the evaluation team and reviewed by DG SANCO. They comprised a series of closed and open-ended questions, capturing the following five themes: (1) the impact of the CSF; (2) exchange of good practice; (3) HIV/AIDS prevention, treatment and care; (4) European added value; and (5) barriers to implementation and the uptake of HIV-related services. These themes were identified through reviewing data that had already been collected by the ECDC and the Directorate-General for Research and Innovation (DG RTD), in order to identify information gaps where additional survey questions could usefully add value and help answer the EQs. The survey instruments were tailored to different audiences while providing sufficient room to allow for the views and perceptions of a wide range of experts to be collected. The questionnaires are presented in Appendix B.

Potential survey respondents were invited by email; with regard to the CSF survey, we were able to draw on AIDS Action Europe (CSF co-chair) to disseminate the survey and so

[2] This data source has not been referred to in the main report.

enhance the response rate from CSF members [25]. Data collection took place from 6 January to 6 February 2014 for the Think Tank survey (including two sets of reminders to complete the survey) and from 17 January to 7 February 2014 for the CSF survey (including one reminder).

Of the 39 members of the Think Tank (28 from EU Member States and EEA countries, 11 from ENP and candidate countries), 17 responded, representing a response rate of 44 per cent (Western Europe[3]: nine; Central Europe[4]: six; Eastern Europe[5]: two). Of representatives from the 35 NGOs that currently (as at January 2014) form the CSF, 14 responded (40 per cent) (Western Europe: four; Central Europe: four; Eastern Europe: three).

Some respondents did not answer all of the survey questions; consequently, the total number of responses presented in the findings of this evaluation varies for individual questions as we present the results based on all those who answered the survey question. The survey results are presented in Appendix B. Given the limited response rate, the findings from the survey may not be fully consistent with other data sources.

2.2.2. ImpactFinder

To determine the added value of European Union action in the domain of research, a specific survey of PIs, work package leaders and technical scientists of EU-funded research projects in the field of HIV/AIDS was conducted. It was designed to elucidate the diverse range of impacts that might have arisen from the research projects funded by the EC, drawing on the *ImpactFinder* method for identifying research that has contributed to impact, the RAND ARC Impact Scoring System, which was developed by RAND Europe for the Arthritis Research Campaign [26]. The *ImpactFinder* tool is a proven methodology for identifying impactful research and innovative activities across an organisation's investment portfolio. It is a low-burden, efficient and comprehensive way of capturing a broad range of impacts, from economic impacts to social, cultural and scientific impacts. The survey tool was implemented as an online questionnaire and is shown in Appendix E. Data collection using the *ImpactFinder* survey tool was undertaken between 20 January and 12 February 2014, and it included one reminder. A total of 77 PIs, work package leaders and technical scientists of selected FP7 projects were invited to participate (the selection of FP7 projects to be included in the survey is presented in Section 2.4.2). Of these, 30 responded. The EuroCoord survey was completed by 11 respondents, and the microbicides survey was completed by 19 respondents (1 representing AIM-HIV, 1 representing APO-HSV-2/HIV, 1 representing FUTURE-PHARMA, 14 representing CHAARM and 3 representing MOTIF).

[3] West: Andorra, Austria, Belgium, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Israel, Italy, Liechtenstein, Luxembourg, Malta, Monaco, Netherlands, Norway, Portugal, San Marino, Spain, Sweden, Switzerland, United Kingdom.
[4] Centre: Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Czech Republic, Hungary, the former Yugoslav Republic of Macedonia, Montenegro, Poland, Romania, Serbia, Slovakia, Slovenia, Turkey.
[5] East: Armenia, Azerbaijan, Belarus, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Moldova, Russia, Tajikistan, Turkmenistan, Ukraine, Uzbekistan.

2.3. Key informant interviews

A series of key informant interviews were conducted to enhance the evaluation team's understanding of the more salient issues pertaining to the context and the process of implementation of the Communication. The evidence from the interviews informed a range of evaluation questions (see Appendix A), as did the in-depth country case studies (Bulgaria, Latvia, Spain and the United Kingdom) and research case studies (EuroCoord and microbicides development). For interviews carried out as part of the case studies, please see Section 2.4 below.

Interviews were conducted with a range of key informants involved in, or acting as close observers of, the Communication: Think Tank members (in their capacity as representatives of EU national authorities); CSF members (representing civil society); and representatives of the European Commission, related agencies, and international organisations. Key informants for the evaluation (not for the specific case studies) were identified using the following selection criteria:

- **Think Tank members**: Four countries were targeted that were not already presented by CSF members or by country case studies (see below). Recognising the small number of interviews considered, we sought to capture positive experiences (e.g. countries that have implemented innovative approaches to addressing HIV, such as through strong involvement of civil society) or negative experiences (e.g. countries that have recorded recent HIV outbreaks). Two out of the four key informants who were approached by the evaluation team participated in the key informant interviews.
- **CSF members**: The current and former chairpersons of the CSF Secretariat and CSF members from countries that were not already presented by Think Tank members or by country the case studies were targeted. Given the limited number of interviews, we aimed to include countries that showed prominent or less prominent engagement of civil society in addressing HIV/AIDS. Four out of a targeted four key informants participated in the key informant interviews.
- **European Commission services, EU agencies and international organisations:** Interview participants were selected according to their role and their degree of involvement in the implementation of the Communication. All seven key informants who were approached by the evaluation team participated in the key informant interviews.

Interviews were conducted by telephone following a semi-structured topic guide. Topic guides were developed by the evaluation team in consultation with DG SANCO and are presented in Appendix C. In total we conducted 13 interviews with 14 key informants (two representatives from DG SANCO were interviewed together).

Interviews were recorded with the permission of the participants and subsequently paraphrased using a thematic approach, guided by the evaluation questions. Key informants (KI) were numbered consecutively and referenced accordingly as [KI-number] to ensure that individual statements remain unidentifiable.

2.4. Case studies

We conducted two types of case studies: country case studies (n=4) and research case studies (n=2). These contributed to addressing a number of evaluation questions, as described in Appendix A.

2.4.1. Country case studies

Countries for further review were selected on the basis of the following: (i) degree of implementation of comprehensive policies on HIV surveillance, prevention and treatment; (ii) involvement in, and contribution to, research; and (iii) impacts of the global financial crisis on the provision of comprehensive and equitable services for the prevention and treatment of HIV. On this basis, the evaluation team, supported by senior HIV experts, developed a long list of potential countries. Then, in consultation with the project's steering group, the team identified the following countries for review: Bulgaria, Latvia, Spain and the United Kingdom. The reasons for choosing each country are briefly outlined below. It should be noted that the issues identified are not necessarily unique to the countries selected for review, but, rather, that these same issues should be seen as applicable to a range of countries across the European Union.

- **Bulgaria**: selected because it is a beneficiary of the Global Fund. The focus of the case study was to understand how activities to combat HIV were supported by the Global Fund and how sustainable current approaches to funding are.
- **Latvia**: selected because of the impact of the financial crisis on the health system and challenges in relation to providing access to HIV services.
- **Spain:** selected because of documented impacts of the global financial crisis on access to healthcare [27] and because of its recent adoption of a new strategy to combat HIV/AIDS.
- **United Kingdom:** selected because of its advanced HIV policies in terms of surveillance (i.e. the collection of national HIV incidence data) and active participation in research projects on HIV/AIDS.

The country case studies used (i) a targeted document review and (ii) semi-structured interviews with representatives of national authorities, civil society and academia in the four selected countries as described above. In total, eight interviews were conducted: Bulgaria (two), Latvia (two), Spain (three), UK (one). A detailed description of methods used is presented in Appendix D. Key informants were numbered consecutively and referenced accordingly as [country code-KI-number] to ensure that individual statements remain unidentifiable. For example, ES-KI-3 signifies the third key informant from Spain.

Country case reports did not serve as a finding emerging from the evaluation as such; rather, they were used as a data source to address individual evaluation questions. For this reason, the full country case study reports are documented in Appendix D and are referred to in the main body of the report where appropriate and relevant.

2.4.2. Research case studies

We conducted two research case studies to inform EQs 9, 10 and 3. The selection of the research case studies was informed by a review of all HIV-related projects funded under FP7, in consultation with DG SANCO and DG RTD. Following further consultation with the

steering group to the evaluation, the evaluation team focused on two areas of research: HIV progression and the long-term effects of antiretroviral therapy (explored through EuroCoord) and microbicides development.

The reasons for choosing these case studies are briefly outlined below:

- **EuroCoord:** selected because of the perceived success of the project among the evaluation steering group. EuroCoord, a network of HIV/AIDS cohort collaborations, was perceived to be a relatively successful FP7 project because it brought together a large number of organisations and individuals to combat HIV/AIDS in Europe and has resulted in a number of scientific publications.
- **Microbicide development:** selected because of the perceived shortcomings of this line of research among the evaluation steering group. Microbicide development projects were perceived to be relatively less successful because they have not yet resulted in the production of an effective product, despite significant investment into this area of research.

These case studies allowed us to understand the contribution of both the EC and, to some extent, external factors in determining the outcomes of these projects. Data collection involved (i) targeted document review; (ii) a survey of PIs of selected FP7 projects using the *ImpactFinder* tool, detailed above; and (iii) six semi-structured interviews with selected representatives of project coordinators and independent stakeholders from international organisations. The detailed description of the method used and the full case study reports are presented in Appendix E.

Key informants were numbered consecutively and referenced accordingly as [R number-KI-number] to ensure that individual statements remain unidentifiable; for example, R1-KI-1 signifying the first key informant from the first research case study (EuroCoord) and R2-KI-1 signifying the first key informant from the second research case study (microbicide development).

Similar to the country case reports, the research case studies did not serve as a finding emerging from the evaluation as such; rather, they were used as a data source to address individual evaluation questions. For this reason, the full research case study reports are documented in Appendix E and are referred to in the main body of the report where appropriate and relevant.

3. Changes in the HIV epidemic and access to key services

This chapter reports on the key findings on (i) changes in the HIV epidemic across the European region from 2009 to 2013, (ii) changes in access to key services (HIV testing and treatment), (iii) barriers to accessing HIV services, (iv) barriers to the provision of HIV services, and (v) the European added value of the Communication. This chapter primarily seeks to inform EQs 1, 17 and 18 (see Box 3.1) and to contribute to addressing EQ 3. The summary section of the chapter reports on each of the four evaluation questions that were addressed in this chapter.

Box 3.1. Evaluation questions addressed in Chapter 3

Evaluation question 1

To what extent has the Communication contributed to:

(1) Reducing the number of new HIV infections?
(2) Improving access to key services, including early cARV treatment?
(3) Improving quality of life for PLWHIV?

Evaluation question 3

What is the European added value of the Communication?

Evaluation question 17

What are the obstacles for better outcomes in HIV prevention?

Evaluation question 18

What are the problems in implementation of HIV-related policies?

3.1. Changes in the HIV epidemic (EQ 1-1)

One of the overarching objectives of the 2009 Communication was to reduce new HIV infections across all European countries by 2013 [14]. An assessment of the extent to which this objective has been achieved requires an understanding of trends in the incidence of HIV infections. Such an understanding rests on the assumption that a precise measure of new HIV infections exists (i.e. incidence) and that any changes in the number of new HIV infections can be directly attributed to the Communication. However, at present, these assumptions cannot be verified with certainty.

Measuring HIV incidence is crucial for understanding the population-level effect of interventions, but carrying out such an assessment is challenging [28]. Available routine data, including the surveillance data collected by the ECDC [29-33], measure new diagnoses of HIV infection rather than new infections. However, the number of new HIV diagnoses is a

poor proxy for incidence because an HIV diagnosis is the result of two interacting processes: HIV transmission and HIV testing. The number of new HIV diagnoses therefore reflects a combination of both long-standing and recent infections [34]. Where new diagnoses have been used as a proxy for incidence, populations that do not seek testing or that have less access to testing services may be overlooked. Observed changes in the number of new HIV diagnoses thus reflect actual changes in incidence but also changes in the availability and uptake of testing and treatment services [35]. Although trends in new diagnoses remain a key measure of the HIV epidemic, they do not permit a precise assessment of HIV incidence. The lack of suitable tools for the direct measurement of HIV incidence poses a major challenge to any evaluation of the impact of HIV prevention activities [36].

The remainder of this section reports on evidence of change in new infections (HIV incidence) in Europe over the period of interest, with evidence of change in new HIV diagnoses also presented.

3.1.1. Changes in HIV incidence

To date, understanding of trends in new infections rests on estimations, using such approaches as mathematical modelling or a Recent Infection Testing Algorithm (RITA). RITA testing was the subject of a recent systematic literature review by the ECDC [23]. We briefly reflect on both approaches.

Mathematical models

Mathematical models have been used to estimate the incidence of HIV among different population groups, mostly men having sex with men (MSM), in European countries and to assess the trajectories of infection under different scenarios, thereby providing insights into the potential impacts of different policies. For example, Birrell et al. (2013) used a CD4-staged back-calculation method to estimate the incidence of HIV among MSM in England and Wales. They found that neither HIV incidence nor the number of undiagnosed HIV infections had changed between 2001 and 2010, despite an increase in antiretroviral drug uptake from 69 per cent in 2001 to 80 per cent in 2010 [34]. Phillips et al. (2013), using an individual-based simulation model for MSM in the UK, found an increase in HIV incidence between 1990–1997 and 1998–2010, from 0.30 per 100 person-years to 0.45 per 100 person-years [37]. They also estimated the consequences of a range of scenarios on HIV incidence; for example, the authors predicted that the introduction of antiretroviral therapy for all individuals diagnosed with HIV since 2001 would have resulted in a 32 per cent lower incidence rate of HIV among MSM. Van Sighem et al. (2012) used differential equations to describe HIV transmission, progression and the effects of cARV among MSM in Switzerland [38]. They found an increase in HIV transmission from the mid-1990s onward, which they attributed to continuing unsafe sexual behaviour. Similarly to Phillips et al. (2013), Van Sighem et al. (2012) estimated that undiagnosed HIV-positive MSM accounted for around 80 per cent of new HIV infections. McDonald et al. (2012), using a regression model to estimate trends in HIV incidence and prevalence in MSM, people who inject drugs (PWID) and heterosexuals in Scotland, found a reduction in the incidence of HIV among people who inject drugs from before 1995 to the period 2005–2009, but not among MSM [39]. Similar observations were reported for the Netherlands, with van der Knaap et al. (2013) documenting reductions in HIV transmission among PWID [40], while reporting an increase in HIV incidence among MSM [41 42].

Mathematical models, such as those described above and others [43-48], can provide important insights into the dynamics of the HIV epidemic in different population groups over time. Such models could potentially be implemented, using routine surveillance data. For example, the Modes of Transmission (MOT) model was originally developed by UNAIDS to help countries estimate the proportion of new infections that likely occur through key transmission modes [49]. Analyses using the MOT model have been conducted in more than 30 countries, including some in Eastern Europe (Armenia, Belarus, Georgia and Moldova) [50]. The MOT model uses data on the distribution of prevalent infections in a given population and assumptions about patterns of risk behaviours in different groups to calculate the expected distribution of new adult HIV infections. However, the model's usefulness and reliability to inform decisionmaking crucially depend on data quality and availability, and it may not be entirely appropriate for EU Member States because of the type and maturity of the HIV epidemic and the type of surveillance data that are available.

Recent Infection Testing Algorithm (RITA)

Several studies, and a small number of national surveillance systems, employ Recent Infection Testing Algorithm (RITA) tests to estimate HIV incidence. All RITA tests use an immunoassay to detect specific biomarkers in the individual's blood, the presence of which can then be used to determine the likelihood that an infection was recently acquired. In general, a positive RITA test indicates that the infection was likely to have been acquired within the previous six months [23]. Since 2009, Public Health England (formerly the Health Protection Agency) has routinely applied RITA tests to new HIV diagnoses [51]. Results indicated a high level of ongoing transmission among key populations in England, Wales and Northern Ireland, particularly among MSM. The only other country that currently applies RITA to routine case-based surveillance data is France, where RITA has been a component of the national surveillance of HIV since 2003 [52]. Similar techniques have been used to estimate the incidence of HIV in particular regions or within particular subgroups of the population in a number of other European countries [52-57]. However, most of these analyses are limited in scope and have not attempted to estimate the incidence of HIV at the national level. Globally, groups such as the WHO Technical Working Group on HIV Incidence Assays are working towards improving the estimation of HIV incidence using immunoassays [58]. The Working Group set out a framework for progressing with the development, evaluation, validation and comparison of different immunoassay techniques. In Europe, the ECDC has developed a technical guide, which is complementary to the Working Group's report and references the principles outlined in the Working Group's guidelines throughout [23].

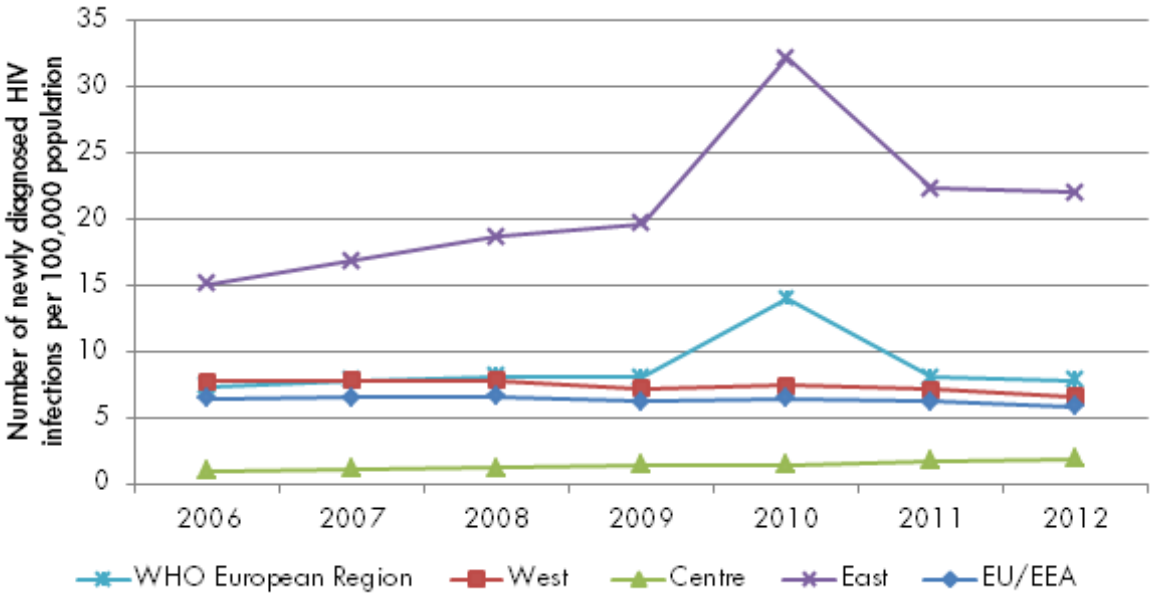
3.1.2. Changes in new diagnoses

Currently, surveillance of HIV incidence is not systematically implemented at the European level. The HIV epidemic in Europe is monitored based on newly diagnosed cases of HIV that are reported to the European Surveillance System (TESSy), which is managed by the ECDC and the WHO Europe Regional Office [59].

The most recent ECDC data on the HIV epidemic in the European region were published in November 2013, reporting on newly diagnosed infections up to the end of 2012 [33]. The data indicate that, following a steady increase from the mid-1980s, the number of newly diagnosed HIV cases in the EU/EEA appears to have reached a plateau from the mid-2000s,

with some indication of a slight decline in the most recent period. Between 2009 and 2012 (the period that overlaps with that covered by this evaluation), the annual number of new diagnoses in the EU/EEA fell by just over 7 per cent, from 30,162 (6.2/100,000 population) to 29,381 (5.8/100,000). These figures are lower than those in the wider WHO European Region, which are primarily driven by the substantially higher rates of new diagnoses in the East,[6] at 22/100,000 in 2012, compared with 1.9/100,000 in the Centre[7] and 6.6/100,000 in the West.[8] It is important to note that not all of the countries in the Centre and East were within the scope of this evaluation; they were, however, included for comparison where data were available.

Figure 3.1. Rates of reported HIV diagnoses by year of diagnosis, WHO European Region, 2006–2012



NOTE: *West* (23 countries): Andorra, Austria, Belgium, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Israel, Italy, Liechtenstein, Luxembourg, Malta, Monaco, Netherlands, Norway, Portugal, San Marino, Spain, Sweden, Switzerland, United Kingdom; *Centre* (15 countries): Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Czech Republic, Hungary, the former Yugoslav Republic of Macedonia, Montenegro, Poland, Romania, Serbia, Slovakia, Slovenia, Turkey; *East* (15 countries): Armenia, Azerbaijan, Belarus, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Moldova, Russia, Tajikistan, Turkmenistan, Ukraine, Uzbekistan

SOURCE: Adapted from ECDC, 2013 [33]

Across the WHO European Region, the most common route of transmission has continued to be through heterosexual contact, but there have been substantial differences at the regional level (Table 3.1) [33]. In the EU/EEA, the most common route of transmission has remained

[6] East: Armenia, Azerbaijan, Belarus, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Moldova, Russia, Tajikistan, Turkmenistan, Ukraine, Uzbekistan.
[7] Centre: Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Czech Republic, Hungary, the former Yugoslav Republic of Macedonia, Montenegro, Poland, Romania, Serbia, Slovakia, Slovenia, Turkey.
[8] West: Andorra, Austria, Belgium, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Israel, Italy, Liechtenstein, Luxembourg, Malta, Monaco, Netherlands, Norway, Portugal, San Marino, Spain, Sweden, Switzerland, United Kingdom.

sexual transmission among MSM, although heterosexual transmission has become increasingly important. Conversely, in the East region, HIV transmission has primarily occurred among PWID and their sexual partners, while sexual transmission among MSM accounted for a small proportion of infections. There are also substantial within-country variations, as illustrated by recent HIV outbreaks among PWID in Greece and Romania [60-62].

Table 3.1. Characteristics of HIV diagnoses by geographical area

	WHO European Region (n=53)		West (n=23)		Centre (n=15)		East (n=15)		EU/EEA (n=31)	
	2009	2012	2009 *	2012	2009 †	2012	2009 ‡	2012	2009	2012
Reporting countries/number of countries		51		23		15		13		30
Number of HIV diagnoses	58,156	55,494	28,479	27,315	2,554	3,715	27,123	24,464	30,162	29,381
Number of diagnoses per 100,000	8.0	7.8	7.2	6.6	1.4	1.9	19.6	22.0	6.2	5.8
Proportion of new diagnoses by transmission mode §										
Heterosexual	42.7	45.6	25||	35.4	24.0	24.6	45.9	60.2	24.0	33.8
MSM	18.1	22.8	36.6	41.7	29.5	26.2	0.6	1.2	35.0	40.4
PWID	22.0	17.8	3.9	5.1	8.0	7.3	39.4	33.6	5.0	6.1
Not known	15.9	12.3	18.1	17	37.2	36.9	12.7	3.2	20.3	18.7

NOTE: *West* (23 countries): Andorra, Austria, Belgium, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Israel, Italy, Liechtenstein, Luxembourg, Malta, Monaco, Netherlands, Norway, Portugal, San Marino, Spain, Sweden, Switzerland, United Kingdom; *Centre* (15 countries): Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Czech Republic, Hungary, the former Yugoslav Republic of Macedonia, Montenegro, Poland, Romania, Serbia, Slovakia, Slovenia, Turkey; *East* (15 countries): Armenia, Azerbaijan, Belarus, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Moldova, Russia, Tajikistan, Turkmenistan, Ukraine, Uzbekistan
* excluding Austria and Monaco; † excluding Turkey; ‡ excluding Russia; § 2009 figures for West and for EU/EEA do not add up to 100 per cent. This is because 2009 figures for all regions exclude cases of unknown age and sex, limiting direct comparability to 2012 data; || excludes individuals originating from countries with generalised epidemic.

SOURCE: Adapted from ECDC, 2013 [33]

As noted in the introduction to this section, it is difficult to interpret trends in new HIV diagnoses, as these reflect a combination of long-standing and recent infections. An increased number of new diagnoses will reflect both a higher number of people testing for HIV as well as a 'true' increase in the number of HIV cases; likewise, a decline in the number of diagnoses will reflect a combination of a reduced number of people testing for HIV and a true decline in the number of HIV cases.

This challenge of interpreting trends in new HIV diagnoses was reflected in the responses to the Think Tank and CSF surveys. While the majority of respondents to the CSF survey thought that the number of new HIV diagnoses has increased between 2009 and 2013 (7 out of 10 respondents), only half of the respondents to the Think Tank survey supported this notion (7 out of 14 respondents). Five respondents from the West region highlighted that new

diagnoses had risen among MSM (three from the Think Tank and two from the CSF) and among some migrant populations (one from Think Tank and two from CSF), including asylum seekers and refugees. Respondents from both the West and Centre regions mostly attributed increases in new diagnoses to increases in HIV testing rates. However, one respondent from the Centre region noted that an observed increase in new diagnoses in the respondent's country was likely to reflect an actual increase in HIV incidence (see Appendix B, Section III).

One respondent stressed that a focus on observable changes in new diagnoses at the aggregate level conceals important changes within certain at-risk groups. This issue was also raised by respondents from many Western European countries, who emphasised the different rates of change in new diagnoses among subgroups of the population (see Appendix B, Section III).

3.2. Changes in access to key services and quality of life of PLWHIV (EQ 1-2 and EQ 1-3)

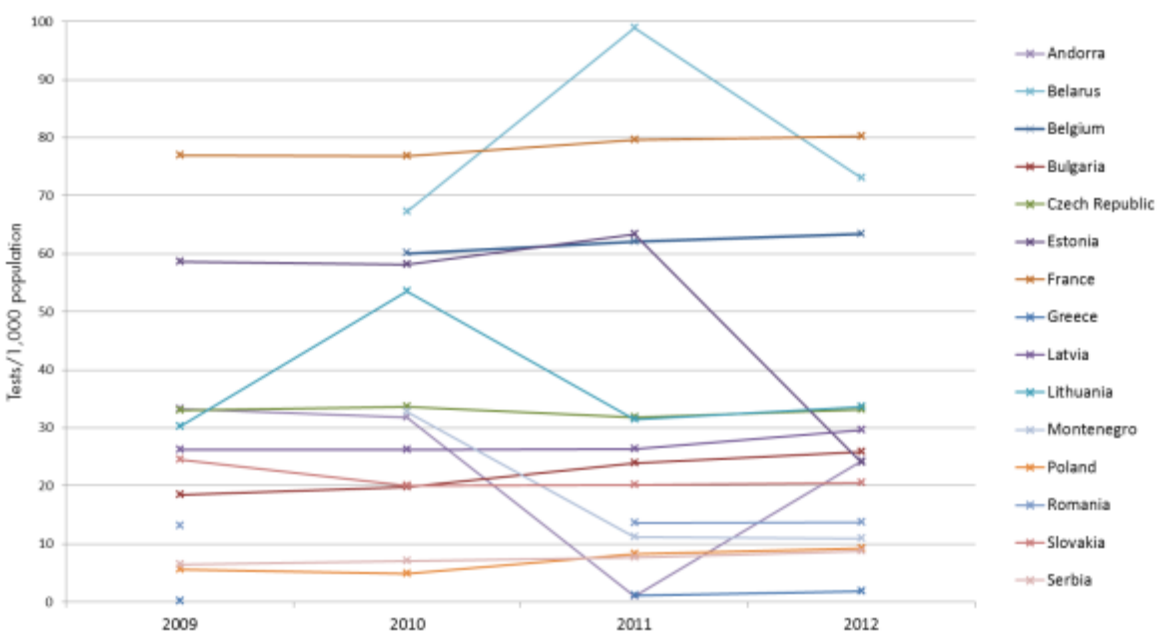
This section reports on changes in access to key services and changes in the quality of life of PLWH. Key services considered are HIV testing and HIV treatment. Because of the absence of systematic data collection on the quality of life of PLWHIV at the European and national levels, we here use changes in access to key services as an indirect measure of quality of life of PLWHIV. Improved access to HIV testing can result in earlier diagnosis, and increased access to HIV treatment can result in improved health outcomes [63]. We address these issues in turn.

3.2.1. HIV testing

It is difficult to establish the annual number of HIV tests performed in European countries and assess trends over time because HIV testing data is not collected on a routine basis. To estimate the number of HIV tests conducted in Europe, the ECDC collates information from a number of sources, including annual activity reports from HIV testing sites, extrapolations from laboratory networks and estimates based on survey results [30]. Among the 23 countries covered by the ECDC reporting system that have consistently reported on the number of tests performed annually, 11 have documented a year-on-year increase since 2006 [33].

During 2009–2012, the number of EU/EEA countries reporting HIV testing data to the ECDC increased from 13 to 14 and the number of tests performed increased from 6,644,422 to 7,907,352 overall [33]. There was variation between countries. For example, in 2009, testing rates ranged from 0.2 per 1,000 population in Greece to 77/1,000 in France. In 2012, the overall testing rate had increased, but it still showed variation, namely, 1.9/1,000,000 in Greece and 80.3/1,000 in France (Figure 3.2) [30 33]. In non-EU/EEA countries of the WHO European Region, the number of countries reporting on HIV testing rose from 9 to 16, but again HIV testing rates varied, ranging, in 2009, from 4.0/1,000 in Georgia to 132.0/1,000 in San Marino and, in 2012, from 1.1/1,000 in Albania to 124.5/1,000 in Kazakhstan [30 33]. As before, the majority of non-EU/EEA countries in are not within the scope of this evaluation and are included for the comparison only [30 33].

Figure 3.2. Number of tests performed per 1,000 population, excluding unlinked anonymous testing and testing of blood donations, EU/EEA and neighbouring countries, 2009–2012



SOURCE: Adapted from ECDC HIV/AIDS Surveillance in Europe report 2009, 2010, 2011 and 2012 [30-33]. Countries are only included if they reported data for three out of the four years.

Changes in access to HIV testing can be illustrated by the country case studies that were carried out as part of this evaluation. For example, available evidence from Bulgaria shows that the scale-up of a network of low-threshold centres (voluntary HIV counselling and testing services, VCT), mobile medical units and NGOs delivered services for the most-at-risk groups (PWID, sex workers, MSM, Roma, prisoners, vulnerable youth), which were financed through the Global Fund–supported programme 'Prevention and Control of HIV/AIDS' (2008–2015). This scale-up resulted in an increase in the number of HIV tests performed among these groups, from 59,626 in 2007 to 95,255 in 2010 (a 70 per cent increase) [64]. This increase in HIV testing in Bulgaria is also reflected in the ECDC surveillance reports, which showed that the number of HIV tests performed in Bulgaria increased from 140,000 (18/1,000 population) in 2009 to 190,000 (25.9/1,000 population) in 2012 [30 33]. Conversely, in Latvia, rates of HIV testing fell between 2009 and 2011, despite an increase in the number of testing sites [65]. One key informant from Latvia noted that HIV testing coverage had remained insufficient: *'[I]n Riga with 10,000 IDUs [injecting drug users] we have three low-threshold centres*' (LV-KI-2). Also, the same key informant believed these centres to be inadequate to address the needs of the population, noting that, for example, the current opening hours of the centres (regular working hours) would be a barrier to accessing HIV testing for PWID.

A complementary measure for understanding access to HIV testing is to consider the number of people who are diagnosed late. Individuals who are diagnosed with a more advanced infection are less likely to benefit from treatment compared with those who start treatment early [66]. Therefore, high and increasing numbers of AIDS cases may be taken as a proxy for late HIV diagnosis, but also for low coverage and delayed initiation of treatment [67]. Where

testing services are operating efficiently and are accessible to at-risk groups, the proportion of new diagnoses that are made late should be low [68].

Late diagnosis can be measured by means of the CD4 cell count at the time of diagnosis (<350 cells/mm^3). The number of EU/EEA countries reporting on late diagnoses increased from 18 in 2009 to 20 in 2012, and the proportion of HIV diagnoses for which a CD4 cell count was available rose to 55.3 per cent during the same period [30 33]. In the remainder of the WHO European Region, the number of countries reporting CD4 cell counts rose from 4 to 10, respectively, but the proportion of HIV diagnoses for which a CD4 cell count was available remained low, at 8.7 per cent (compared with 33.6 per cent for the entire WHO European Region).

In 2012, among those with a CD4 cell count at diagnosis, 49.3 per cent were diagnosed late and 29.6 per cent were diagnosed very late (<200/mm^3), with an advanced stage of infection [33]. The proportion of late presenters was highest among those with heterosexually acquired infection and PWID and lowest for mother-to-child transmission and MSM in both time periods. Considering trends over time, the majority of respondents to the Think Tank and CSF surveys reported that the proportion of people diagnosed late had either decreased (5 out of 14 respondents from the Think Tank; 2 out of 14 respondents from the CSF) or had not changed (6 out of 14 respondents from the Think Tank; 2 out of 14 respondents from the CSF). Among the four respondents who reported that late diagnosis had increased (two respondents from the Centre [Think Tank] and two from the East [CSF survey]), one commented that *'HIV/AIDS is not on the top of public health priorities, there are not enough campaigns, not enough activities targeting medical staff'* (see Appendix B, Section III).

Against this background, most survey respondents considered late diagnosis to constitute a moderate or significant problem in their country or region (16 out of 17 respondents to the Think Tank survey; 8 out of 10 respondents to the CSF survey), and they highlighted particular challenges for specific population groups, such as MSM and PWID. Similar observations are documented in ECDC surveillance reports [29-33]. The 2010 European MSM Internet Survey (EMIS) found that respondents generally reported access to free or affordable HIV testing but that access to HIV testing varied substantially across and within different regions [69].

3.2.2. HIV treatment

Access to treatment for HIV is measured as the number of persons with HIV who are receiving antiretroviral therapy (ART), while ART coverage is estimated by dividing the number of people receiving treatment by the estimated number of people needing treatment (the ECDC distinguishes the number of people 'known to require treatment' from those 'estimated to be in need of ART') [67]. Available data suggests that the number of people with HIV receiving ART has increased across the WHO European Region, from 329,609 in 33 countries in 2010 to 512,134 in 2012 in the same 33 countries [67]. However, there is currently no systematic data collection of the coverage with ART across the WHO European Region. In 2012, of 53 countries in the WHO European Region, only 28 had reported data on ART coverage (16 EU/EEA countries and 12 non-EU/EEA countries), up from 24 countries in 2010 (12 EU/EEA and 12 non-EU/EEA) [67]. These observations are further supported by the 2010 European MSM Internet Survey, with 92 per cent of respondents with a diagnosed HIV infection reporting that they had access to treatment. However, levels of access varied,

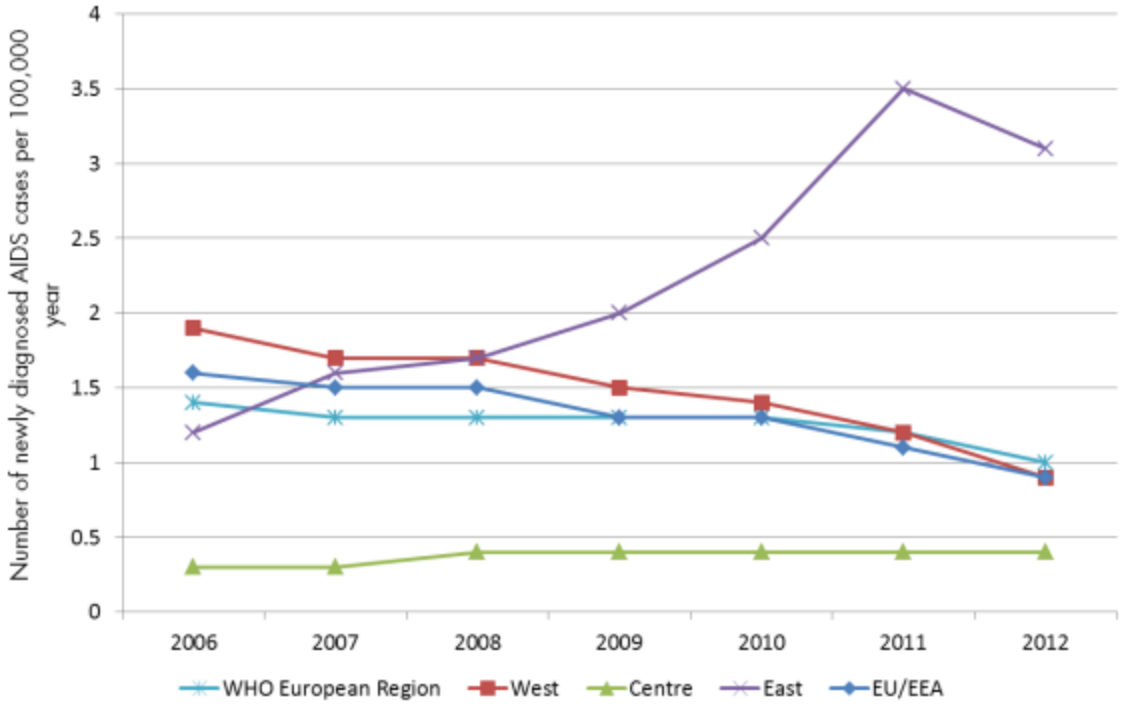
with those from Bulgaria, Cyprus, Romania and Malta as well as those from the Eastern and south-eastern European countries of Belarus, Moldova, Russia and Ukraine reporting lower levels of access to treatment [69].

Among the 18 countries in the WHO European Region for which data on ART coverage were available for both 2010 and 2012, all but three (Romania, the United Kingdom and Tajikistan) recorded an increase in ART coverage between 2010 and 2012 [67]. Reported increases in ART coverage were highest in Central and Eastern Europe. Some countries in these regions saw substantial increases in the number of people receiving ART, for example, Estonia and Lithuania saw a tripling of the numbers between 2010 and 2012. Other countries, such as France, saw only modest increases, in this case of 7 per cent, over the same time period. However, these differences need to be set against the starting point. In France, access to HIV treatment was already high in 2010, and the potential to increase treatment rates further was comparatively smaller than in countries starting with lower access rates [67].

These observations were reflected by respondents to the Think Tank and CSF surveys; the majority reported that the uptake of ART had increased since 2009 (9 out of 15 respondents from the Think Tank; 7 out of 13 respondents from the CSF). Among Think Tank members who noted that there had been no change in uptake (6 out of 15), several highlighted that uptake was already high in their country. Conversely, access to ART had remained a significant concern elsewhere, as reported by 4 out of 16 respondents to the Think Tank survey and 7 out of 14 respondents to the CSF survey (Appendix B, Section III). One key informant stressed that, in the Centre and East regions of the WHO European Region, the scale-up of ART had remained insufficient (KI-13). When considering treatment coverage, it is important to note, as Think Tank and CSF survey respondents highlighted, that increases in treatment coverage followed increases in the number of people diagnosed with HIV, but that this does not necessarily correspond to increased ART coverage in settings were the number of people in need of treatment is unknown (KI-4).

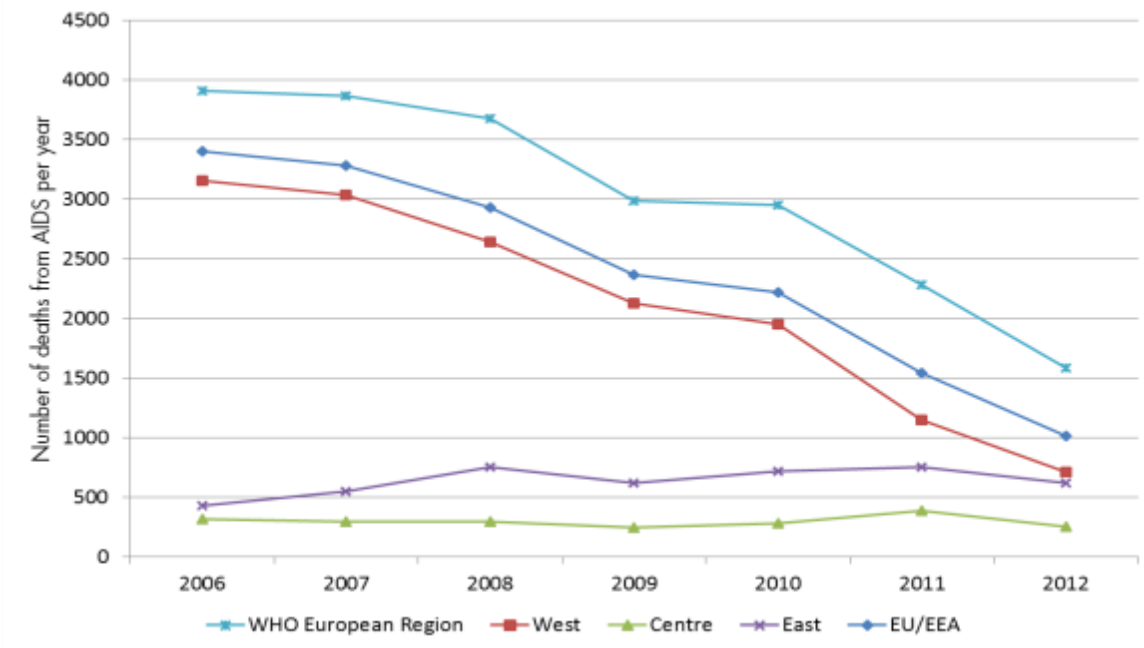
Two indirect measures of access (and adherence) to HIV treatment are the number of newly diagnosed AIDS cases and the number of deaths from AIDS, as noted earlier. Country-specific data show that increases in the number of people receiving ART were accompanied by declines in the number of people newly diagnosed with AIDS and the number of AIDS deaths, across the WHO European Region, over the same time period (Figure 3.3, Figure 3.4) [33]. The total number of newly diagnosed AIDS cases in the EU/EEA decreased from 6,665 (1.3/100,000 population) in 2009 to 4,313 (0.9/100,000) in 2012. But in non-EU/EEA countries, the total number of newly diagnosed AIDS cases increased, from 1,986 (1.1/100,000) in 2009 to 2,148 (1.3/100,000) in 2012 [33]. The number of deaths among people living with AIDS fell from 2,370 in 2009 to 1,017 in 2012 in the EU/EEA and from 625 in 2009 to 466 in 2012 in non-EU/EEA countries. Among EU/EEA countries, the decrease in AIDS cases and deaths was mostly driven by improvements in countries considered part of the West region while little change was seen in either indicator in countries considered part of the Centre region (Figure 3.3, Figure 3.4). Countries in the East region experienced a recent fall in the number of newly diagnosed AIDS cases, following after a steady increase until 2011, while the number of AIDS deaths has seen little change over recent years.

Figure 3.3. Number of newly diagnosed AIDS cases per 100,000 population, WHO European Region, 2006–2012



SOURCE: ECDC, 2013 [33]

Figure 3.4. Number of AIDS deaths, WHO European Region, 2006–2012



NOTE: *West* (23 countries): Andorra, Austria, Belgium, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Israel, Italy, Liechtenstein, Luxembourg, Malta, Monaco, Netherlands, Norway, Portugal, San Marino, Spain, Sweden, Switzerland, United Kingdom; *Centre* (15 countries): Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Czech Republic, Hungary, the former Yugoslav Republic of Macedonia, Montenegro, Poland, Romania, Serbia, Slovakia, Slovenia, Turkey; *East* (15 countries): Armenia, Azerbaijan, Belarus, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Moldova, Russia, Tajikistan, Turkmenistan, Ukraine, Uzbekistan

SOURCE: Adapted from ECDC, 2013 [33]

3.3. Reported barriers to uptake of HIV testing and treatment (EQ 17)

Uptake of HIV testing and treatment is determined by a wide range of factors that can be distinguished into those acting at the individual level, those acting at the provider or organisational level and those acting at the system level [70]. In the following we use this distinction to report on identified barriers to accessing HIV testing and treatment in European countries, focusing on individual- and provider-level factors, while recognising that boundaries are not clear-cut and that the relative importance of a given issue will vary across and within countries.

Individual-level factors

There is a wide range of factors acting at the individual level that can impact on whether and how people at risk will take up HIV testing and treatment options [70]. Examples include perception of being at no or low risk of infection; fear of discrimination and social exclusion; concerns about potential need to disclose status to third parties (life insurance, immigration application, workplace); or inadequate or lack of knowledge of and awareness about HIV prevention, transmission or treatment options, alongside general socio-demographic factors, such as age, gender, ethnicity, income and others.

Available data did not permit directly assessing the impact of the various factors listed, but respondents to the Think Tank and CSF surveys suggested lack of awareness (all 16 respondents to the Think Tank survey and 9 out of 11 respondents to the CSF survey perceived this to be a barrier to some extent), migration status (10 out of 16 respondents to the Think Tank survey and 6 out of 10 respondents to the CSF survey perceived this to be a barrier to some extent) and stigma (15 out of 16 respondents to the Think Tank survey and all of the 15 respondents to the CSF survey) to act as important barriers to take-up of HIV testing.

Migration status was identified as a barrier to uptake of HIV testing in that some groups of migrants may not have access to health insurance or to public health services. This issue was raised by two CSF survey respondents, while two other respondents suggested that migrants' fear that a positive test could influence the possibility of becoming a permanent resident could pose an important barrier for individuals to seek testing in the first place. Some respondents highlighted the particular challenges faced by undocumented migrants in this respect.

One respondent to the Think Tank survey pointed to the role of fear of stigma, rather than stigma itself, in preventing people at risk to take up HIV services. The notion that fear of stigma can act as a barrier is supported by a review by Fakoya et al. (2010), citing two studies set in England that reported that low visibility of HIV and lack of positive imagery increased HIV-related stigma within African communities [71]. The authors suggested that low uptake of HIV testing might result because of fear of isolation and social exclusion in the event of a positive diagnosis.

Other factors that were mentioned as posing a barrier to uptake of HIV testing included criminalisation of transmission (Think Tank: 8 out of 15 respondents perceived it to be a barrier to some extent and 6 out of 15 did not think it to be a barrier at all; CSF: 7 out of 10 respondents perceived it to be a barrier to some extent and 3 out of 10 did not think it to be a barrier at all) and access to treatment (Think Tank: 5 out of 16 respondents perceived it to be

a barrier to some extent and 11out of 16 did not think it to be a barrier at all; CSF: 6 out of 10 respondents perceived it to be a barrier to some extent and 4 out of 10 did not think it to be a barrier at all) (Appendix B, Section III). One respondent noted that access to treatment was unlikely to be a barrier to HIV testing because the '*majority of people do not consider treatment options before testing themselves*'. They attributed low uptake of HIV testing to a potential lack of awareness of the services that are available (KI-3, KI-11, KI-4).

Turning to uptake of HIV treatment, migrant status was again described as an important barrier (12 out of 16 respondents to the Think Tank survey; 7 out of 10 respondents to the CSF survey), as was stigma (12 out of 16 respondents to the Think Tank survey and 9 out of 10 respondents to the CSF survey), and 3 survey respondents noted that only legal migrants had access to HIV treatment in their country.

Respondents to both surveys varied in the extent to which they perceived lack of education (Think Tank: 9 out of 16 perceived it to be a barrier to some extent and 7 out of 16 did not think it to be a barrier at all; CSF: 8 out of 10 respondents perceived it to be a barrier to some extent), criminalisation of transmission (Think Tank: 7 out of 16 respondents perceived it to be a barrier to some extent and 8 out of 16 did not think it to be a barrier at all; CSF: 4 out of 10 perceived it to be a barrier to some extent and 4 out of 10 did not think it to be a barrier at all) and access to treatment (Think Tank: 4 out of 16 respondents perceived it as a barrier to some extent and 12 out of 16 did not think it to be a barrier at all; CSF: 6 out of 10 respondents perceived it to act as a barrier to some extent and 3 out of 10 did not think it to be a barrier at all) to be barriers to the uptake of HIV treatment. One respondent noted that lack of education was unlikely to act as a barrier because '*people who are diagnosed as HIV positive are usually informed on the possibility of treatment*'.

This section has so far focused on barriers to uptake of HIV testing and treatment, which reflects, in part, the design of the data collection instruments employed in this evaluation. These centred on identifying perceived barriers, while views on facilitators were not assessed explicitly, except in country case studies. At the same time, data presented above provide indirect pointers to perceived facilitators, mirroring identified barriers. For example, survey respondents highlighted issues around knowledge about HIV and awareness of HIV services as important barriers to take-up of testing and treatment. The corollary of this would thus be that enhanced knowledge and awareness should act as facilitators to uptake, as was shown in published evidence, such as the systematic review by Kaai et al. (2012). Their review also identified other issues that act as facilitators at the individual level for service uptake, such as a concern about risk, having previously tested for HIV, experiencing illness and having symptoms, having access to public health services, or having contact with people who are HIV-positive or have AIDS [70]. Arguably, not all of these factors lend themselves to translation into policy action to enhance HIV service uptake, but evidence collated here points to the importance of continued efforts to enhance the understanding of and knowledge about HIV among the population, with a particular focus on those at risk, alongside securing access to services for vulnerable groups in particular.

Provider-related factors

Factors acting at the provider level that may affect uptake of HIV testing and treatment services include availability and accessibility of information on HIV testing and treatment

pathways, ability to provide linguistically and culturally acceptable services, the provider–patient relationship and attitudes of health professionals, among others [70].

As reported above, the majority of respondents to the CSF and Think Tank surveys perceived stigma to act as a barrier to the uptake of HIV testing and treatment (12 out of 16 respondents to the Think Tank survey; 9 out of 10 respondents to the CSF survey). Also, as noted above, lack of education of people at risk was perceived by some survey respondents to impact on access to treatment (9 out of 16 respondents to the Think Tank survey and 8 out of 10 respondents to the CSF survey). Three CSF respondents (two from the Centre and one from the East region) noted that affected populations, especially those that are hard to reach, were often not well informed of the purpose, availability or benefits of ART. One respondent placed the responsibility of ensuring awareness of the benefits of ART on healthcare workers who, according to the respondent, often had poor knowledge of HIV themselves.

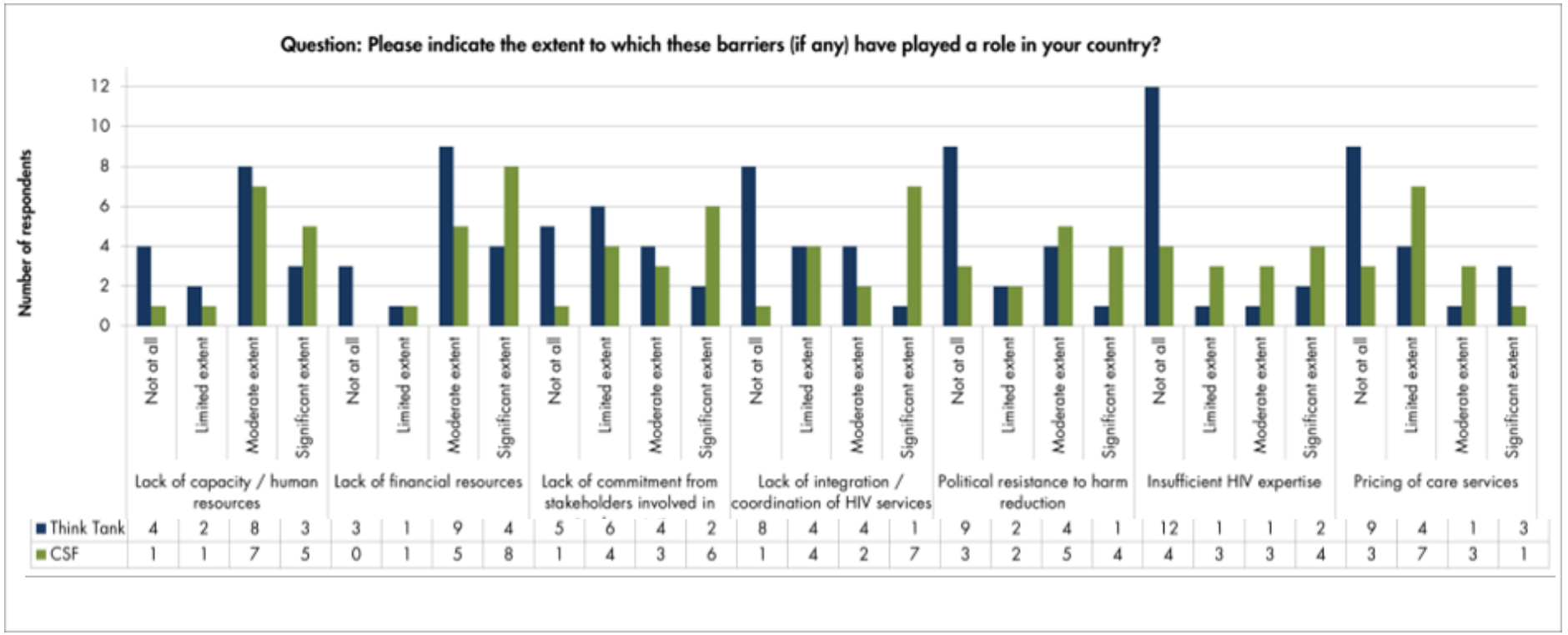
Country case studies undertaken for this evaluation pointed to the key role that NGOs can play in delivering pre-test counselling and social support for at-risk groups and so support uptake of HIV services. One key informant from Latvia believed '*the lack of knowledge and motivation among medical staff*' to be the primary reason for low testing rates in Latvian prisons, even though HIV tests were offered, free of charge, to all inmates (LV-KI-1). Reflecting on the situation of pre-test counselling in Europe more broadly, one other key informant judged pre-test counselling to be inadequate and of poor quality across the European region (KI-3).

As before, there was a tendency among respondents to focus on factors at the provider level acting as barriers to service uptake, although responses point to some important facilitators also. Examples include a perceived need to 'normalise' HIV testing as part of regular health service delivery and the need to make appropriate information and guidance accessible to providers in order to enable delivery of relevant services. These issues were also highlighted in the aforementioned review by Kaai et al. (2012).

3.4. Reported barriers to the implementation of HIV-related policies, activities and programmes (EQ 18)

Think Tank and CSF survey respondents were presented with a range of potential barriers that might impede the implementation of HIV-related policies, activities and programmes in the countries or regions they were working in. These included issues around capacity and human resources, financial resources, commitment from stakeholders involved in implementation, harm reduction, HIV expertise, and pricing of care services. Respondents varied in the weight they placed on each of these perceived barriers, which is further illustrated in Figure 3.5. Each of the identified barriers is discussed below. It is important to note that, given the relatively small number of respondents to either survey, it is difficult to draw conclusive observations regarding the relative importance of identified barriers or, indeed, their applicability across the WHO European Region.

Figure 3.5. Reported extent to which barriers impede the implementation of HIV-related policies, activities and programmes



SOURCE: Think Tank and CSF member surveys

Lack of capacity and human resources

Lack of capacity and human resources was highlighted as an important concern by the majority of Think Tank and CSF survey respondents (Figure 3.5). Examples of its impact were given by respondents from the Centre (two respondents) and East regions (one respondent). For example, one Think Tank respondent noted that lack of human resources would impede the opening of new voluntary counselling and testing facilities in their country, while one CSF survey respondent highlighted that lack of capacity would reduce availability and accessibility of testing and counselling services. One CSF respondent also reported a perceived lack of national oversight in the healthcare sector and on health-related initiatives, which would impede the country's response to HIV. However, as noted above, it is difficult, on the basis of data collected here, to generalise across the European region. For example, respondents from countries located in the West region (four out of five) did not consider lack of capacity as a barrier to implementation.

Lack of financial resources

The majority of survey respondents noted that lack of financial resources posed a moderate or significant barrier to the implementation of HIV-related policies, activities and programmes. One Think Tank survey respondent highlighted the impact of financial constraints as a consequence of the financial crisis ('*the most important barrier is the economic crisis, which creates problems regarding the implementation of the programme*'), while one other respondent noted that lack of financial resources would act as a barrier to establishing new HIV testing and counselling services, to the procurement of testing kits and to the production of information materials. Lack of resources was also reported to impede the provision of harm reduction services, including needle exchange programmes, as suggested by one CSF member, who also reported on instances of stock-outs of ARTs in the region the respondent was working in. Again, it is difficult to generalise from this sample of responses to the European region more broadly, and countries' experiences will differ, as highlighted by country case studies conducted for this evaluation (Box 3.2).

Box 3.2 Impacts of lack of financial resources on implementation of HIV-related policies and programmes in Latvia and Bulgaria

In Latvia, all antiretroviral medicines for the treatment of HIV infection have been included in the list of government reimbursed medicines from 2010 [72]. However, as part of the government's austerity measures in response to the global financial crisis, which affected the health sector more broadly, there has effectively been a freeze in the funding allocated to HIV treatment and care in 2010, raising concerns about the ability to scale up, or even maintain, treatment for those on ART [73]. Specifically, restrictions were placed on the number of PLWHIV provided with ART free of charge, and new treatment guidelines issued in response to the budget constraints stipulated that the threshold for treatment initiation was to be set at a CD4 cell count of 200/mm^3, which is lower than international recommendations (at <350 cells/mm^3) [73]. Some progress has been made since then. For example, efficiency savings achieved on antiretroviral drugs through cost-effectiveness analysis and negotiations with pharmaceutical companies have led to price reductions, based on international comparisons, of between 3 and 49 per cent compared with 2009 [74 75]. However, one key informant from Latvia expressed concern over the long-term sustainability of HIV funding as the number of PLWHIV has continued to increase (LV-KI-1).

The sustainability of financial resources was also a recurring theme that emerged from the Bulgarian case study. In Bulgaria, reliance on financial support through the Global Fund has created concerns about the sustainability of activities launched under the programme Prevention and Control of HIV/AIDS. Key informants voiced concerns

about the ability of the country to support services after financial support provided by the Global Fund comes to an end in 2014 (BG-KI-1, BG-KI-2) (see Section 6.5 and Appendix D for further detail).

Lack of commitment from stakeholders involved in the implementation

Views varied on the role played in the implementation of HIV policies by a perceived lack of commitment from stakeholders, with CSF members tending to rate this factor more frequently as of moderate or significant importance compared with Think Tank members (Figure 3.5). One CSF respondent and one Think Tank respondent suggested that lack of commitment would negatively influence the provision of prevention services ('*the main barrier being lack of commitment from stakeholders threatens implementation of preventive action*'), although one of these respondents equated lack of commitment with lack of funding. In a similar vein, on other CSF respondent noted that there was '*limited interest and structures are missing*'.

Lack of integration or coordination of HIV services

Perceptions on the importance of integration or coordination of HIV services differed among respondents, with CSF members tending to rate this factor more frequently as moderate or significant than did Think Tank Members (Figure 3.5). However, interpretations of 'integration' differed, which some respondents interpreting it as the degree to which public health decisionmaking is centralised at the national level or devolved to different regions within a country. Based on this interpretation, lack of integration can be seen as an impediment towards the implementation of comprehensive and consistent HIV policies at a national level, as was suggested by respondents from two West region countries (see also Box 3.3). Others viewed integration as the extent to which HIV services are linked with other services, such as substance abuse services or services that target other at-risk groups. For example, one CSF respondent suggested that '*lack of integration of HIV and STI [sexually transmitted infection] services is a big barrier to making the most efficient use of healthcare resources.*' This latter point was also raised by key informants interviewed for this study who highlighted a lack of horizontal integration of services as forming a potential barrier to accessing treatment, with available evidence pointing to better outcomes where health services are integrated with, for example, opioid substitution treatment [76 77].

Box 3.3. The role of centralisation of service delivery on implementation of HIV-related policies and programmes in Latvia

A variation of an instance of perceived lack of integration of services was provided by the Latvia country case study. Key informants from Latvia highlighted the challenges of restricting the provision of services to a small number of central providers, which could effectively exclude selected risk groups from accessing services. For example, in Latvia, in 2009, ART was available in two cities only, the capital Riga and the town of Jelgava [67]. By the end of 2011, this number had risen to 10 cities, suggesting that access to ART has substantially increased, although uptake of treatment services has remained slow. One key informant highlighted the role of international organisations, including the European Commission, in supporting the roll-out of services across the region (KI-13). For example, in Latvia, country visits by the ECDC and the United Nations Office on Drugs and Crime were seen to be '*vital*' in encouraging the government to roll out the provision of ART treatment across the country (LV-KI-1). This was seen to have led to improved accessibility for the most at-risk groups, although treatment coverage was still perceived to be not sufficient (KI-13).

Political resistance to harm reduction

Political resistance to harm reduction was more frequently perceived to be a barrier by CSF respondents than Think Tank respondents. However, respondents who considered political resistance to constitute an impediment tended to not provide any further detail as to the nature and impacts of this issue. Only one CSF respondent noting further detail, namely, that there was resistance to incorporate new prevention tools. Overall, it is difficult to generalise from this observation to the role of political resistance to harm reduction in the context of HIV policies and programmes, although we note that attitudes towards harm reduction more generally have posed challenges elsewhere [78]. The 2013 report on the 2003 Council Recommendation on the prevention and reduction of health-related harm associated with drug dependence highlighted that coverage of harm reduction measures has increased in most EU and candidate countries [79]. However, it also noted that further improvements would be required, including coverage of needle exchange programmes, surveillance and treatment of hepatitis C infection, hepatitis B vaccination, outreach, and peer and family support.

Insufficient HIV expertise

Although the majority of CSF respondents considered insufficient HIV expertise to pose a barrier to the implementation of HIV-related policies, activities and programmes, the nature and scope of what constitutes 'insufficient expertise' was not explained further by the respondents. The majority of Think Tank respondents did not perceive this to pose a barrier.

Pricing of care services

Pricing of care services was reported to pose a significant barrier by only a small number of respondents to either survey. It is difficult to interpret this observation vis-à-vis reported issues around availability of financial resources, as discussed above (Figure 3.5). However, one Think Tank respondent highlighted that the pricing of anonymous HIV (and STI) testing continues to cause concern in that it poses '*a barrier to implement all the official recommendations (e.g. MSM with a high rate of new sexual partners should test themselves at least twice-yearly for HIV and the most prevalent STIs, but the costs are an effective barrier dissuading people to do so)*'. In addition, key informants interviewed for the evaluation further highlighted the costs associated with ART, which were considered to be too high in the countries or regions they worked in to ensure sufficient coverage, particularly in the Centre and East parts of the WHO European Region (KI-10, KI-12, KI-8, and KI-3).

Other factors

A small number of respondents to the Think Tank and CSF surveys (four) also mentioned that legislative, regulatory and policy obstacles act as significant barriers to the implementation of HIV policies, referring specifically to legal stipulations or policies that exclude certain at-risk populations from accessing HIV services. Examples of such legal restrictions to accessing HIV services were raised in relation to undocumented migrants and other at-risk groups, such as sex workers, with one Think Tank member observing that '*ineffective anti-discrimination laws still impede people living with HIV to come forward as soon as possible. Sub-optimal implementation of the health insurance coverage still leads to the fact that around 80 per cent of undocumented migrants do not have health insurance coverage, and thus no guaranteed access to HIV testing and treatment*'. Indeed, evidence

from a recent survey of HIV testing policies for migrants and ethnic minorities in EEA countries found that, while many countries were aware of the benefits of HIV testing in migrants and ethnic minorities, variation in provision of universal HIV prevention, treatment and care for migrants of uncertain legal status constituted an important deterrent for the control of HIV in the region [80].

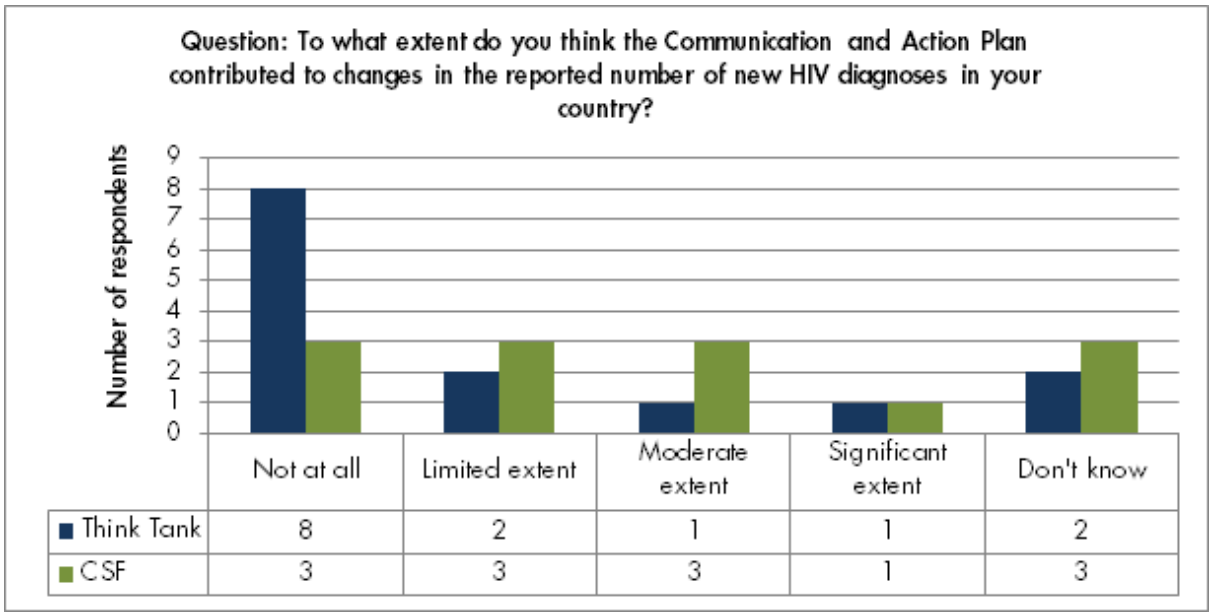
3.5. European added value (EQ 3)

Before discussing the European added value of the 2009 Communication and its Action Plan in relation to changes in the HIV epidemic and access to key services from 2009 to 2013 as assessed in the evaluation, it is important to note that it is the responsibility of individual EU Member States to develop and implement national responses to HIV/AIDS. Therefore, the Communication and its accompanying Action Plan will only have an indirect impact on the dynamics of the HIV epidemic through their influence on Member States' policies and priorities and through the Member States' contribution to funding for HIV (e.g. contributions to the Global Fund, HIV research funding, FP7 activities). This section focuses on the contribution of the Communication and its Action Plan to national HIV policy development and implementation. The contribution of the Communication and its Action Plan to the funding of HIV-related activities is discussed in Chapter 6.

3.5.1. Changes in the HIV epidemic

Reflecting on the extent to which observed changes in new diagnoses, where these occurred, can be associated with the 2009 Communication and its Action Plan, most respondents to the Think Tank survey (8 out of 14) did not believe there to be a direct correlation (Figure 3.6). Respondents to the CSF survey (n=14) contributed varied reflections on the degree to which the Communication and its Action Plan might have contributed to changes in new diagnoses across Europe. Three respondents each believed that the Communication and its Action Plan either did not have an impact (n=3), had a limited impact (n=3), or had a moderate impact (n=3). Only one respondent noted a significant impact (Appendix B, Section III). Among those who believed that the Communication and its Action Plan have had an impact, the most commonly reported reason given was the Communication and Action Plan's focus on at-risk groups and their ability to generate political support for HIV services. This view was also shared by key informants (UK-KI-1, KI-3, KI-7).

Figure 3.6. Perceptions of Think Tank and CSF members of the Communication's contribution to changes in new HIV diagnoses



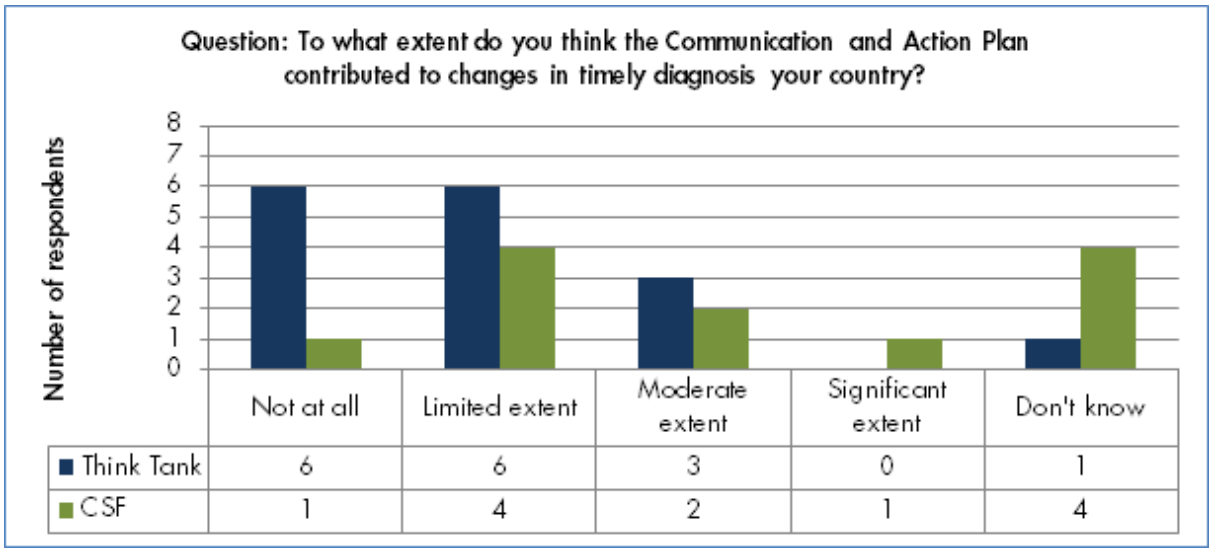
SOURCE: Think Tank and CSF member surveys

3.5.2. Changes in access to key services

Testing services

Considering the contribution of the Communication and its Action Plan to observed trends in HIV testing across countries in Europe, there appeared to be consensus among the respondents to the Think Tank and CSF surveys that the Communication and its Action Plan had little impact, if any, on HIV testing (Think Tank: 6 out of 15 no impact; 6 out of 15 limited impact, 2 out of 15 moderate impact; CSF: 1 out of 12 no impact, 4 out of 12 limited impact, 2 out of 12 moderate impact, 4 out of 12 not known) (Appendix B, Section III).

Figure 3.7. Perceptions of Think Tank and CSF members of the Communication's contribution to timely diagnosis

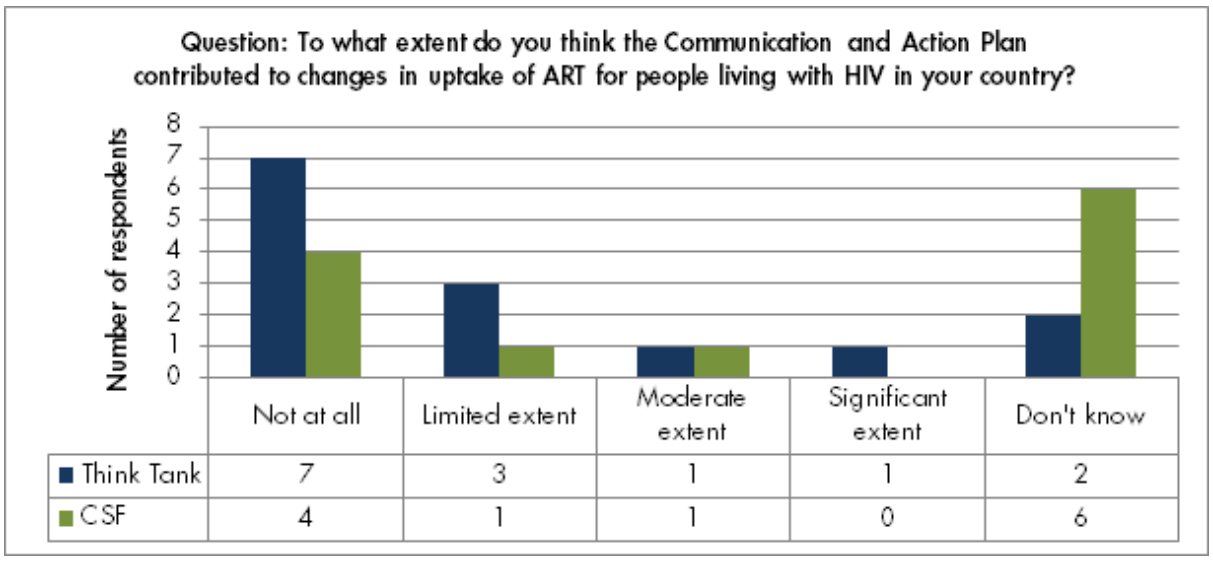


SOURCE: Think Tank and CSF member surveys

Treatment services

Most respondents to the Think Tank survey (7 out of 14) did not consider the Communication and Action Plan to have contributed to changes in the uptake of ART, while the majority of CSF respondents (6 out of 12) stated that they were unaware of any contribution of the Communication and its Action Plan to changes in the uptake of ART (Figure 3.8).

Figure 3.8. Perceptions of Think Tank and CSF members of the Communication's contribution to the uptake of ART



SOURCE: Think Tank and CSF member surveys

3.6. Summary

In this chapter we sought to understand (i) the extent to which the 2009 Communication and its Action Plan have contributed to reducing the number of new HIV infections, improving access to key services, including early cARV treatment, and improving quality of life for PLWHIV; (ii) the obstacles for better outcomes in HIV prevention; (iii) the problems in implementation of HIV-related policies; and (iv) the European added value of the Communication in relation to changes in the HIV epidemic and access to key services from 2009 to 2013. Findings reported in this chapter can be summarised as follows.

Changes in the HIV epidemic

It is difficult, on the basis of available data, to provide firm conclusions on changes in the HIV epidemic in the WHO European Region during 2009–2013. Surveillance of HIV incidence is not systematically implemented at the European level, and only two countries are currently able to provide estimates for HIV incidence at the national level through the use of Recent Infection Testing Algorithm (RITA) tests as part of their national surveillance systems. Instead, current approaches to HIV surveillance in Europe rely primarily on proxy measures of incidence, such as the reporting of new diagnoses of HIV (and AIDS) cases, and on documenting the numbers of those accessing HIV-related treatment and care services. However new diagnoses are a poor proxy for new infections, as they will include both recently acquired and long-standing infections. An observed change in the number of newly diagnosed cases will thus reflect a change in HIV transmission (i.e. new infection) or a change in testing of undiagnosed infections, or both.

Available data on newly diagnosed infections suggest that across the EU/EEA region the rate has decreased from 6.2 per 100,000 population in 2009 to 5.8 per 100,000 in 2012, a decline of 7 per cent. The rate of new diagnoses remained highest in the eastern part of the WHO European Region (as classified according to WHO criteria) and lowest in the central part. The most common routes of transmission in the EU/EEA continued to be through MSM, although heterosexual contact has become more important, while in the East region transmission tends to occur among PWID and their sexual partners. However, data presented at the regional level conceal important differences between and within countries in the dynamics of the HIV epidemic.

In order to arrive at a better understanding of the HIV epidemic in the European region, it will be important to implement surveillance of HIV incidence more systematically. The ECDC has developed a framework and technical guidance for coordinating and strengthening HIV incidence surveillance activities across European Member States through the integration of RITA as part of routine HIV surveillance. Such an approach would provide insights into current transmission patterns and dynamics of HIV infection within and across countries and thereby better inform HIV prevention and health promotion efforts, in particular with regard to targeted interventions for those most at risk.

Changes in access to key services

Data on the number of HIV tests performed are not collected on a routine basis across the region, and data reported by the ECDC are based on estimates compiled from a number of sources, which are only available for about half of the EU/EEA countries. Data that are available suggest an increase in the number of tests performed in the EU/EEA during 2009–

2012, but there was considerable variation among countries. Thus, in 2009 the rate of HIV testing ranged from 0.2 per 1,000 population in Greece to 77/1,000 in France, and while aggregate rates increased overall, differences between countries remained.

Access to and uptake of HIV testing can be inferred from the proportion of those diagnosed who presented late, as measured by CD4 cell count at the time of diagnosis (<350 cells/mm^3). ECDC data indicate an increase in the proportion of HIV diagnoses for which a CD4 cell count was available during 2009–2012, to 55 per cent among EU/EEA countries. Of these, about 50 per cent were diagnosed late, including just under 30 per cent who were diagnosed at an advanced stage of infection. This points to persisting problems in access to and uptake of HIV testing and counselling, in particular among those groups where late presentation was most frequent, such as those who had acquired the infection through heterosexual contact and PWID. Key informants and survey respondents reported that reductions in late diagnosis had been achieved in those countries where services have been set up to target specific at-risk groups.

Considering access to ART and ART coverage, again there is little systematic data collection at the European level. Access to treatment for HIV as measured by the number of persons with HIV receiving ART has increased across the WHO European Region since 2009, in particular in countries in the Centre and East regions. However, an increase in the number of people receiving ART does not necessarily equate to an increase in ART coverage, with the latter taking into account the number of those known or estimated to require treatment. As noted by key informants, it is difficult to know whether the increase in the number of people receiving ART reflects an increase in treatment coverage or is a result of the increase in the number of those newly diagnosed with HIV.

Access to treatment can also be inferred from the number of AIDS cases and deaths, and an observed decline in the rate of newly diagnosed AIDS cases in EU/EEA countries, from 1.3/100,000 in 2009 to 0.9/100,000 in 2012, suggests improved access to treatment. Conversely, non-EU/EEA counties saw an increase in the number of recorded new AIDS cases during the same period (from 1.1/100,000 to 1.3/100,000), mostly driven by a rise in cases in the eastern part of the WHO European Region which only reversed in 2011. This illustrates that although improvements in access to treatment have been achieved, ensuring adequate ART coverage remains a concern.

Reported barriers to uptake of HIV testing and treatment

Drawing on a combination of surveys among Think Tank members and members of the CSF, key informant interviews and in-depth country reviews, we identified a range of factors that were perceived to act as barriers to the accessing of HIV services. Factors that were described to act mostly at the individual level include lack of awareness and knowledge of HIV, such as understanding of the risks of acquiring HIV and risk perception, and awareness about the availability of testing and counselling options and treatment; entitlement status, an issue of particular relevance for migrants, in particular undocumented migrants; and (perceived) stigma, such as fear of isolation and social exclusion in case of a positive diagnosis.

Factors identified to act largely at the provider level include an identified need to 'normalise' HIV testing (and treatment) as part of regular health service delivery and the need to make accessible appropriate information and guidance to providers in order to enable delivery of appropriate services; attitudes and motivations of healthcare staff and the wider system to

ensure provision of appropriate services for hard-to reach groups in particular; and the provision of counselling and support to facilitate access to and uptake of services by those at risk.

Barriers to implementing HIV-related policies, activities and programmes

Think Tank and CSF members who responded to the surveys placed different weights of importance on a range of pre-identified barriers to the implementation of HIV-related policies, activities and programmes. The majority highlighted lack of resources, both human and financial, to be among the key obstacles, while views on the relevance of political commitment and resistance to harm reductions were more mixed. Lack of capacity (and oversight) was cited as a particular challenge in the central and eastern parts of the European region, impeding the scale-up of HIV services, with lack of financial resources acting as a key driver of shortages, not only in relation to human resources but also in relation to service infrastructure and equipment, with concerns about the long-term sustainability of HIV services where the number of PLWHIV is rising. Other barriers that were cited included legislative, regulatory and policy issues more broadly, mainly those that exclude certain at-risk populations from accessing HIV services, which were linked to ineffective anti-discrimination laws and suboptimal service coverage provisions and which were seen to affect undocumented migrants in particular.

European added value

In general, key informants and respondents to the Think Tank and CSF survey did not consider the Communication to have had an impact on the observed changes to the HIV epidemic and access to key services. The contribution was considered to be largely indirect, through focus of the Communication and its Action Plan on the most at-risk groups and their ability to generate political support for the provision of services and interventions for these groups.

4. Role and impact of the Civil Society Forum

This chapter reports on the findings regarding the performance and efficiency of the HIV/AIDS Civil Society Forum (CSF). The findings presented here address four evaluation questions, concerning (i) the impacts of the CSF activities (EQ 6); (ii) the effectiveness of the CSF communication (EQ 7); (iii) the financial resources of the CSF (EQ 8); and (iv) the European added value (EQ 3) (Box 4.1). We conclude the chapter with a summary of the findings.

Box 4.1. Evaluation questions addressed in Chapter 4

Evaluation question 3

What is the European added value of the Communication?

Evaluation question 6

To what extent has the Civil Society Forum contributed to:

(1) the development of programmes to address stigma and discrimination?
(2) improving access of key populations to important HIV-related services and prevention programmes?
(3) the monitoring of new infections?
(4) the development and implementation of national/regional HIV/AIDS policies?

Evaluation question 7

How effective was the CSF in providing interested parties, including NGOs and the Think Tank, with relevant information on HIV/AIDS issues and policies?

Evaluation question 8

Are the resources allocated to the CSF commensurate with its objectives or needs?

According to the Commission Communication 'Combating HIV/AIDS in the European Union and the neighbouring countries, 2009–2013' [14], the CSF was established in 2005 by the EC. Its mandate or role was not formally defined by means of an official document or terms of reference. Indeed, the 'Call for the expression of interest to become a member of the EU HIV/AIDS Civil Society Forum' [81] issued by DG SANCO stated that the forum is '*not a formal structure within the Commission*'. It describes the forum's role as including the following: identifying issues that are of relevance to the HIV/AIDS Think Tank and the European Commission services; providing advice, in particular regarding the implementation of the EU HIV/AIDS policy; and serving as an exchange platform for civil society organisations.

The following provides a brief summary overview of the CSF's structure, which is based on information provided by CSF representatives and a review of the call for the expression of interest to become a member of the CSF [81]:

(1) **The CSF coordination team**: in charge of the operational management of the forum's activities. Its main tasks are to facilitate the meetings of the CSF (i.e. preparation of the agendas, identification and invitation of speakers, co-chairing, etc.), to draft and finalise

the reports of the CSF meetings and to follow up on action points agreed by the CSF during and in between meetings. The CSF coordination team is composed of four people: one co-chair and one coordinator from AIDS Action Europe[9] (AAE), and one co-chair and one policy officer from the European Aids Treatment Group (EATG).

(2) **The members of the forum**: membership of the CSF is open to national civil society organisations (NGOs) and regional or national networks in EU Member States, candidate and accession countries, EEA countries, and selected countries belonging to the ENP area. The number of members is limited to 40 organisations, of which at least five must be from the Russian Federation and the European neighbourhood countries. The CSF includes organisations working with or representing key populations and/or involving PLWHIV in their activities. The CSF members are selected for a three-year period and act as focal points to (i) keep the relevant stakeholders from their countries informed about the CSF activities and (ii) share information regarding the HIV situation in their countries with other CSF members.

4.1. CSF contributions to the development of HIV/AIDS services, programmes and policies at the national level (EQ 6)

This section reports on the CSF contributions to the development of HIV/AIDS services, programmes and policies in line with four aspects as described in Box 4.1: (i) the development of programmes to address stigma and discrimination; (ii) the improvement of access by key populations to important HIV-related services and prevention programmes; (iii) the monitoring of new infections; and (iv) the development and implementation of national or regional HIV/AIDS policies and plans.

Before presenting our findings, we feel it is worth noting, based on an assessment of the multiple sources of information collected for this evaluation (including CSF's meetings reports [82], key informant interviews and Think Tank and CSF surveys), that:

(i) CSF actions and activities carried out during 2009–2013 were diverse and included the organisation of and the participation in meetings with, for example, representatives of national competent authorities and of European institutions; the attendance and delivery of presentations at conferences; the development and adoption of written positions (papers, letters, statements, etc.) informing members of the European Parliament, EU Commissioners, EC services and national authorities.

(ii) While CSF activities concerned the aspects of EQ 6 as described above, the forum paid particular attention to aspects of discrimination and stigma and to the uptake of HIV/AIDS services by key populations.

(iii) Views on the contribution of the CSF varied by stakeholder groups, with the majority of key informants and CSF survey respondents typically providing more favourable perceptions compared with respondents to Think Tank survey. It is conceivable that views expressed by the CSF survey may be biased due to the vested interests they have in the forum's activities and due to the role they play in delivering the CSF's outputs.

[9] NGO partnership on HIV/AIDS in Europe and Central Asia

(iv) In this context it is important to reiterate that caution is required when considering survey respondents in particular. As we have noted in preceding chapters, response rates to the Think Tank and CSF surveys were only around 40–44 per cent, and it is therefore difficult to generalise from responses provided; they cannot be taken to represent the views of all Think Tank or all CSF members.

(v) It was difficult to establish a direct causal link between the CSF activities and observed changes in HIV policies. This is because factors other than the CSF contribute to the policy process, and these might have a greater influence than the CSF, although arguably the CSF was thought to succeed in well representing the interests of civil society.

(vi) There are examples of successful CSF contributions to changes at the national level as reported by several CSF survey respondents and some Think Tank survey respondents, most frequently relating to issues around stigma and discrimination and the uptake of key services by MSM and PWID.

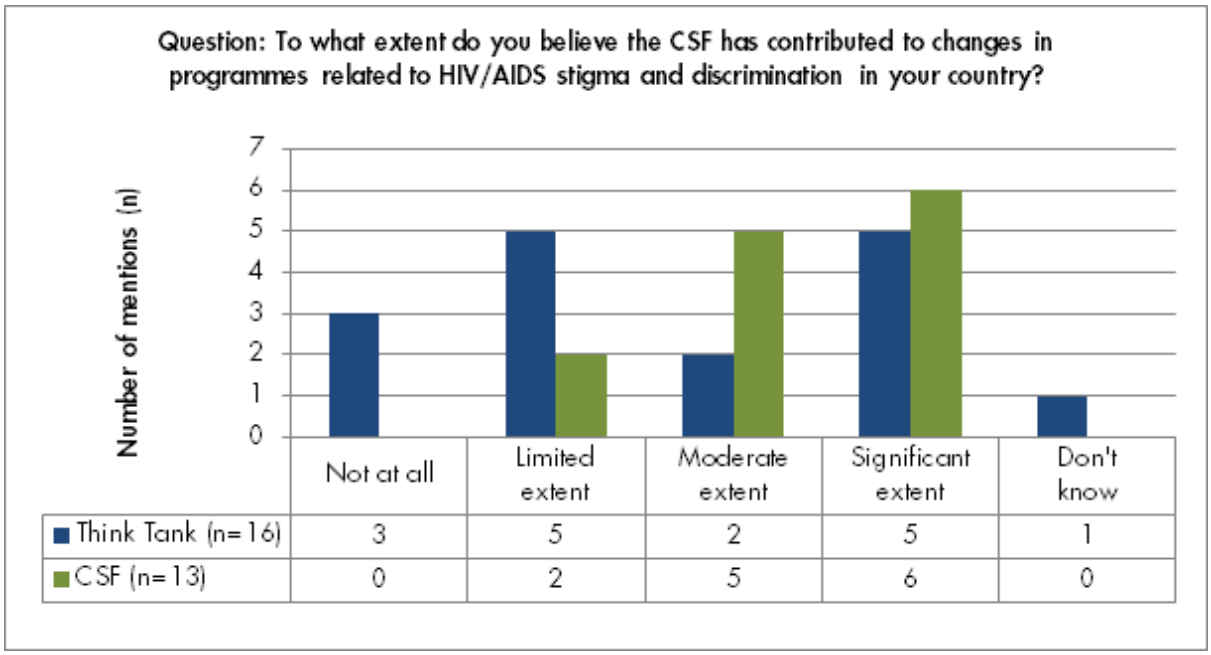
4.1.1. Development of programmes to address stigma and discrimination (EQ 6-1)

Based on the minutes and the reports drafted by the CSF following its biannual meetings, the evaluation team noted that stigma and discrimination formed a continuous agenda item throughout the period 2009–2013.

Two key informants (KI-8 and KI-10) mentioned that they perceived the CSF as the guardian of the rights to health and to a decent life of infected or at-risk people, and seven key informants (KI-1, KI-4, KI-5, KI-6, KI-9, KI-10 and KI-11) believed that the forum had been so far effective in warning and advocating at the EU and national level against discrimination. For example, one key informant reported that the informant's organisation had invited a CSF spokesperson to a meeting with representatives from European countries as a means to include the civil society's concerns and perspective regarding stigma and discrimination into the discussions, to show to the countries the legitimacy given by the EC to the civil society, and to illustrate the role it could play at their national level (KI-5). Two key informants highlighted the different mobilisation actions taken by the CSF in response to criminalisation and compulsory testing of sex workers in Greece (KI-3, KI-9) while two survey respondents (one Think Tank and one CSF member) considered as successful achievement by the CSF in raising their awareness of developments in other countries and in alerting the EC of discriminatory national situations.

Figure 4.1 illustrates perceptions of Think Tank and CSF members of the contributions of the CSF to changes in national programmes related to HIV/AIDS stigma and discrimination.

Figure 4.1. Perceptions of Think Tank and CSF members of the contributions of the CSF to changes in national programmes related to HIV/AIDS stigma and discrimination



SOURCE: Think Tank and CSF member surveys

Out of 13 CSF survey respondents, 5 gave examples of impacts of the CSF activities in the countries. For example, one CSF respondent highlighted that '*our national partners in health have incorporated a vast number of positive practices found at each CSF meeting into their organisational culture and strategic plans, which in turn were reflected in the field during implementation of the activities*'. One other respondent noted that '*CSF's support (and especially the advocacy letters) was crucial during our advocacy campaign against the draft national homophobic laws which were adopted by our national parliament in first reading in October–December 2012. After the advocacy letters of the CSF were sent to our President, the Heads of Parliament Factions, the Commissioner on Human Rights, and the Head of Parliament Committee on Freedom of Speech and Information, these draft laws had never been taken in consideration by Parliament again*'.

Among the 12 Think Tank respondents who indicated some changes that can be attributed to CSF action, none provided illustrations of successful contributions of the CSF within their country.

4.1.2. Improving access of key populations to important HIV-related services and prevention programmes (EQ 6-2)

Key populations as defined in the EC Communication and Action Plan as the priority groups (most at-risk populations) include men having sex with men, people who inject drugs and migrants.

Several CSF members who we consulted by email highlighted the differences in the 'strength' of various civil society actors across Europe, reflecting the key populations primarily affected by HIV. Thus, as shown in Chapter 3 of this report, in countries that have recently joined the

EU, the main population group primarily affected by HIV is PWID, while in many Western European countries, the key population has remained MSM. CSF members highlighted that MSM have traditionally been represented by very vocal action groups, ensuring that HIV has remained on the political agenda. Conversely, in the eastern part of the European region, civil society advocacy is as not strongly developed [83]. While this is, in part, due to historical reasons and because HIV became an issue of concern later than in Western Europe, CSF members also suggested that PWID may be more vulnerable and less organised than MSM. In addition to lacking the 'know-how' and skills to engage successfully in advocacy initiatives, PWID may thus also be less able to secure funding.

Another aspect that was raised was a perceived 'generational gap' in the level of activism of civil society associations. For example, it was noted that the willingness to engage in advocacy may be lower for younger than for older MSM, partly because MSM has become more accepted in society more generally. This has implications for the degree to which the interests of MSM are being advocated, although several CSF members believed that events such as Gay Pride or gay rights violation continue to generate considerable interests or reaction from younger representatives of MSM.

Several CSF and Think Tank members surveyed have commented on the CSF's contribution to bringing about change in the access of key populations to testing and treatment services. It should be noted, however, that views diverged between Think Tank and CSF members, and the former appeared to have a tendency to rate the CSF as less influential than do the CSF members:

- Of 28 CSF and Think Tank respondents, 16 believed that the CSF has brought changes in access to testing and treatment services for both MSM and PWID
- In addition, 14 CSF and Think respondents thought that the CSF had also contributed to some changes for migrants' access to HIV testing, and 11 highlighted changes regarding access to HIV treatment that was attributed to the CSF.

Five key informants (KI-5, KI-7, KI-8, KI-9, and KI-11), one Think Tank and six CSF respondents reported CSF actions such as the presentation of projects, the sharing of experiences and of innovative approaches and the dissemination of good practices within countries to be highly valued. In particular, these activities were seen to provide insights and motivation for implementing new approaches or initiatives. It was felt that through the collection of information from community-based organisations, and through sharing this information with all the relevant players, the CSF would help empower national stakeholders to advocate for the implementation of HIV testing and treatment services. For example, one CSF respondent underlined that '*the information received through CSF supported us in intensifying our harm reduction efforts and in advocating more successfully for services for this group*', while one key informant noted that '*CSF offers a good opportunity to share experience between countries; it is useful for customising national actions. These last years, treatments in our country were out of stock, we have informed the CSF members who have put pressure on governments, which was useful even if it did not change the whole situation*' (KI-8).

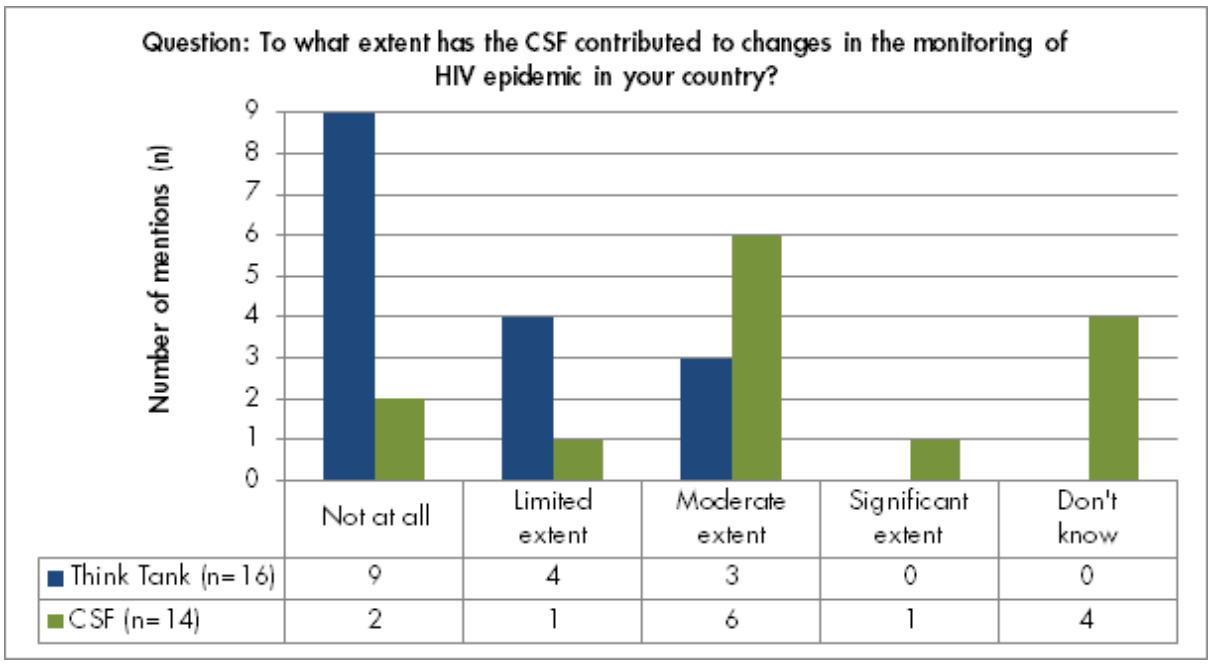
4.1.3. Monitoring new infections (EQ 6-3)

The difficulties related to monitoring of new infections have been discussed in Chapter 3. For the purpose of this evaluation question, we inquired about the role of the CSF in monitoring the HIV epidemic more broadly than just focusing on new infections.

Whenever relevant, the CSF raised surveillance of the HIV epidemic at its own meetings, as documented in meeting reports, although the subject may have been given somewhat less attention than the problem of stigma and discrimination and of universal access to key services.

Figure 4.2 shows perceptions of CSF and Think Tank respondents of CSF contributions to the monitoring of the HIV epidemic at the national level.

Figure 4.2. Perceptions of Think Tank and CSF members of contributions of the CSF to the monitoring of the HIV epidemic at the national level



SOURCE: Think Tank and CSF member surveys

While divergent between Think Tank and CSF members, the overarching view of respondents pointed to a limited (or lack of) contribution, which is reflective of the fact that monitoring and surveillance activities are not the main objective of the CSF. This was also confirmed by one key informant (KI-9) and three Think Tank survey respondents: '*The CSF doesn't influence national monitoring authorities because it is not their job to do so. This is the role of ECDC! Members of the CSF are included in Monitoring Activities of the ECDC. This is very useful and they give valuable input*'. '*By the way, I see the role of CSF rather not in the monitoring. For this there are specialised agencies inside the country*'.

At the same time it is important to emphasise that the CSF co-chairs are invited to attend the surveillance meetings of the ECDC and are also members of the Dublin Monitoring Group. Three key informants (KI-1, KI-5 and KI-9) thought that the CSF was a key partner in the

discussions about surveillance activities at the EU level, and that its views and suggestions were heard and welcomed. As an example, one key informant believed that the CSF had contributed to improve surveillance in individual countries by raising awareness of the need to collect CD4 cell counts at the country level, which is an essential surveillance indicator (KI-5).

Finally, another way to contribute to the monitoring of new infections is to involve CSF members in EU-funded initiatives. This can be illustrated by SIALON II – a capacity-building project funded by the Health Programme that aims at carrying out and promoting combined and targeted prevention complemented by meaningful surveillance among MSM – in which CSF members participate.

4.1.4. Development and implementation of national or regional HIV/AIDS policies (EQ 6-4)

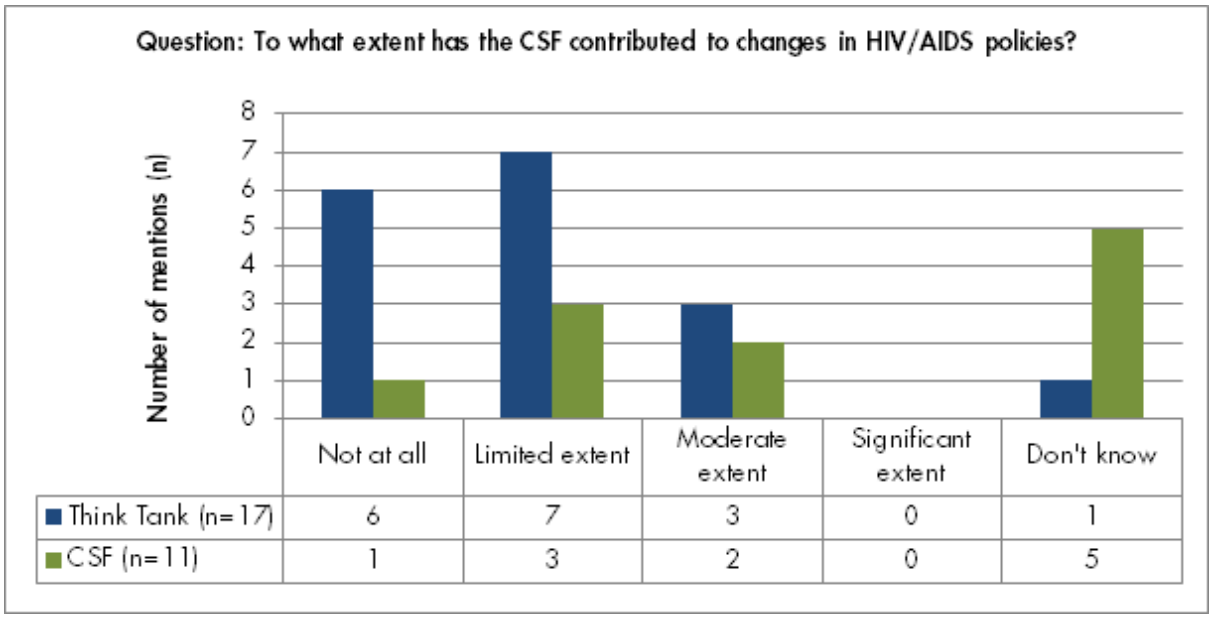
The CSF's role is to inform, alert, influence and advocate in order to enable an appropriate response to HIV/AIDS and the implementation of the EU HIV/AIDS policy in the EU Member States and neighbouring countries. The analysis of the CSF reports for the period 2009–2013 confirmed that each meeting provided occasions to discuss successful and problematic policies, strategies and regulations of European countries, and that several actions were taken by the CSF as a follow-up of their discussions (e.g. dissemination of good practices, alerting on poor practices).

Drawing on key informant interviews and the Think Tank and CSF member surveys, it may be contended that the CSF was broadly recognised to play a fundamental role and that its meetings were considered to provide a unique opportunity for those attending in accessing information on (policy) developments at the level of the European Union and within European countries regarding HIV/AIDS.

However, the impact of CSF activities and advocacy in countries and the extent to which they are listened to by national competent authorities were difficult to assess by CSF members. The main reason given was that the implementation of national policies and strategies was the competence of national authorities. One CSF survey respondent thought that it even if change occurred in individual countries following discussions with Think Tank members, it was difficult to know whether these were attributable to the CSF.

However, as illustrated by survey responses, of 31 respondents to the Think Tank and CSF surveys, 10 Think Tank and 5 CSF members thought that the forum had helped at least to some extent effect changes in HIV/AIDS policies at the national or regional levels (Figure 4.3). One CSF respondent specifically mentioned that '*information disseminated during CSF meetings regarding HIV and health related policies from other countries were shared at my national level. On that basis my country could only include and work to implement those initiatives*'. Another respondent stressed that '*the CSF contributed to institutional campaign focused on raising awareness of the general population regarding the strengthening of the perception of risk of HIV infection, mode of transmission and measures*'.

Figure 4.3. Perceptions of Think Tank and CSF members of contributions of the CSF to national or regional HIV/AIDS policies



SOURCE: Think Tank and CSF member surveys

4.2. Communication of the CSF to its stakeholders (EQ 7)

4.2.1. Communication channels of the CSF

Different channels are used by the CSF to communicate with the relevant actors involved in addressing HIV/AIDS and to keep them informed about relevant developments and activities at the EU and national levels. Communication channels most frequently mentioned by respondents to the Think Tank and CSF surveys included formal presentations during CSF and Think Tank member meetings, alongside email exchanges, and, less frequently, telephone contacts, bilateral meetings, and social networking (Table 4.1).

Table 4.1. Reported channels of communication of the CSF

Channels of communication of the CSF	Number of mentions in Think Tank survey	Number of mentions in CSF survey
Formal presentations during CSF/Think Tank meetings	14	14
Email exchanges	8	14
Telephone contacts	3	3
Bilateral meetings	3	1
Other: social networks	0	2
Other 2: EU events (conferences)	1	0

SOURCE: Think Tank and CSF member surveys

The CSF has set up two email distribution lists, one targeting its members (although recipients also include the representatives of the European Commission services, EU agencies and international organisations), and one targeting Think Tank members. Drawing on information derived from CSF meeting reports, we found that the distribution list targeting the CSF members was used most frequently, for the following purposes:

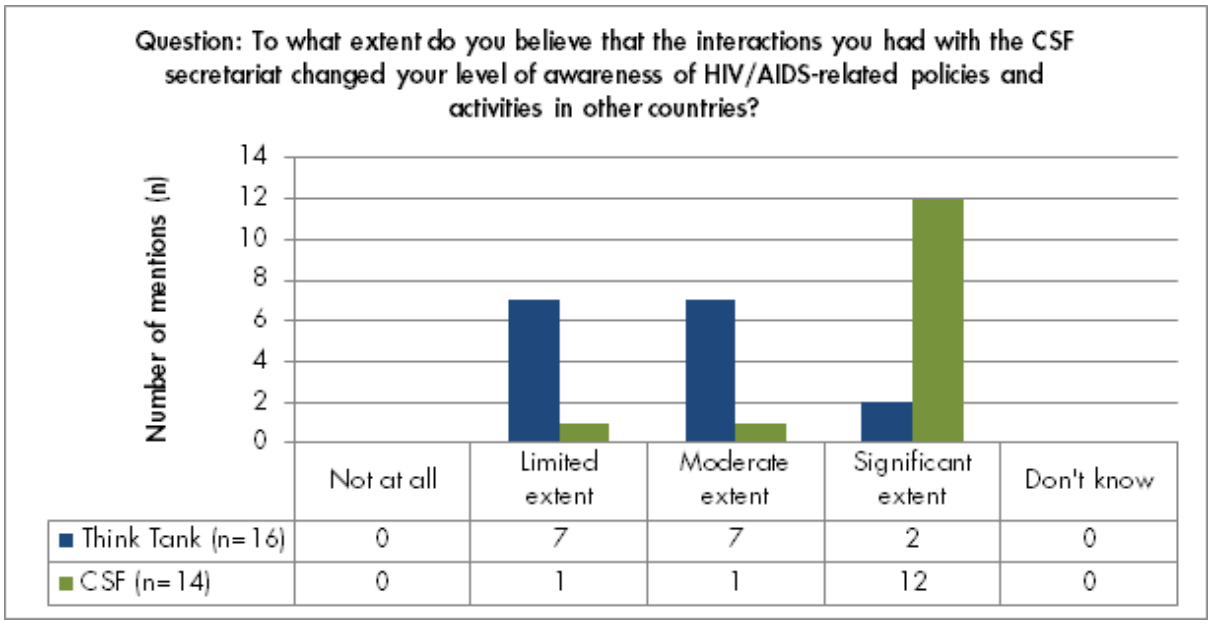
- To share information, through circulation of reports from external stakeholders, dissemination of advocacy positions issued by the CSF, alerts of cases of violations of the human rights of affected people, etc.
- To invite feedback, contributions, and comments from members on specific items
- To share good practices and experiences between the CSF members on national policies and systems, etc. (topics included compensation mechanisms for people infected with HIV, national HIV testing guidelines).

One CSF survey respondent noted that the Think Tank member list was used more occasionally than the internal list of the CSF members. One key informant highlighted that the list would keep the Think Tank informed on subjects and topics the CSF is working on and also to alert countries of challenging issues that require special attention or specific action (KI-9).

4.2.2. Perceived effects of interactions with the CSF on the awareness of stakeholders of HIV/AIDS-related policies and activities in other countries

All 16 Think Tank and 14 CSF survey respondents indicated that their interactions with the CSF during the period 2009–2013 had changed their level of awareness of HIV/AIDS-related policies and activities implemented in other countries (Figure 4.4). While Think Tank respondents did not further explain how the CSF helped raising awareness, one respondent mentioned finding it valuable to get familiar with the situation of countries from an angle other than a political one.

Figure 4.4. Perceptions of Think Tank and CSF members of how the CSF changed the level of awareness of its stakeholders



SOURCE: Think Tank and CSF member surveys

CSF survey respondents did provide further comments, noting that the forum had raised awareness and understanding on (i) issues of policy concern in other countries and how these countries had addressed the problems they faced, (ii) ongoing policy developments and processes, and (iii) initiatives and programmes available at the EU level. This was further illustrated by one respondent who explained that '*for our national strategy, it is good to know how other countries are struggling with aspects like funding, or to see how other NGOs are dealing with new issues in prevention (i.e. drug use by MSM); for o ur international department, NGOs in Europe are important partners for projects at the European or international level'.* One other respondent stated that '*exchange of HIV situations in other countries helped immensely to get a grip of the larger issues that need to be tackled on the European level, but also in my country*'.

From survey responses it appears that different discussions and debriefings were seen as enhancing the motivation of representatives of civil society for continuing and improving their work. One CSF survey respondent commented that the information disseminated by the CSF may have implications for other countries and that it would therefore be important to have an initiator such as the CSF for starting this process.

The following topics and issues were mentioned as useful points raised through interaction with the CSF by three Think Tank and eight CSF survey respondents:

- The HIV outbreak in Greece and the related issue concerning sex workers (frequency of mentions: 5)
- The different HIV testing policies and the exchanges on the different levels of access issues (pricing, scale-up, etc.) across Europe (frequency of mentions: 4)
- The situation of PWID in Russia and Eastern European countries (frequency of mentions: 3)
- Cuts due to the economic crisis in Romania, Greece and Spain (frequency of mentions: 2)

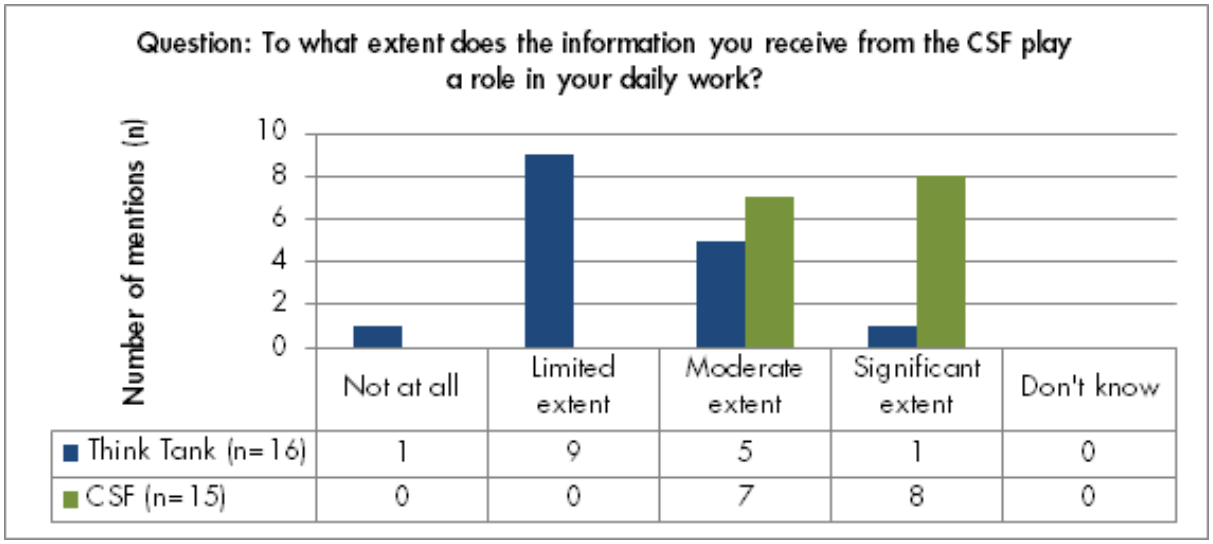
4.2.3. Perceived effects of information provided by the CSF on the daily work of CSF and Think Tank members

Figure 4.5 illustrates the perceptions of Think Tank and CSF survey respondents of the role of the information provided by the CSF in the daily work of stakeholders. It shows that all CSF survey respondents felt that information provided by the CSF influenced their day-to-day work to some extent, with examples including an increased capacity to inform national advocacy actions; an improved knowledge of EU programmes that fund HIV/AIDS projects as well as the submission of applications; and the development of specific initiatives at the national level. One CSF survey respondent highlighted that '*the discussions in the Civil Society Forum helped frame our policy papers and initiatives on the issues of HIV criminalisation. The discussions and exchanges around HIV testing helped inform the position and policy papers on HIV testing in the national civil society. The involvement of the Civil Society Forum in the EU Communication on HIV/AIDS and other updates by ECDC, UNAIDS, WHO Europe, etc. helped to sharpen our arguments in our lobbying and advocacy issues, making sure that the newest policy papers were being taken into consideration'*. One other CSF survey respondent noted that '*the CSF gave us the*

opportunity to learn about many things we can apply or adjust to that are very specific (like advocacy campaigns for MSM, or bright examples of human rights protection). We learn while working with EU parliamentarians. We can count on the support and pieces of advice from EU Civil society community in case of advocacy campaigns. And taking direct part in discussions and elaboration of EU HIV policies and [action plans] we analyse the politics we have in [our country] and try to find ways to make them more effective'.

Conversely, the majority of Think Tank survey respondents believed that the information provided has had only limited impacts on their daily work. One respondent thought that the explanation lies in the respondent's country's long-standing tradition of partnering with its national civil society.

Figure 4.5. Perceptions of Think Tank and CSF members of the role of the information provided by the CSF in the daily work of stakeholders



SOURCE: Think Tank and CSF member surveys

4.2.4. CSF's communication in future

There was a perception among Think Tank (6 out of 16) and CSF survey respondents (11 out of 15) that future CSF communication activities would benefit from some improvement. Examples of proposed improvements included:

- Enhancing the frequency of information distribution by email, for example, on 'hot topics' (five Think Tank members) through, for example, the circulation of a CSF newsletter (four Think Tank members, two CFS members). One respondent also suggested an intensification of interactions between meetings to be potentially beneficial.
- Better targeting of information circulated to the CSF members through the email distribution list (four CSF members). Contrary to the suggestion made by Think Tank members, as illustrated in the preceding paragraph, there appeared to be a perception among CSF survey respondents that there was 'too much email' traffic and that the large number of recipients of the distribution list meant that recipients would inevitably be provided with information that was not in their direct interest.

Respondent expressed a need for clearer identification of the purpose and the target of email distribution lists.

- Timely provision of information. One Think Tank survey respondent and one CSF survey respondent noted that the dates of the CSF and Think Tank meetings were communicated too late, leading to lower attendance levels.

4.3. CSF resources and efficiency (EQ 8)

4.3.1. Costs of EU HIV/AIDS CSF activities

Interviews with two key informants (KI-1 and KI-9) and several email exchanges with representatives of the organisations co-chairing the CSF (i.e. AAE and EATG) provided insight into the costs associated with the activities of the EU HIV/AIDS Civil Society Forum. The CSF is funded through the following sources:

- DG SANCO: supports the participation of CSF members in the biannual meetings by reimbursing travel expenses (airplane tickets and allowances) for one participant for each of the 30 members of the CSF. The meeting rooms are also provided by DG SANCO.
- AIDS Action Europe: supported by an annual operating grant funded through the EU Health Programme (SANL). This grant is allocated to AAE to permit a greater involvement of the civil society in the combating of HIV/AIDS, and part of this grant is dedicated to fund the work of the CSF coordination team and secretariat (see Appendix F).
- European AIDS Treatment Group: finances the secretariat of the CSF through its own funds (these are also partly funded by external sources).

Table 4.2 provides an overview of estimated annual CSF costs and staff resources broken down according to funding source, as derived from key informant interviews. Costs supported by AIDS Action Europe and EATG are likely underestimated with regard to staffing (full-time equivalent, FTE) as co-chairs in particular may not systematically record all their working hours.

Table 4.2. Annual CSF costs and number of FTE allocated to CSF activities

Sources of funding	Annual costs of the CSF (in Euros)	Number of FTE allocated to the CSF activities
DG SANCO CSF meetings	70,000	0.2 (administrator function) 0.1 (assistant function)
AIDS Action Europe (through SANL projects funded by the Health Programme)	23,800*	
EATG	1,500 (annual overhead) †	0.06 (co-chair function) 0.12 (policy officer function)

NOTE: * Average amount spent by AAE, 2009–2013. This covers the workload of the co-chair and of the coordinator of the CSF activities within AAE. The annual workload of the co-chairs has been estimated as the equivalent of 16

days. † Includes part of the rent, utilities, office material, phone and Internet, printer lease and printing costs.

SOURCE: Key informant interviews

4.3.2. Appropriateness of CSF resources to meet its objectives and needs

When considering the question of whether the resources that are being allocated to the CSF are 'commensurate with its objectives or needs', one key informant thought that the members of the CSF coordination team appreciated that the EC (i) continued to pay attention to providing opportunities for members of the civil society from European countries to come to together through committing financial resources and (ii) facilitated the collaboration of CSF and Think Tank members.

There was a perception that the operating grant allocated to AAE through the EU Health Programme as described above (based on a 50 per cent co-financing mechanism, shared between the Health Programme and the network itself) was sufficient to carry out the activities of the CSF secretariat, at least until 2012. However, in 2013, the AAE was no longer able to maintain the required co-financing of the SANL projects at the same level, reducing the size of the grant, which means that it may become challenging to continue covering the costs of the CSF activities at the same levels as in the past. However, no examples were given of whether and how this gap in financing has impacted the activities of the secretariat, with the possible exception that the CSF incurred higher costs in 2013 as a consequence of organising a human rights conference in May 2013 [84], and related meetings and postal mail exchanges with Commissioner Borg to discuss future HIV policy developments.

Overall, it is difficult, based on data collected, to draw any conclusions regarding the appropriateness of resources allocated to the CSF (or lack thereof) to conduct its activities.

The absence of a formal and unified financial reporting system implemented by AAE and EATG for the allocation of resources prevented us from assessing the effectiveness of the CSF in managing its financial resources. It was also not possible to draw conclusions from the benchmarking analysis that sought to compare the efficiency of the HIV/AIDS CSF with a comparable advisory body, for example, the CSF on drugs. This analysis is described in detail in Appendix H.

It is important to highlight that a lack of evidence for any failure of the CSF in achieving its mandate does not necessarily imply there is evidence for appropriate financial management.

4.4. European added value (EQ 3)

Although the CSF both predates and postdates the period covered by the 2009–2013 Communication, it is considered an important mechanism in implementing the Communication. The analysis of findings presented in this chapter suggests that there are several aspects of the CSF's activities that generate 'a true added value' to addressing HIV/AIDS as supported by the EC Communication. Thus, the CSF was seen to provide an important platform for networking at the EU level as facilitated though its regular meetings and the channels of communication it established with the EC and other relevant stakeholders. In addition, the CSF was seen to contribute to improving informal

collaboration between stakeholders and to facilitate the exchange of knowledge and experiences, which was perceived to enhance the ability of civil society to optimally represent the interests of people living with, or at risk from, HIV/AIDS at the national level.

Furthermore, as the CSF was seen to preserve the human rights of people living with HIV and to deliver its activities by taking account of the most recent trends and developments at the EU level on HIV/AIDS, its members are able to position themselves in relation to their counterparts and to identify progress that had to be made at the respective national, regional and local levels.

A further aspect that was mentioned was the legitimacy given by the European Commission to the CSF and its members. This was seen to be essential to strengthen the role and voice of civil society in national and European fora, such as the HIV/AIDS Think Tank, and in the development of national HIV/AIDS policies. The Communication was seen to be of particular relevance for empowering civil society in Member States that have joined the EU more recently and for providing them with significant political leverage.

4.5. Summary

This chapter has sought to understand (i) the impacts of the Civil Society Forum activities in relation to the development of programmes to address stigma and discrimination, improving access of key populations to important HIV-related services and prevention programmes, the monitoring of new infections, and the development and implementation of national/regional HIV/AIDS policies; (ii) the effectiveness of CSF communications; (iii) the financial resources of the CSF; and (iv) the European added value in relation to CSF activities during 2009–2013. Findings reported in this chapter can be summarised as follows.

CSF contributions to the development of HIV/AIDS services, programmes and policies at the national level

The role of the Civil Society Forum was perceived to be important in combating HIV/AIDS in Europe during the period 2009–2013 for the following reasons:

- The CSF was seen to have facilitated exchanges and discussions on relevant HIV/AIDS issues, thus providing to its members and Think Tank members information on developments of HIV policies at the EU level; enabling the exchange of good practices and experience; and facilitating informal collaborations between different players, such as EU Member States, civil society, EU institutions and international organisations, and others seeking to control HIV/AIDS in Europe
- Through its meetings, the CSF was seen to offer a platform to its members for planning and implementing coordinated follow-up actions to support advocacy and to influence HIV/AIDS policies and initiatives aimed at an increased representation of the interests of people at risk or suffering from the disease.

It was difficult, based on data collected for this evaluation, to assess with certainty whether and to what extent observed changes at the country level can be attributed to CSF activities and outputs, given that policy development is influenced by many other factors that may have a greater influence than the CSF, even if the latter performs well.

The overall perception of key informants and CSF and Think Tank survey respondents was that the CSF had helped to bring about some change in national HIV/AIDS policies. CSF survey respondents in particular provided examples of successful action by the CSF at the national level in relation to addressing stigma and discrimination and the uptake of key HIV services by vulnerable populations (MSM and PWID), with some examples also relating to the monitoring of the HIV epidemic and to national HIV/AIDS policies.

Communication of the CSF to its stakeholders

We found that CSF had established regular interactions with its members and the HIV/AIDS Think Tank, mainly through biannual meetings and email exchanges. The communication and the information disseminated by the CSF were judged as helpful by key informants and survey respondents in raising awareness of meeting participants and of Think Tank members on development in HIV/AIDS at the EU level. Respondents suggested a range of improvements to optimise the flow of information between meetings and to make it more targeted.

CSF resources and efficiency

Drawing on limited evidence we found that the financial resources allocated to the running and management of the CSF were rated as being sufficient, at present, to carry out its mandate and the activities it is currently implementing.

European added value

The legitimacy awarded by the European Commission in the HIV/AIDS Communication and Action Plan to the Civil Society Forum was seen to be crucial to (i) empower stakeholders involved in combating HIV/AIDS through increasing their knowledge and informing their actions at the national level and (ii) influence perceptions of stakeholders on the added value of the civil society perspective in developing HIV/AIDS policies at the EU level. The contribution of the EC Communication was seen to be particularly important in Member States that have joined the EU more recently, as a means to strengthen the civil society movement.

5. Contribution through EU-funded research and public health projects

This chapter reports on our findings regarding the contribution of EU-funded research and public health projects, conferences, operating grants and joint actions to combat HIV/AIDS in Europe. Within the period covered by the evaluation (2009–2013), EU-supported research was principally funded under the Seventh Framework Programme, which is operated by DG RTD, and the Health Programme, which is operated by DG SANCO. In the following sections, we consider the contribution of these two programmes separately. The evidence presented here primarily addresses evaluation questions 3, 5, 9, 10 and 11 (see Box 5.1).

Box 5.1. Evaluation questions addressed in Chapter 5

Evaluation question 3

What is the European added value of the Communication?

Evaluation question 5

To what extent have the EU programmes facilitated an exchange of good practice among the EU Member States in the area of HIV/AIDS?

Evaluation question 9

(1) To what extent has EU-funded research on HIV/AIDS led to outputs in terms of novel preventive tools and therapeutic options, and surveillance methods?
(2) To what extent have these research outputs contributed to the expected objectives set out in the Commission Communication?

Evaluation question 10

Is there evidence of structural change towards improved education, knowledge and awareness on HIV as a result of EU-funded research projects? Is there evidence the activities will have lasting impacts?

Evaluation question 11

To what extent have actions funded through the Health Programme led to outputs that have contributed to the attainment of objectives set out in the Commission Communication?

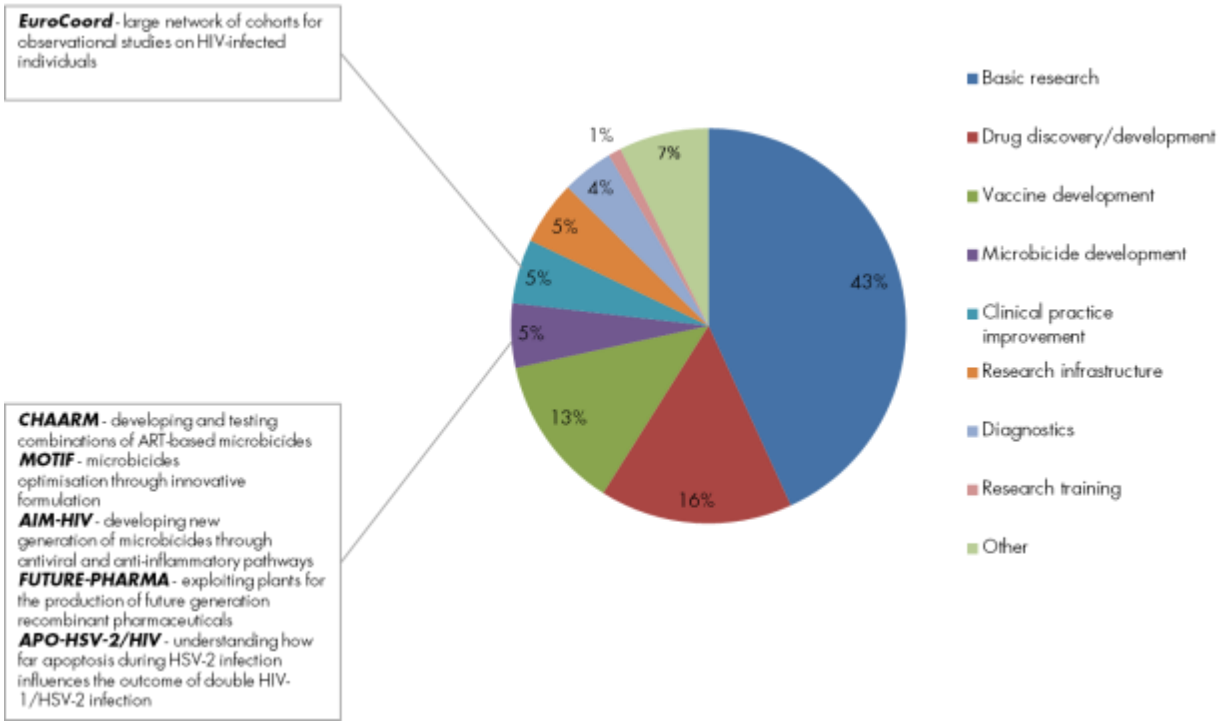
5.1. FP7 research funding and HIV (EQ 9)

The evidence presented in this section draws on data provided by DG RTD. This consisted of a list of all projects funded under the FP7 in relation to HIV, detailing project title; project call identifier; the EU programme theme (e.g. health, ideas, people); a project abstract; whether small–medium enterprises were engaged in the project; the research activity; and the area in which the project was focused, such as vaccine development or drug discovery. The data also included the financing provided to the projects by the EU, as well as other

administrative details. A total of 80 projects were solely focused on HIV, and 15 projects were focused on multiple conditions, including HIV.

The successive Framework Programmes are the EU's primary instrument for funding research in Europe. FP7, which was operational from 2007 to 2013, allocated over €210 million to research on HIV-related projects, ranging from basic science to clinical research, capacity building, diagnostics and research infrastructure [85]. Of the HIV-related projects considered as basic research, 72 per cent related to drug discovery and development of vaccines and microbicides. The breakdown of the distribution of projects across research areas is shown in Figure 5.1, together with an indication of where the two research case studies that were conducted for this evaluation (see Chapter 2) sit within the distribution.

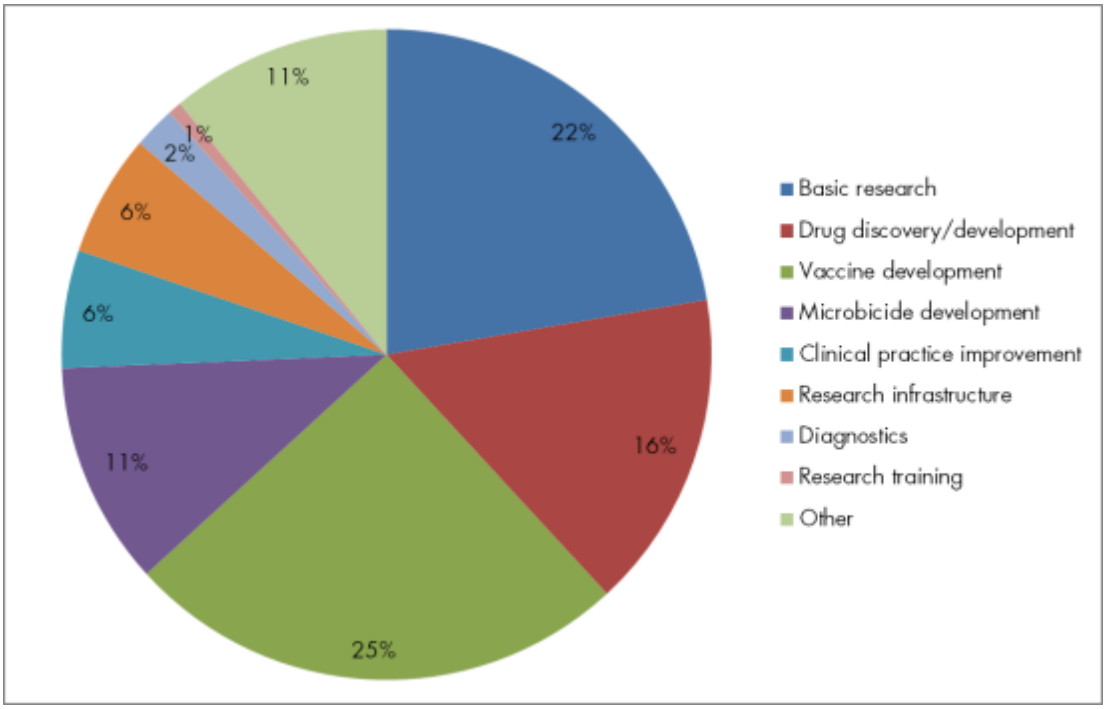
Figure 5.1. Distribution of HIV research projects funded through the European Seventh Framework Programme, 2007–2013



SOURCE: Based on data provided by DG RTD, 2014

Figure 5.2 depicts the distribution of FP7 spending on research on HIV across categories. It shows that, although there are a greater number of basic research projects, the area of vaccine development has received the most funding, followed by basic research and drug discovery or development. Therefore, most of the basic research projects will be relatively small in nature, which is not surprising given that they are relatively inexpensive to undertake and can be carried out by individual academic laboratories. Vaccine research, on the other hand, requires complex clinical trials, which tend to incur comparatively high costs.

Figure 5.2. Distribution of HIV research spending through the European Seventh Framework Programme, 2007–2013



SOURCE: Based on data provided by DG RTD, 2014

From the nine overarching areas of HIV-related research, two topics were selected for detailed review in the form of research case studies: HIV progression and the long-term effects of antiretroviral therapy (explored through EuroCoord) and microbicide development. The complete research case studies are presented in Appendix E.

EuroCoord is one of five projects funded under the clinical practice improvement research area (see Figure 5.1). EuroCoord is an integrated network of the four largest European HIV cohorts [86]: CASCADE, EuroSIDA, PENTA and COHERE [87]. Together they consist of more than 270,000 PLWHIV from across Europe. The creation of a single large cohort has enabled subgroup analysis to an extent that would be less feasible with the use of smaller, single-country or site cohorts. The stated objective of EuroCoord is to contribute to HIV research by developing a greater understanding of HIV progression across Europe and the long-term effects of ART [88].

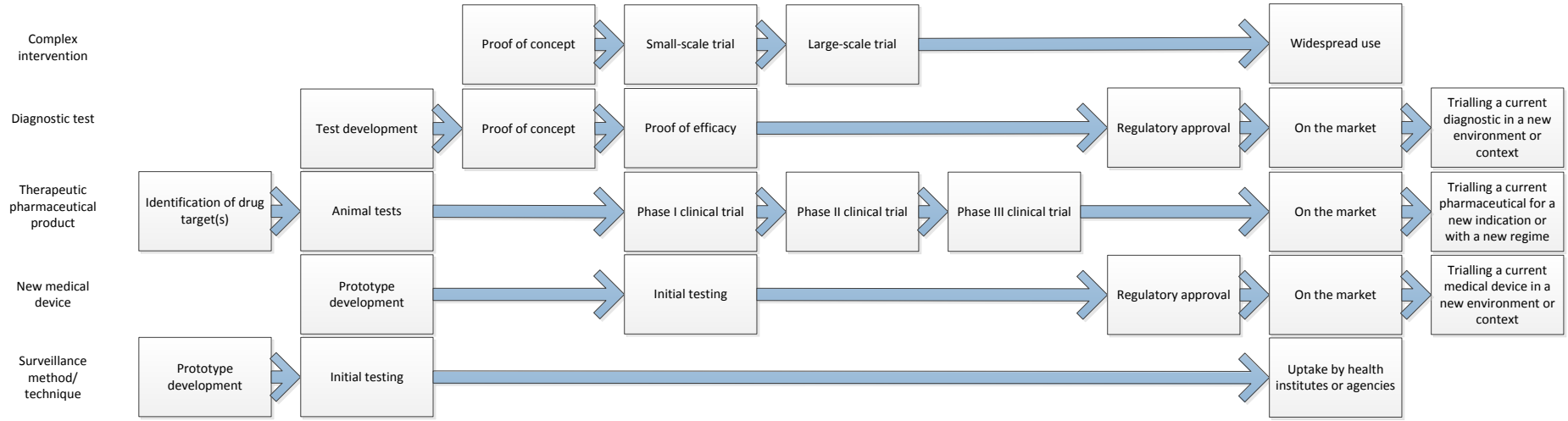
Microbicide development forms a whole FP7 research area and is comprised of five separate projects: AIM-HIV, APO-HSV-2/HIV, FUTURE-PHARMA,[10] CHAARM and MOTIF [89-93]. Overall, microbicide development is concerned with the development of compounds (gels, creams, films or suppositories) that can be applied inside the vagina and/or rectum before intercourse to provide protection against STIs, including HIV. They work in a number of ways, including providing a physical barrier that prevents the HIV virus from reaching the target cells; enhancing the body's natural defence mechanism, for example, by increasing the

[10] It should be noted that, although FUTURE-PHARMA has been classified as a microbicides project, the main aim of the FUTURE-PHARMA project is to build on earlier work under the previous Framework Six Programme and to develop further proof of concept and clinical trials for plant-derived products (R2-KI-2). This could be in the form of a microbicidal cocktail, although the final outcome will not necessarily be a microbicide.

vagina's acidity; killing the virus outright; or preventing the virus from replicating once it has entered the cells [94]. However, research into microbicide development has not yet progressed beyond the early stages. As of May 2014, only one trial (the CAPRISA trial focusing on tenofovir [95]) has shown a microbicidal gel to be effective, which has led to proof of concept of microbicides (see also Figure 5.3).

It should be noted that the terminology to describe product development is different for each category of product or intervention (i.e. complex intervention, diagnostic test, therapeutic pharmaceutical product, new medical device and surveillance method/technique), given that the stages of their development differ. Figure 5.3 maps the various stages of development for each category of product and intervention. To describe the development of a particular product or intervention along the value chain, we here apply the same terminology that is used in the *ImpactFinder* survey.

Figure 5.3. Stages of product and intervention development



The remainder of this section considers the impact of FP7 in terms of these two research areas and draws on results from the *ImpactFinder* survey, which aims to capture a broad range of impacts across a large number of projects. As described in Chapter 2, this is a tried and tested method which typically surveys project PIs in order to ask them to identify the impacts arising from their project. Given the size of EuroCoord, CHAARM and MOTIF, it was decided to also survey work package leaders and technical scientists where appropriate. We thus included a total of 11 survey respondents for EuroCoord, 14 for CHAARM, 2 for MOTIF and 1 each for AIM-HIV, FUTURE-PHARMA and APO-HSV-2/HIV. Where any of the respondents has noted an impact arising from the project (even if it has not been reported by all respondents), this has been reported here. Any disparities between survey respondents regarding impacts that have arisen are highlighted.

In the following, we first provide a general overview of impact. We then discuss in more detail the contribution of these two research areas to (i) the development of novel preventative tools and therapeutic options; (ii) HIV/AIDS surveillance in Europe; and (iii) the expected objectives set out in the Communication (EQ 9).

5.1.1. Overview of the impacts of FP7-funded HIV projects

Using the *ImpactFinder* survey approach, we identified a range of impacts from FP7, related to research outputs, capacity building (for both people and infrastructure) and wider outcomes (such as socio-cultural impacts, impacts on public policy and public services and the generation of inventions, products and intellectual property). The results for each category are briefly summarised below and in Table 5.1.

Table 5.1. Overview of impacts arising from the projects considered in research case studies

Type of impact	Summary
Research outputs	• 96 academic publications have arisen from CHAARM • 66 academic publications have arisen from EuroCoord • 2 academic publications have arisen from APO-HSV-2/HIV • 1 academic publication has arisen from AIM-HIV
Capacity building	• Engagement with the wider public and collaboration with academia, the public sector and the private sector has had beneficial effects
Socio-cultural impacts	• All case study projects other than APO-HSV-2/HIV reported an impact on raising awareness around HIV (see below)
Impacts on public policy and public services	• EuroCoord has identified priority policy areas and has contributed to national and WHO HIV/AIDS guidelines
Generation of inventions, products and intellectual property	• IP has arisen from CHAARM and AIM-HIV • IP is likely to arise from MOTIF and FUTURE-PHARMA in future

Research outputs

The number of academic publications resulting from research projects provides a rough proxy of new knowledge contributed to the field. Since 2011 EuroCoord's output has included 66 publications in academic journals (20 in 2013, 22 in 2012 and 24 in 2011) and 40 conference presentations [96]. For microbicide development the most successful project in terms of the number of publications has been CHAARM, which has published 96 academic journal articles since 2011 (6 in 2013, 47 in 2012, 20 in 2011 and 23 in 2010) [97]. CHAARM research has also been presented at seven conferences and events. To date (May 2014) MOTIF has not produced any publications [98]. For the remaining microbicide research studies the respondents to the *ImpactFinder* survey noted that two peer-reviewed journal articles have arisen from APO-HSV-2/HIV, one has arisen from AIM-HIV and two from FUTURE-PHARMA.

Capacity building

The *ImpactFinder* survey also asked about impacts on capacity. Respondents revealed that both EuroCoord and all microbicides projects had engaged with the wider public in their research. Of the EuroCoord respondents, 7 out of 11 noted that they had engaged the wider public, including the public and private sectors, academia and quasi-governmental organisations. Of the CHAARM respondents, 7 out of 14 also noted engagement with these groups and 1 out of 14 noted the use of a project website and social media. One of two respondents for MOTIF also noted wider public engagement, as did the respondent for AIM-HIV and APO-HSV/2-HIV.

One key informant commented that EuroCoord had also facilitated, through its engagement of patients, both knowledge sharing and capacity building, which are at the core of EuroCoord's work (R1-KI-2). All projects also reported an impact on the research infrastructure, including facilitating further research, contributing to new methods and producing research materials that were not previously available. The facilitation of further research was reported by 3 of 11 EuroCoord respondents, 10 of 14 CHAARM respondents and the FUTURE-PHARMA respondent. The contribution of new methods was outlined by 1 of 11 EuroCoord respondents, 9 of 14 CHAARM respondents, the FUTURE-PHARMA respondent and the AIM-HIV respondent. Finally, the production of research materials that were not previously available was reported by 5 of 11 EuroCoord respondents, 5 of 14 CHAARM respondents and the AIM-HIV respondent.

Socio-cultural impacts

The primary socio-cultural impacts arising from these projects were their impacts on education, knowledge and awareness, which are explored below, in the section titled Improving education, knowledge and awareness of HIV/AIDS.

Impacts on public policy and public services

The two key informants interviewed as part of the EuroCoord case study both considered EuroCoord to have had a positive impact on policy through the network's identification of particular priority areas for HIV/AIDS research and policy (R1-KI-1, R1-KI-2). According to one of the key informants, these had been directly communicated to policy makers (R1-KI-1). For example, one key informant stated that

the EuroCoord 2013 policy brief had specifically drawn attention to the important role of socioeconomic inequalities in the HIV/AIDS epidemic (R1-KI-2) [99].

Both of the key informants considered that EuroCoord has had an important impact on the development of HIV/AIDS treatment guidelines. For example, the research from the EuroCoord network had directly contributed to the development of national guidelines on HIV/AIDS in a number of European countries and had indirectly contributed to national policies and guidelines through its influence on the WHO guidelines (R1-KI-1, R1-KI-2).

For microbicide development, 3 of 14 respondents to the *ImpactFinder* survey reported that CHAARM had also disseminated its work to policymakers, although the direct impact of this is not clear.

Generation of inventions, products and intellectual property

Although none of the microbicide projects have yet resulted in the development of therapeutic or prophylactic pharmaceutical products, 7 of 14 respondents to the *ImpactFinder* survey revealed that CHAARM has produced microbicide candidates going into phase 1 clinical trials. The two MOTIF survey respondents, as well as the respondents from FUTURE-PHARMA and AIM-HIV, noted that the development or trialling of a therapeutic pharmaceutical product was likely to occur in the future.

Intellectual property has arisen from CHAARM and AIM-HIV, with MOTIF and FUTURE-PHARMA reporting that intellectual property is likely to arise from future developments.

EuroCoord has not resulted in the production of interventions, products and/or intellectual property. This is not surprising, given that its objective is to facilitate knowledge generation and exchange, rather than the production of tools or products. However, one survey respondent (out of 11) noted this was likely to occur in the future.

5.1.2. Novel preventive tools and therapeutic options developed through FP7 research

The development of novel preventive tools and/or therapeutic pharmaceutical products applies to microbicide development only. The five microbicide development projects are currently operating at different stages of the research life cycle. Both CHAARM and AIM-HIV set out to develop new microbicides [100 101], while FUTURE-PHARMA aims to exploit plants for the production of future generation recombinant pharmaceuticals [91]. However, it was not the explicit aim of either APO-HSV-2/HIV or MOTIF to develop new products (the former was an Intra-European Fellowship which aimed to understand how far apoptosis during HSV-2 infection may add to the disruption of vagina epithelium integrity, and consequentially how far it influences the outcome of double HIV-1/HSV-2 infection [90], and the latter aimed to develop generic procedures for co-formulating chemically incompatible drugs [102]). The MOTIF project aims to deliver prototype microbicide products for phase 1 clinical trials, although it does not intend to go beyond this prototype development. Therefore, the production of novel preventive tools as a result of these projects should not necessarily be used as a success criterion. In addition, future research could build on

the knowledge and products generated by these projects, such that positive impacts resulting from the projects may occur in the future.

The only project to report the current development of a prophylactic pharmaceutical product is CHAARM, which has co-formulated two drugs that are going through phase 1 clinical trials (R2-KI-1). One key informant from CHAARM noted that three or four early stage microbicide candidates had already been identified, which were expected to enter into a macaque challenge study (i.e. the animal testing stage of development) (R2-KI-1). The key informant indicated that these candidates would not be entered into clinical trials, however, because of a lack of time and resources and because clinical trials were not within the scope of the project. The *ImpactFinder* survey also indicated that the production of a 'complex intervention' designed to improve patient health or care was at the proof of concept and/or small scale trial stages of development. In relation to product development, one key informant indicated that CHAARM's progress had been greater than anticipated and that products had been developed with an '*impressive degree of efficiency*' (R2-KI-1). According to the same key informant, the collaborative nature of CHAARM's work had allowed at least one pharmaceutical product to be produced '*astonishingly quickly',* on a relatively low budget. In addition, the key informant repeatedly emphasised the '*absolutely crucial*' role of FP7 funding in enabling the dynamic transnational collaborations between project partners that formed the structure of the CHAARM project (R2-KI-1).

Although the AIM-HIV survey respondent reported the existence of intellectual property arising from AIM-HIV in the form of patents, all other impacts we surveyed for were anticipated to happen in the future across all of the projects. These future developments included the development or trialling of a therapeutic pharmaceutical product (reported to be at the animal testing stage), diagnostic tests (variously reported to be at the proof of concept or proof of efficacy stage) and a new medical device (reported to be at prototype development stage).

Similarly, the respondent from a FUTURE-PHARMA project reported that, in the future, the research conducted under FUTURE-PHARMA was likely to lead to the development, or trialling, of a therapeutic pharmaceutical product, which was reported to be at the animal testing stage at present and the two MOTIF respondents noted the research would lead to the production of a 'complex intervention' designed to improve patient health or care (reported to be at the small-scale trial and proof of concept stages of development) as well as the development or trialling of a therapeutic pharmaceutical product (reported to be at the identification of drug target(s) and animal testing stages of development). In addition, one of the two MOTIF respondents reported that applications for patents would likely be submitted in the future. Both MOTIF respondents also felt that, in the future, the project was likely to lead to the development or trialling of a new medical device.

5.1.3. HIV/AIDS surveillance in Europe

The two key informants highlighted that EuroCoord had made important contributions to national surveillance systems across Europe (R1-KI-1, R1-KI-2). For example, one key informant stated that the CASCADE network worked closely with national surveillance systems to improve the surveillance of HIV in the UK, France and

Germany, among other countries (R1-KI-1). The other key informant, from an external organisation, believed that EuroCoord had contributed to the quality of European and national surveillance systems by demonstrating the need for, and importance of, collecting CD4 cell count data (R1-KI-2). The compilation of data by EuroCoord also has significant implications for its own surveillance capabilities. COHERE pools data from CASCADE, PENTA, and EuroSIDA into a common dataset (R1-K1-1). According to one key informant, it also includes a number of national datasets, for example, the French, Swiss and UK national HIV datasets, among others (R1-K1-1). In total, the network comprises data from over 270,000 people living with HIV, which is open to everyone from each of the collaborations via a proposal to access the data [86].

In relation to MOTIF, one of the two survey respondents indicated that the project was likely to contribute to methods or techniques to enhance HIV/AIDS surveillance capabilities in Europe in the future, although the respondent did not specify how this would take place and no other respondents from the other microbicides projects noted an impact of microbicide development projects on HIV surveillance. However, one key informant noted that microbicides projects have the potential to contribute to surveillance data in the future (R1-K2-KI3). Specifically, the development of microbicides will require large behavioural studies in order to produce a product that the target population will actually use. These studies will provide information on behavioural practices and may impact on the types of data that are collected.

5.1.4. Contributions to the expected objectives set out in the Commission Communication

Reducing the number of new HIV infections

As outlined in Chapter 3, there are a number of difficulties in assessing the rate and number of new HIV infections. Therefore, it is not possible to ascertain the contribution of FP7-funded research to reducing new infections. However, a number of projects have led to outcomes that have the potential to affect the number of new infections (although an assessment of the actual contribution of these projects to that end will not be attempted here). For example, as mentioned above, CHAARM has co-formulated two drugs that are going through phase 1 clinical trials, and it has identified three or four early-stage microbicide candidates. Similarly, MOTIF aims to deliver prototype microbicide products for phase 1 clinical trials, and AIM-HIV is also looking to develop new microbicides. If these projects are successful in developing microbicides (although this is not likely to happen in the foreseeable future), they have the potential to have a significant impact on reducing new HIV infections.

In addition, 6 of 14 survey respondents for CHAARM noted that the project had improved public awareness of HIV/AIDS, while 3 of 14 noted it had improved relevant education programmes and 5 of 14 stated it had improved public understanding of HIV/AIDS and related issues. Similarly, one of two MOTIF respondents noted that the research had improved public understanding of HIV and associated issues/risks, improved education programmes on HIV/AIDS, and improved public awareness of HIV/AIDS, while both the AIM-HIV and FUTURE-PHARMA respondents noted that the research had improved both public understanding and public awareness of HIV.

These impacts on education, knowledge and awareness of HIV/AIDS were reported to have occurred through a range of activities, from informing the delivery of events and campaigns, to providing educational material. We have noted in Chapter 3 that improving education and awareness of HIV and associated issues has the potential to reduce the number of new infections [103], an issue repeatedly raised by several key informants and respondents to the Think Tank and CSF surveys.

Improving access to key services

The research case studies yielded little evidence on the impact of FP7 funding on improving access to key HIV services, which is perhaps to be expected as this was not a primary goal of the research. However, the key informant from CHAARM and MOTIF stated that it could be argued that MOTIF and CHAARM might contribute indirectly to improving access to key services through the development of products that are more suited to the needs of people at risk (R2-KI-1). However, the development of microbicides in these two projects was at an early stage, and impact on access to services will be dependent on their availability on the market. Moreover, if/when these microbicides do become available, their actual contribution to improving access to services will be difficult to measure, given that access is determined by a wider range of factors, as outlined in Chapter 3 of this report, including the availability of funding, and awareness of, and knowledge about, these and other products on the market, among others.

Improving the quality of life for PLWHIV

Given that the microbicides projects are at an early stage of development, they have not had a direct impact on PLWHIV, as described above. However, the knowledge that results from EuroCoord has the potential to have a direct impact on patients. The cohorts that participate in the EuroCoord network follow patients over time to achieve the network's objective of optimising the clinical management of PLWHIV [104]. Interventions or strategies that result in improvements in the clinical management of patients with HIV can have a significant impact on patients as well as their families and communities [104]. EuroCoord facilitates the sharing of advances in patient management where it occurs across Europe, through its numerous publications with high healthcare delivery impact (see Appendix E, Table 3).

5.1.5. Improving education, knowledge and awareness of HIV/AIDS (EQ 10)

Improving education, knowledge and awareness of HIV/AIDS as a result of EU-funded research is specifically related to EQ 10. This evaluation question is important for a number of reasons, although it should be noted that improving education, knowledge and awareness was not a key goal of any of the case study projects. One key informant noted that, in the past, advocacy groups within the community were not well aligned with HIV research (R2-KI-3). The key informant reported that this had led to what the informant perceived to be unrealistic expectations regarding the timeline for the likely development of microbicides, vaccines or even HIV cures, and that this might have negatively impacted on risk-taking behaviour among vulnerable groups. This highlights the need for the provision of regular and timely information on research developments and advances. It was also contended that research developments may be

affecting the way HIV and associated behaviours are conceptualised. For example, the same key informant noted that developments in areas such as 'treatment as prevention' had changed society's understanding of safe sex, a change that would have to be taken into account for policy development, highlighting that the term 'prevention' in relation to HIV had now extended beyond the notion of condom use (R2-KI-3).

Several of the case study projects highlighted the role of FP7-funded research in the education and training of future researchers and decisionmakers. The AIM-HIV *ImpactFinder* survey respondent described the contribution of master's degree students to the development of their project, the involvement of undergraduate students in conducting the research, and the project's role in informing a live presentation and providing mentoring for students. Similar activities were reported by the FUTURE-PHARMA survey respondent and by respondents from the CHAARM project (8 of 14 respondents). CHAARM respondents also reported that the project contributed to education and training through informing the modification of teaching methods and approaches, exams, course content and online research tools/resources that are used by educational institutions. Other contributions that were mentioned included the addition of CHAARM outputs to school reading lists and the development of free access websites used or referred to in higher educational institutions (one CHAARM respondent). This latter contribution was also mentioned by one of the two MOTIF survey respondents.

The *ImpactFinder* survey further indicated that EuroCoord's research had improved education programmes on HIV/AIDS, improved public understanding of HIV and associated issues and improved public awareness of HIV/AIDS. However, one key informant noted that it was unclear to what extent EuroCoord has had a direct impact on improving public knowledge and understanding of HIV/AIDS in Europe (R1-KI-1). According to one key informant, '*EuroCoord isn't that good at working with the public*' (R1-KI-2). The same key informant noted that '*a weakness is getting this information out to the public*' (R1-KI-2). It is possible that EuroCoord may have had a greater impact on the more informed public. It was noted that EuroCoord had engaged civil society organisations, although there was a perception that more could be done to involve groups who are affected by HIV/AIDS in the research (R1-KI-2). Although it is clear that there have been numerous activities within the case study projects designed to enhance knowledge, awareness and education, the actual impact in these areas is difficult to measure, as is their ability to lead to lasting, long-term impacts.

5.2. The Health Programme (EQ 11)

Evaluation question 11 seeks to understand the extent to which actions funded through the Health Programme have led to outputs that have contributed to the attainment of objectives set out in the Communication. However, it should be noted that the Health Programme 2008–2013 was launched before the Communication and its Action Plan were adopted (October 2009). For this reason, we focused our research on projects, joint actions, conferences, direct grant agreements and tenders (hereafter referred to as projects) funded from 2009 onwards.

We have identified 25 projects that are directly or indirectly related to HIV with a total budget of €12.2 million (see Table 5.2) [105]. The Consumers, Health and Food Executive Agency (Chafea) has screened various descriptions of these projects for the mention of the Communication and its Action Plan and reported that 17 of these mentioned at least one of the documents or explained how actions were aligned with them. For example: '*In line with the last Communication on combating HIV/AIDS in the European Union and neighbouring countries (2009–2013) the overall objective of this project is to carry out and promote combined and targeted prevention complemented by a meaningful surveillance among MSM*' (description of the SIALON II project) [106].

Table 5.2. Overview of Health Programme projects that directly or indirectly address HIV, 2009–2013

#	Acronym (ID number)	Title	Year of funding	Communication / Action Plan contribution described *	Status †	Final Report ‡	Evaluation Report §	Lead
1.	SANL_FY2009 (20083271)	AIDS Action Europe support: Public policy dialogue and linking and learning - Operating grant	2009	Mentioned	Finalised	Available	Evaluation part Final report	NL
2.	IHRA (20094205)	International Harm Reduction Association's International Conference	2009	Not mentioned	Finalised	Available	Available	UK
3.	HIV-COBATEST (20091211)	HIV community-based testing practices in Europe project	2009	Mentioned	Finalised	Available	Available	ES
4.	BORDERNET work (20091202)	Highly active prevention: Scale up HIV/AIDS/STI prevention project	2009	Mentioned	Finalised	Available	Available	DE
5.	Imp.Ac.T (20091201)	Improving Access to HIV/TB testing for marginalised groups project	2009	Mentioned	Finalised	Available	Available	IT
6.	HPYP (20091212)	Health Promotion for Young Prisoners project	2009	Mentioned	Finalised	Available	Available	DE
7.	SRAP (20091218)	Addiction Prevention within Roma and Sinti Communities project	2009	Not mentioned	Finalised	Available	Available	IT
8.	UNAIDS (20095201)	UNAIDS Awareness Raising on HIV/AIDS with a particular focus on Eastern Europe: Support to the World AIDS Conference 2010 in Vienna direct grant agreement	2009	Mentioned	Finalised	Available	Available	WHO
9.	AIDS2011 (20104301)	HIV in European Region - Unity and Diversity conference	2010	Mentioned	Finalised	Available	Available	EE
10.	FEMP2011 (20104305)	Men, Men, Sex and HIV 2011 - The Future of European Prevention among MSM conference	2010	Not mentioned	Finalised	Available	Not planned	SE
11.	SANL_FY2010 (20093206)	AIDS Action Europe support: Public policy dialogue and linking and learning - Operating grant	2010	Mentioned	Finalised	Available	Evaluation part Final report	NL
12.	EU-HEP-SCREEN (20101105)	Screening for Hepatitis B and C among migrants in the European Union project	2010	Not mentioned	Ongoing	Interim report available	Planned	NL
13.	SIALON II (20101211)	Capacity building in combining targeted prevention with meaningful HIV surveillance among MSM project	2010	Mentioned	Ongoing	Interim report available	Planned	IT
14.	TUBIDU (20101104)	Empowering civil society and public health system to fight tuberculosis epidemic among vulnerable groups project	2010	Not mentioned	Ongoing	Interim report available	External planned	EE
15.	HIV CONCEPTS (20116201)	HIV and co-infection prevention strategies - concepts for the future contract	2011	Mentioned	Finalised	Available	N/A	NL

#	Acronym (ID number)	Title	Year of funding	Communication / Action Plan contribution described *	Status †	Final Report ‡	Evaluation Report §	Lead
16.	CR2003 HR (20116111)	Current state of play of the 2003 Council Recommendation on the prevention and reduction of health-related harm, associated with drug dependence, in the EU and candidate countries contract	2011	Not mentioned	Finalised	Available	N/A	LU
17.	HIV in Europe (20114202)	HIV in Europe Copenhagen 2012 Conference	2011	Mentioned	Finalised	Available	Available	DK
18.	SANL_FY2011 (20103207)	AIDS Action Europe support: Public policy dialogue and linking and learning - Operating grant	2011	Mentioned	Finalised	Available	Evaluation part Final report	NL
19.	QHP (20122102)	Improving Quality in HIV Prevention Joint Action	2012	Mentioned	Ongoing	Planned	Planned	DE
20.	FRG (20123304)	Correlation-net / Reduce health inequalities and improve accessibility - Operating grant	2012	Not mentioned	Finalised	Available	Evaluation part Final report	NL
21.	SANL_FY2012 (20113210)	AIDS Action Europe support: Public policy dialogue and linking and learning - Operating grant	2012	Mentioned	Finalised	Available	Evaluation part Final report	NL
22.	SANL_FY2013 (20123201)	AIDS Action Europe support: Public policy dialogue and linking and learning - Operating grant	2013	Mentioned	Finalised	Available	Evaluation part Final report	NL
23.	ICAN	Increasing Capacities, Achieving Novelty: Pan-European Conference on Community Empowerment and Sustainable Response to HIV/AIDS conference	2013	Mentioned	Ongoing	Planned	Planned	BE
24.	EUROHIV EDAT (20131101)	Operational knowledge to improve HIV early diagnosis and treatment among vulnerable groups in Europe project	2013	Mentioned	Ongoing	Planned	Planned	ES
25.	OPT TEST HiE	Optimising testing and linkage to care for HIV across Europe project	2013	Not mentioned	Ongoing	Planned	Planned	DK

NOTE: * Chafea database abstracts, deliverables, including final reports or survey performed by Chafea in 2013; † Status by June 2014; ‡ Following Chafea dissemination rules: final reports are considered confidential documents, as they include personal and financial data. In line with the EU publications, they can be obtained upon request to Chafea, CHAFEA@ec.europa.eu; § Evaluation reports are not planned for the contracts or request for services.

SOURCE: Chafea information sources: database abstracts, deliverables, including final reports or survey performed by Chafea in 2013 [107]

The projects address five main areas, which are also covered by the Action Plan: (1) leadership (including policies and wider society); (2) HIV prevention; (3) priority regions; (4) priority groups (including PWID, MSM, sex workers, migrants and prisoners); and (5) knowledge, monitoring and evaluation and thus contribute, directly or indirectly, to the three objectives set out by the Communication [108].

The analysis of project objectives as stated in the descriptions of projects available from the Chafea website and reviewed here showed that they are aligned most directly with the second objective of the Communication (improving access to services); the notion of 'prevention in relation to HIV' was mentioned in the descriptions of 20 projects. Conversely, the first objective of the Communication, 'reducing new infections', was not mentioned in any of the project descriptions included in this review and only one referred to 'quality of life of people living with HIV' (the third objective of the Communication).

Of the key informants interviewed for this study who commented on the extent to which Health Programme actions have led to outputs that have contributed to the attainment of the Communication's objectives, one believed that such had contributed to improving access to HIV testing in health centres and that had also enabled the implementation of community-based testing (KI-3). This informant also thought that the HIV COBATEST project had helped change legislation to authorise rapid testing at a community level in one central European country. The informant further commented that a number of Health Programme projects had contributed to scaling up treatment among priority target groups (such as PWID, migrants and prisoners).

Overall, there was little published evidence on actual measurable outcomes of Health Programme projects that mentioned or were aligned with the Communication objectives. According to the Chafea, by June 2014, 18 of these projects had been completed and of these, 15 had provided an evaluation report. Six other projects (of all 25 analysed) documented plans to evaluate their activities and publish evaluation reports, but at the time of writing, information on the methods or results of these evaluations was not available.

In 2013 the Chafea reported that '*it is too early to measure the results [of the Health Programme funding] and particular the effects on the HIV epidemic in Europe*' [109]. At the same time, the Chafea was able to identify a small number of relevant project outputs [109 110]:

- epidemiological and behavioural surveys conducted by BORDERNETwork and Imp.Ac.T, which focused on screening for HIV and co-infections among sex workers, migrants and PWID
- the development of training tools and materials by, for example, BORDERNETwork, Imp.Ac.T, SRAP, TUBIDU, SANL and SIALON II
- capacity building and network development (e.g. SANL, HIV-COBATEST, CORRELATION NETWORK).

In 2014, the Chafea reported on the findings of HIV prevention actions funded though the Health Programme in the context of 'situation analysis reports' [110]. These are summarised further in Box 5.2.

Box 5.2. Key outputs of the Health Programme: Situation analysis reports, 2009–2013

1. Politics, policies and involvement of civil society, wider society and stakeholders

The current state of play of the 2003 Council Recommendation on the prevention and reduction of health-related harm, associated with drug dependence, in the EU and candidate countries report provides an overview of the implementation of the Recommendation, including country profiles, regional and EU trends in epidemiology, and the availability of, access to and coverage of harm reduction measures [79].

2. Prevention

The community-based voluntary counselling and testing (CBVCT) programmes were monitored in eight European countries through the HIV-COBATEST project. A qualitative study identified key issues related to the promotion of testing and counselling. The project resulted in the development of a code of good practices for the implementation of CBVCT services and of indicators to monitor and evaluate HIV testing and counselling practices used by CBVCT services in Europe [111].

The Addiction Prevention within Roma and Sinti Communities (SRAP) project used qualitative action research in 6 Member States, targeting young people between the ages of 11 and 25 within Roma communities [112].

3. Priority regions

The BORDERNET work project carried out action research and compared the sentinel surveillance in STI among patients among four countries. The study identified differences in diagnostics, vulnerable groups, and patterns of HIV and STI transmission and it helped build strong regional networks. A survey carried out among female sex workers compared the utilisation of general healthcare in seven Member States [113].

The TUBIDU project (the acronym translates as 'Empowering the public health system and civil society to fight the tuberculosis epidemic among vulnerable groups') reviewed evidence to assess HIV and TB knowledge and the barriers related to access to care among vulnerable groups in Eastern and Central European countries. The project produced a cross-sectional study among injecting drug users [114].

4. Priority groups

The SIALON II project implemented a European bio-behaviour survey in 15 EU countries using time and location sampling (TLS) and respondent-driven sampling (RDS) methods. The SIALON experts have developed a formative research report describing the situation of MSM in 13 countries, covering demographics, gay-friendly commercial and non-commercial sites, prevention activities, legislation and stigma [115].

The Health Promotion of Young Prisoners (HPYP) project carried out a comprehensive review of the policy context of the youth justice system and health promotion in six MS based on literature review, surveys, focus groups and expert interviews.

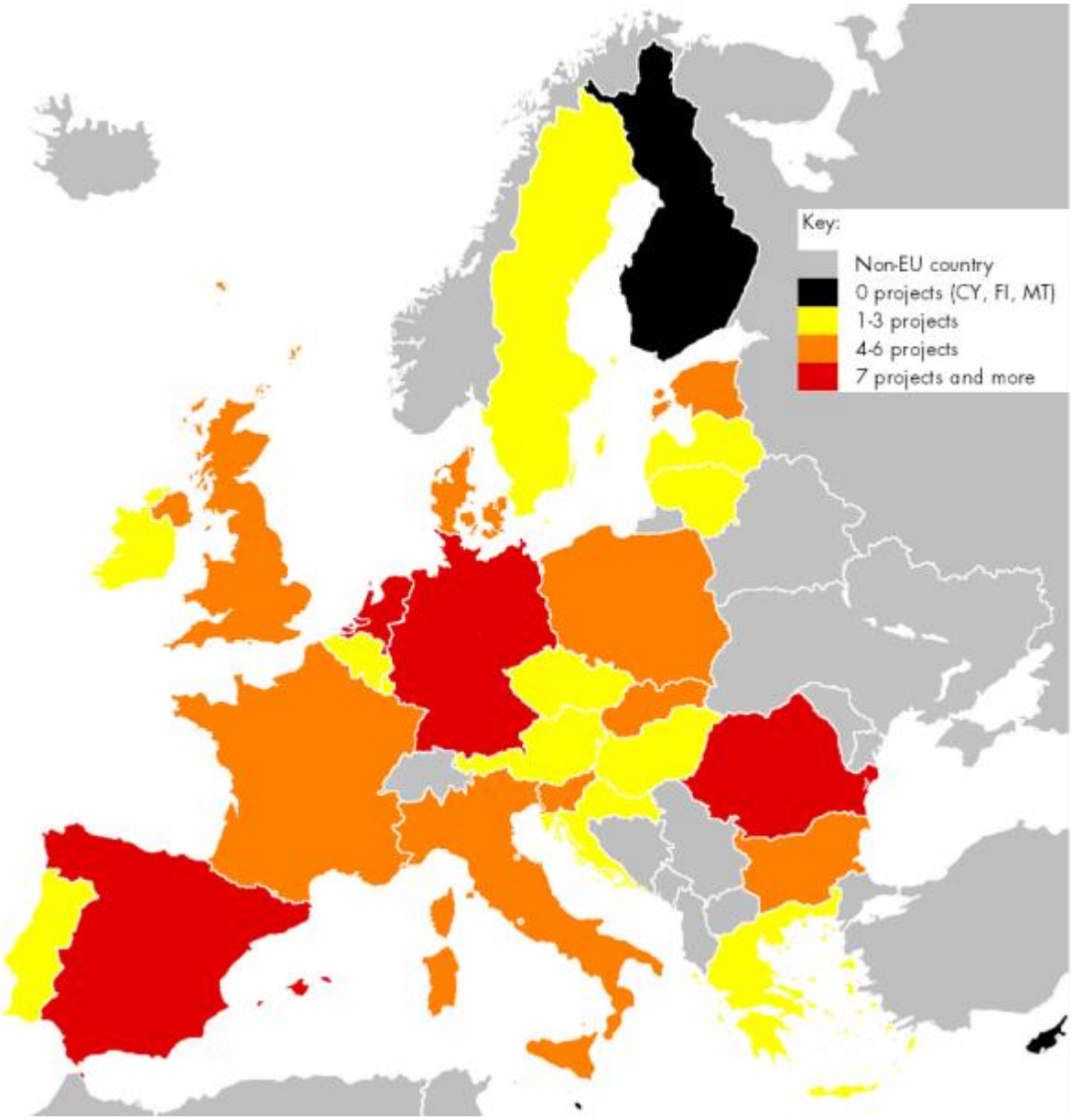
NOTE: The textbox does not include projects funded in 2008 (i.e. prior to the adoption of the Communication).

SOURCE: Chafea, 2014 [107 110]

In its monitoring report to the ECDC 2012, the Chafea reported that at that time '*most of the actions* [that] *are funded in 2009 are still on-going […]. One limitation of several projects is the geographic scope, which is limited to fewer countries or cities, what hamper*[s] *the extension of the interventions*' [109]. According to the Chafea, this situation was modified at a later stage of the implementation of the Health Programme with actions representing large partnerships. Figure 5.4 illustrates the level of involvement of individual EU Member States in Health Programme projects relating to HIV (2009–2013), showing wide variation, from fewer than three projects in the majority of countries to more than seven in countries such as Bulgaria, Germany, the Netherlands and Spain. The figure indicates that Greece has had a relatively low level of participation in the Health Programme, even though it has experienced a major outbreak of HIV in recent years [116]. In the period under review, Portugal and Latvia have had low levels of participation (two and three, respectively), even though they have experienced high rates of new diagnoses and reported AIDS cases [33]. The participation in the 25 Health Programme actions depends on the organisations' capacities

to apply under the annual call for proposals. Thus the low participation of some countries likely reflects insufficient capacity, interest or matching funding required for participation in the Health Programme.

Figure 5.4. Number of Health Programme projects relating to HIV per Member State (2009–2013)



NOTE: CY stands for Cyprus, FI for Finland and MT for Malta. EFTA/EEA countries are eligible for Health Programme funding, yet neither Norway nor Iceland participated in HIV-related projects in the reviewed period.

SOURCE: Chafea

On average, during 2009 and 2013, Member States led, or participated in, 3.5 Health Programme–funded activities, but, as indicated above, average participation rates varied. For example, Germany participated in 9 actions, 9 countries participated in 5 to 7 projects (the Netherland [7], Romania [7], Spain [7], Estonia [6], Italy [6], the UK [6], Bulgaria [5],

Slovenia [5] and Slovakia [5]); 5 countries (Belgium, the Czech Republic, Latvia, Lithuania and Sweden) contributed to 3 actions, and 3 EU countries (Finland, Cyprus and Malta) did not participate in any Health Programme–funded activities.

Of 28 Member States, 9 led HIV-related Health Programme actions, and these were typically based in Western Europe (the Netherlands [8], Germany [4], Italy [3], Denmark [2], Spain [2], and Luxembourg, Sweden and the UK [1 each]); the exception is Estonia, which led 2 two actions. The Netherlands led the highest number of actions (8), followed by Germany (4), Italy (3) and Estonia, Denmark and Spain (2 each), while the remaining countries led 1 project each. Please note that the large number of actions led by the Netherlands results from the fact that five operating grants were managed by Stichting Aids Fonds–Soa Aids Nederland (SANL) on behalf of the AAE network, the CSF co-chair.

With regard to cooperation on Health Programme projects, 25 out of 28 countries were partner on more than one action. The largest number of organisations participating were based in Germany (9), followed by Spain, the Netherlands and Romania (7 each); Estonia, the United Kingdom and Italy (6 each); Bulgaria, Slovenia and Slovakia (5 each); Denmark, France and Poland (4 each); and Belgium, the Czech Republic, Lithuania, Latvia and Sweden (3 each).

Among the EU countries that joined the EU after 2004, Romania was a partner on the greatest number of actions (seven), followed by Estonia (six) and Bulgaria, Slovenia, Slovakia (five each). Poland, Czech Republic, Lithuania and Latvia have actively participated in three actions each. This high level of participation of the Eastern EU countries demonstrates the importance of the Health Programme to tackle the epidemic in the EU's most affected countries, as these countries belong to one of the key priority regions, were the epidemic is driven by the transmission among PWID.

5.3. Exchange of experience in the area of HIV/AIDS through EU programmes (EQ 5)

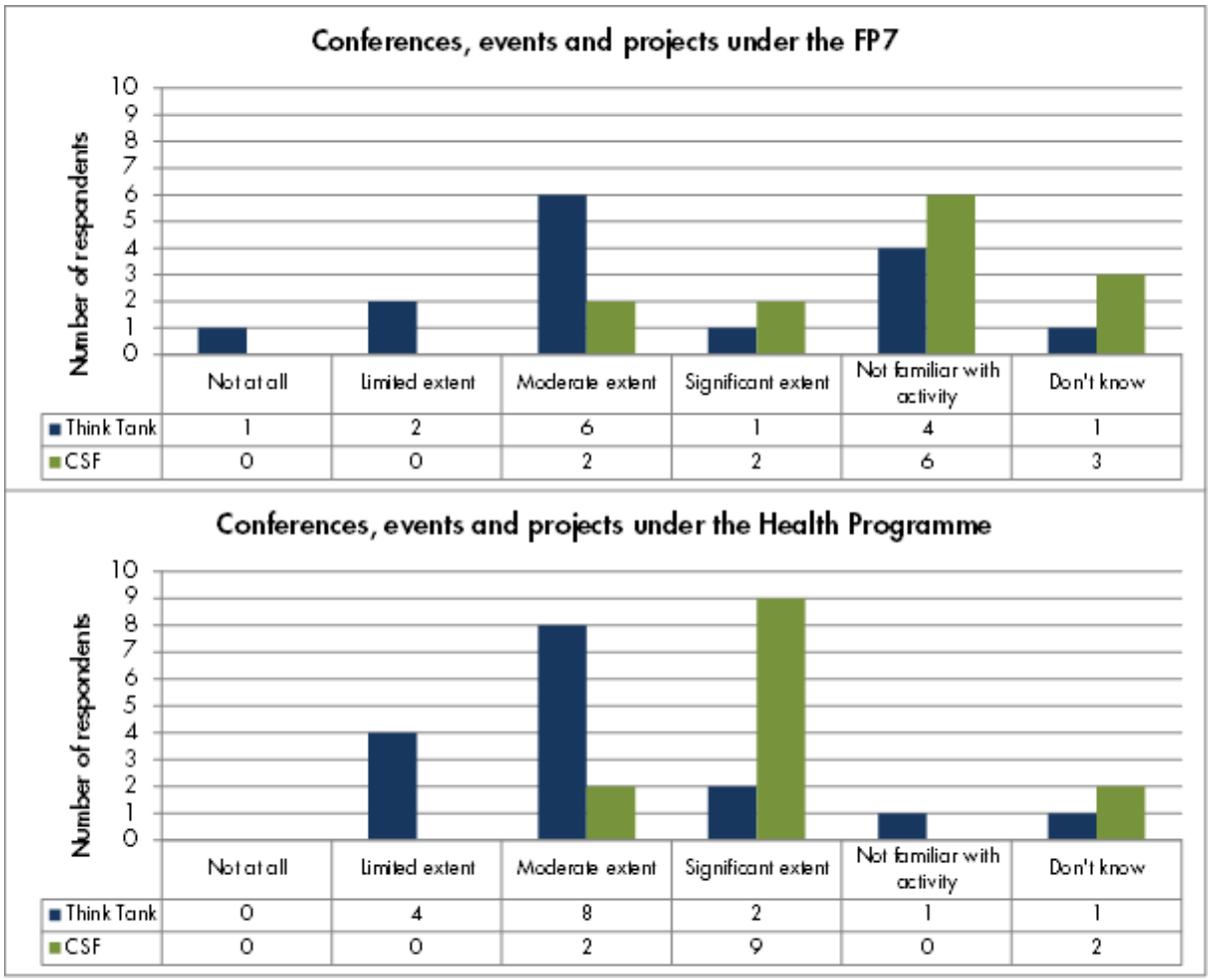
FP7 Cooperation Programme funding, which supports EuroCoord, CHAARM, MOTIF and AIM-HIV, is usually awarded to consortia of research or research-intensive organisations, and it is a requirement that at least three countries participate in FP7-funded projects; this is not a requirement of the FP7 Idea and People Programmes. For example, the EuroCoord and CHAARM projects bring together 16 and 9 country partners, respectively. FP7 project participation is not restricted to collaborations between Member States. For example, both the EuroCoord and CHAARM projects include neighbouring country partners (EuroCoord: Belarus and the Russian Federation; CHAARM: Ukraine) and non-European international country partners (EuroCoord: Israel and Argentina; CHAARM: United States and South Africa). However, while countries such as Belarus, Russia, Ukraine, Argentina and South Africa could apply for funding as International Cooperation Partner Countries and Israel could apply as a country associated with FP7 (providing all minimum conditions are met), the United States would not normally be eligible to receive EC funds covering the costs related to their participation in the project. In the case of the Health Programme, the number of country partners ranges from one main beneficiary to many participating Members States,

such as QHP, with partners from 27 countries, or SIALON II, which includes partners from 13 countries, for different projects, activities and operating grants [117 118].[11]

Respondents to the Think Tank and CSF surveys suggested that conferences, events and projects funded under the FP7 (11 out of 28 respondents) and the Health Programme (21 out of 29 respondents) had played a role in facilitating the exchange of knowledge between countries, allowing for learning from other countries' experience in addressing HIV/AIDS (Figure 5.5). The role of FP7 in sharing experiences was mentioned mainly by respondents from Western European countries, whereas the contribution of the Health Programme to learning was mentioned by respondents from across the European region. It is important to note that 10 survey respondents stated that they were not familiar with FP7 activities and a further 4 did not know of any impact of these activities. However, the nature of a survey does not permit probing of respondents, and it would be misleading to interpret the reported lack of awareness of impacts from these survey respondents as an actual lack of impact. However, the lack of awareness of impacts among survey respondents, especially among the Think Tank respondents (4 out of 15), suggests that there may be room for improvement in the dissemination and communication of FP7 outputs.

[11] This diversity partially reflects a wide range of types of projects funded (from conferences and grant agreements to joint actions and projects).

Figure 5.5. Perceptions of Think Tank and CSF members of the extent to which EU programmes have allowed for learning from other countries' experience in addressing HIV/AIDS



SOURCE: Think Tank and CSF member surveys

Eight respondents provided examples illustrating the exchange of experience in the area of HIV/AIDS as a result of EU-funded programmes. These predominantly concerned a perceived opportunity to interact with colleagues and representatives from other countries (reported by three Western and three Central European countries) and a human rights conference held in 2013 (mentioned by three Western European countries). One Think Tank survey respondent noted that '*even though our participation is limited, we consider those events a great resource for building organisational and country capacity*'.

Respondents to the Think Tank and CSF surveys indicated that the top three instruments that help them learn from other countries' experience in addressing HIV/AIDS were as follows:

- Think Tank respondents: academic literature (12 out of 16), Think Tank meetings (11 out of 16) and ECDC reporting (11 out of 16)
- CSF respondents: reports of international organisations (12 out of 14), CSF activities (10 out of 16) and ECDC reporting (10 out of 16) (Appendix B)

The collaboration between countries as a result of EU-funded programmes was also discussed with key informants. One key informant noted that the collaboration through EU

programmes had led to building '*networks that could not exist before*' (KI-2). One further key informant highlighted that participation in European projects was an important mechanism for the exchange of information between countries (LV-KI-1). However, the ability to engage in European projects may be limited by a lack of financial resources, an issue raised by key informants from Bulgaria and Latvia, who cited a lack of capacity and the requirement for co-financing as major obstacles (BG-KI-1, LV-KI-1). One key informant pointed to the issue of language and the fact that research was predominantly published in the English language, which could act as a barrier to the exchange of experience in some parts of Europe: '*more efforts should be made into translating the science into policy, both from the view point of more easily understood messages but also messages that would more easily reach Eastern Europe*' (R1-KI-1). Reflecting on the Health Programme in particular, one key informant noted that, since 2011, there had been fewer opportunities to obtain funding through that programme and fewer calls for proposals for cooperation between countries (KI-6).

Research case studies undertaken for this evaluation provide further insight into collaboration and learning among countries. EuroCoord contributed to an exchange of experience by including a work package dedicated to improving research skills, specifically statistical methods in observational studies and laboratory clinical training [119]. As described earlier in this chapter, EuroCoord also facilitates knowledge sharing through the development of online resources, residential courses, PhD support and short-term staff exchanges [104].

Activities of AIDS Action Europe (20093206, 20103207 and 20113210), supported by the Health Programme, provide another example of exchange of experience in the area of HIV/AIDS through EU-funded programmes (Appendix F). The funding aimed, among other things, to contribute to capacity development and the exchange of good practice [120]. The key tool in achieving this objective was the clearinghouse managed by the AAE that provided access to good practices on effective and sustainable interventions in the field of HIV/AIDS [121]. The clearinghouse enabled NGOs and other organisations to stay up to date with respect to pertinent developments in the field of HIV and to find potential partner organisations through use of the website [122]. The most recent data provided by the AAE point to an 8 per cent increase in the number of uploads to the clearinghouse (lower than the expected 20 per cent increase due to an update of the database), 12 updates on the clearinghouse and the fact that 80 per cent of new uploads were communicated through social media [123].

5.4. European added value (EQ 3)

EU-funded (research) projects enable their beneficiaries to establish and maintain collaborations and networks with other European countries and, in some instances, with countries outside of Europe. This facilitation of international collaboration between research partners, as opposed to more limited national programmes, was seen as a significant added value of FP7 funding in achieving advances in scientific discovery (R2-KI-1): '*it's hard to get funding that supports international collaboration in that way. National funding tends to mean that research is focused in the country, whereas the EU funding, particularly the FP7, is very much for transnational collaboration. I think that without that, I cannot see how many of these [collaborations] would have happened*' (R2-KI-1). These collaborations were

seen by the key informant to provide researchers with a broader view and understanding of their research area through interaction and knowledge-sharing facilitated across different areas of science (R2-KI-1).

Two key informants further suggested that there may be a larger role for the EU to play in terms of coordinating and funding HIV research (R2-KI-4, R2-KI-3). One thought that DG SANCO, DG RTD and the Directorate-General for Development and Cooperation (DG DEVCO) needed to adopt a more cohesive approach to addressing poverty-related diseases, such as HIV (R2-KI-4), while the second key informant believed there to be a lack of a central research policy direction to select the most promising candidates for drug, vaccine or microbicidal development, at an early stage of research, for further examination and to avoid spending time considering less promising candidates (R2-KI-3). The same key informant also reported that there was a gap, at the European level, between basic science and implementation research, given that '*we do not know a number of issues such as patterns of migration in MSM in Europe, the needs of transgender people in Europe and the actual impact of illegalization and criminalization of HIV on behaviour*' (R2-KI-3). The key informant believed that this type of social science research does not have a home at the European level even though, in the informant's opinion, it was particularly important for designing and developing HIV research, even in relation to basic science (R2-KI-3). The key informant also noted that HIV research on prevention, treatment and a cure should not be separate from basic science research, as breakthroughs in one area are likely to lead to gains in others (R2-KI-3).

5.5. Summary

In this chapter we sought to understand (i) the extent to which FP7 funding has led to the development of novel preventive tools and therapeutic options and how these have contributed to the Communication's objectives; (ii) the effects of EU-funded projects on the level of awareness of HIV; (iii) the extent to which the Health Programme has contributed to the objectives set out in the Communication; and (iv) the extent to which the EU-funded programmes facilitated exchange of experience between countries in the area of HIV.

Contribution of EU-funded research to the objectives set out in the Communication

In evaluating the case study projects against the objectives of the Communication, it should be noted that the objective to develop novel preventive tools or therapeutic or prophylactic pharmaceutical products only applies to the microbicide development projects, given that this is not the intention of the EuroCoord project. The CHAARM project has two microbicide candidates entering phase 1 clinical trials. It is not within the scope of the existing project to take testing beyond this phase, but it is within the remit of the European and Developing Countries Clinical Trials Partnership.

In addition, all microbicide projects anticipated developments in this area in the future, confirming that microbicidal development is at an early stage universally.

The EuroCoord and microbicide development case studies showed that FP7-funded research has contributed to surveillance methods. In particular, EuroCoord has had an impact on national surveillance strategies and the type of data that are collected across Europe. For example, the CASCADE network worked closely with national surveillance systems to

improve the surveillance of HIV in the UK, France and Germany, among other countries, and the pooling of data has had implications on surveillance capabilities.

There is also the potential for other projects to impact on surveillance as they move further down the different stages of product development. Specifically, the development of microbicides will require large behavioural studies in order to produce a product that the target population will actually use. These studies will provide information on practices and the type of data that are collected.

As noted above and in Chapter 3, there are a number of issues in measuring the number of new infections. However, the contributions to improved public awareness and education programmes noted by all case study projects have the potential to, in turn, contribute to a reduction in new HIV infections. However, an assessment of the contribution of these projects to that end has not been attempted here.

This evaluation yielded little evidence on the contribution of FP7-funded projects to improving access to key services. While one interviewee noted that the development of microbicides may indirectly improve access to services by providing a product that at-risk groups are likely to use, measuring the contribution of these projects to that end raises a number of challenges.

The knowledge resulting from EuroCoord has the potential to have an impact on the patients participating in the EuroCoord cohorts. The sharing of advances in patient management facilitated by the EuroCoord project has the potential to positively impact on patients and their families across Europe.

Improving education, knowledge and awareness of HIV/AIDS

The evaluation has found evidence that case study projects (EuroCoord, AIM-HIV, CHAARM, FUTURE-PHARMA and MOTIF) contributed to activities that raised awareness around HIV prevention and treatment. These projects reported impacts on educating and training future researchers and decisionmakers related to HIV/AIDS (AIM-HIV, FUTURE-PHARMA, CHAARM, MOTIF) and improving education programmes on HIV/AIDS, public understanding of HIV and associated issues and public awareness of HIV/AIDS (EuroCoord). However, it is possible that EuroCoord may have had a greater impact on the more informed public and that more could be done to involve groups who are infected or affected by HIV/AIDS in the research. Although it is clear that there have been numerous activities within the reviewed projects designed to impact on knowledge, awareness and education, the actual impact in these areas is difficult to measure, as is their ability to lead to lasting, long-term impacts.

Contribution of the Health Programme to the objectives set out in the Communication

There is some evidence that the outputs arising from actions funded through the Health Programme are in keeping with the objectives of the Communication and its Action Plan. However, there may be some scope to improve the alignment of the objectives of the Communication and its Action Plan with the Health Programme, because only half of the projects explicitly stated that their outputs would contribute to the objectives of the Communication. However, at the time of writing this report, the majority of the Health Programme projects were still ongoing and their preliminary findings have just started to contribute to the objectives set out in the Communication.

The main type of outputs produced by the HIV prevention actions funded through the Health Programme include eight situation analysis reports produced between 2009 and 2011; training packages; and guides or tools for the support of health professionals and community organisations.

Exchange of experience in the area of HIV/AIDS

Data collected in the evaluation supports the notion that EU-funded programmes have facilitated the establishment and development of research networks and have promoted collaboration and exchange of experience among countries. However, the evidence from the survey with Think Tank and CSF members indicated that, in comparison to the academic and grey literature (e.g. reports from the ECDC and other international organisations) and the meetings of the Think Tank members and CSF activities, EU-funded projects and activities have played a smaller role in facilitating learning from other countries' experience.

Out of all 28 Think Tank and CSF respondents, 17 were not familiar with, or did not know of any impact from, EU-funded scientific research. This lack of awareness of the contribution of EU-funded research to combating HIV/AIDS in Europe suggests that more efforts could be made to disseminate the findings of this research to a broader range of stakeholders across Europe.

European added value

Key informants reported that EU funding had been an important enabler of FP7 and Public Health projects. The EU funding was deemed '*crucial*' by one key informant in facilitating international collaborations and networks, and another key informant considered EuroCoord's facilitation of data sharing to be a key strength in bringing together various groups in discussion and enabling the comparison of data.

The EU funding is awarded on a competitive basis, which allows the evaluation committee formed by a panel of independent experts to evaluate and rank proposals that best address the requirements that are set out in the call for proposals of a particular topic and that provide some degree of flexibility in the delivery of projects. This means that calls for proposals are not prescriptive and leave some room for researchers to try out and test different approaches. This flexibility is particularly relevant in FP7 funding because it supports innovation through research and development. However, this evaluation found that the current approach to funding might benefit from better coordination at the European level. This could address the following limitations that were identified in this study: (i) the uneven geographical distribution of funding for HIV-related Health Programme projects; (ii) a perceived disconnect between basic science and the implementation of research findings; and (iii) a perceived lack of strategic orientation of funding in the area of HIV-related research.

6. Funding to support HIV prevention, treatment, care and support

This chapter reports on evidence of efficiency and sustainability of national and EU funding to support HIV/AIDS policies, programmes and actions in EU Member States and neighbouring countries. It explores (i) EU funds allocated to HIV/AIDS and the EC's contribution to the Global Fund (EQ 12); (ii)EU funds allocated to priority groups (EQ 13); (iii) spending on HIV/AIDS and co-infections by Member States (EQ 16); (iv) the way in which the EU could support NGOs (EQ 15); and (v) the effects of the financial crisis in Europe on HIV/AIDS and the potential ways of addressing these (EQ 14). The chapter also explores the European added value of the Communication and its Action Plan in relation to funding at the EU level to combat HIV/AIDS in Europe (EQ 3). An overall summary of the findings is provided at the end of this section.

Box 6.1. Evaluation questions addressed in Chapter 6

Evaluation question 3

What is the European added value of the Communication?

Evaluation question 12

(1) What is the exact amount spent on HIV prevention, treatment, care and support by the EU since 2009?
(2) What is the proportion of funding of the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) in the Member States that is directly attributable to the EU budget contribution?

Evaluation question 13

How have the EU funds been spread across the main target groups?

Evaluation question 14

(1) What are the consequences of the financial crisis on national responses to HIV?
(2) How could these consequences be addressed by the EU?

Evaluation question 15

How can the EU help NGOs to continue their work on HIV that is no longer supported by the Global Fund?

Evaluation question 16

What is the proportion of national funding that is spent on HIV/AIDS and co-infections treatment in the EU Member States?

6.1. Spending on HIV prevention, treatment, care and support (EQ 12-1)

Table 6.1 provides estimates for annual financial support, at the EU level, of HIV prevention, treatment and care for the period 2009–2013 by programme, agency and organisation. Figures shown are based on data directly requested from the relevant beneficiary or on published sources, including the 2013 ECDC monitoring report of the EC Communication (shown in bold) [124].

Figures provided by beneficiaries directly differ at times from those given in the 2013 ECDC, reflecting different reporting periods and differences in the number of countries or regions covered. For example, ECDC estimates for spending under FP7 cover the period 2007–2012, whereas data provided by beneficiaries directly report on 2009–2013. Also, with regard to EU funding allocated to the Investing in People programme, the ECDC report includes all ENP countries, whereas the evaluation documented in this report considers Belarus, Moldova and Ukraine only.

Drawing on data shown in Table 6.1, the overall spending at the EU level on HIV prevention, treatment care and support during 2009–2013 is estimated at approximately €150 million.

Table 6.1. Annual spending at the EU level on HIV prevention, treatment, care and support, 2009–2013 (in million Euro)

EU funding allocation	2009	2010	2011	2012	2013 *	Total	% spent on HIV/AIDS	Total spent on HIV/AIDS	Average spent per year on HIV/AIDS
EC pro-rata contribution to the GFATM in EU MS and the three ENP countries	1.8	1.7	2.0	1.9	1.0	8.4	100%	8.4	1.7
European Health Programme funding for EU MS	4.0	2.9	0.8	1.8	2.8	12.3	100%	12.3	2.4
FP7 projects	38.4	26.5	9.8	52.5	N/A	127.3	100%	127.3	31.8
EU total contribution to ECDC	-	-	-	-	-	-	HIV/AIDS not earmarked	3 †	0.7
EU total contribution to EMCDDA	-	-	-	-	-	-	HIV/AIDS not earmarked	N/A	N/A
EC financing for the activities of the Think Tank and CSF ¥	0.15	0.15	0.15	0.15	0.15	0.75	100%	0.75	0.15
Investing in People programme to build capacity of non-state actors, European Neighbourhood Partnership Instrument and the European Instrument for Democracy and Human Rights (EIDHR)	-	-	1.4	1.6	1.6	4.6	100%	4.6	1.5 §
Development Co-operation Instrument (DCI) funds to non-state actors and local authorities	1.3	1.3	1.3	1.3	1.3	6.5	100%	6.5	1.3
DPIP	N/A ‡								
Structural funds	N/A								

NOTE: * 2013 figures are based on allocated budget; † ECDC budgetary allocation to HIV/AIDS projects excluding ECDC staff time and additional supportive functions; ‡ ECDC, 2013 [21]; § Average calculated on the basis of spending for the period 2011–2013 in Belarus, Moldova and Ukraine.

6.2. Proportion of funding of the Global Fund in the Member States that is directly attributable to the EU budget contribution (EQ 12-2)

6.2.1. Contribution of the European Commission and EU Member States to the Global Fund

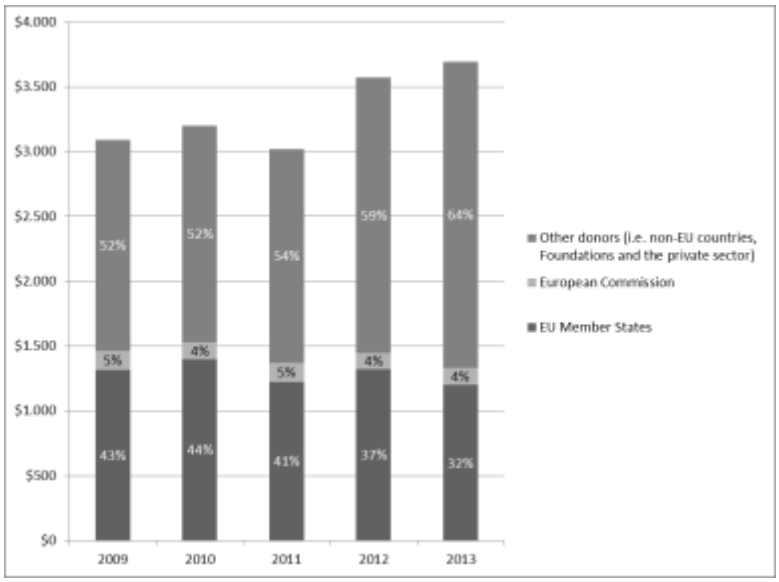
The Global Fund to Fight AIDS, Tuberculosis and Malaria was set up in 2002 to increase resources for combating AIDS, Tuberculosis and Malaria though partnerships between government, civil society, the private sector and communities living with the diseases [125]. The EC contributes to the Global Fund through two separate but matching routes [126 127]:

- The EU Development Cooperation Instrument (DCI), under the thematic programme Investing in People
- The European Development Fund (EDF), through funding in the African, Caribbean and Pacific (ACP) countries

In addition, individual EU MS directly contribute to the GFATM.

Figure 6.1 shows the annual contribution of the EU and EU MS as a percentage of the total GFATM budget for the period 2009–2013.

Figure 6.1. Financial contributions to the Global Fund by category of donor, 2009–2013 (in million USD)



NOTE: All the amounts presented in Section 6.2 are expressed in USD, as this is the currency used by the GFATM. When converting these into EUR, using the official EUROSTAT annual average exchange rate, some granularity would be lost, as financial data gathered by the GFATM are based on the actual exchange rate at the moment of the financial transaction. We therefore prefer to leave the amounts in USD.

SOURCE: GFATM [128]

This finds that:

1. The total financial contribution to the GFATM by all donors has increased from around USD 3.1 billion in 2009 to USD 3.7 billion in 2013.
2. During 2009–2013, the EC contributed an average of about USD 140 million per annum, representing about 4 per cent of the total contribution from all donors. Considering trends, the proportion of the EC contribution to the GFATM has slightly decreased, from 4.6 per cent in 2009 to 3.7 per cent in 2013. The EC contribution is disaggregated further in Table 6.2.

Table 6.2. Yearly contribution of the EC to the Global Fund, 2009–2013

	2009	2010	2011	2012	2013*	2009-2013
Share of EC contribution to the GFATM	4.6%	4.1%	4.9%	3.6%	3.7%	4.1%
Total EC contribution (in million USD)	143.3	130.2	147.1	127.9	135.2	683.7

NOTE: * 2013 figures refer to the amount pledged.

SOURCE: GFATM, 2013 [128]

3. During 2009–2013, EU MS contributions accounted for close to 40 per cent of all donor contributions to the GFATM (Table 6.3). Looking at trends over time, this share fell during the assessed period, from around 43 per cent in 2009 to 32 per cent in 2013. This decrease can be at least partially attributed to the financial crisis and a termination of contributions by Spain, which constituted a major donor until 2011. Ireland also ceased its contributions in 2011 [124]. At the same time, other countries increased their financial contribution to the GFATM, by between 10 per cent (Netherlands, UK) to 20 per cent (France, Sweden) during assessed period. The contribution of Germany remained at the same level.

Table 6.3. Yearly contribution of EU Member States to the Global Fund (2009–2013)

	2009	2010	2011	2012	2013*	2009-2013
Share of EU MS contribution to the GFATM	42.6%	43.8%	40.5%	37.0%	32.5%	39%
Total EU MS contribution (in million USD)	1,318	1,401	1,224	1,322	1,200	6,465

NOTE: * 2013 figures refer to the amount pledged.

SOURCE: GFATM, 2013 [129]

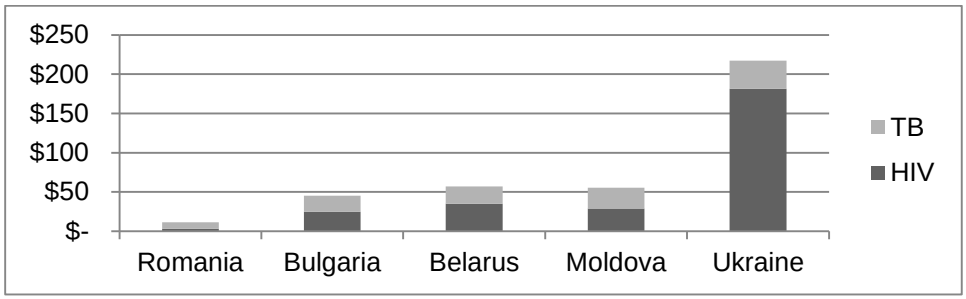
In 2013, the majority of EU Member States' pledged contributions to the GFATM came from the five largest EU donors, France, Germany, the United Kingdom, Sweden and the Netherlands. The precise annual amounts contributed or pledged per individual donor are given in Appendix G.

6.2.2. Contribution of the Global Fund to EU Member States and ENP countries

The GFATM provides grants in support of interventions for the prevention of infection and for the treatment, care and support of persons infected and affected by HIV/AIDS, tuberculosis (TB) and malaria. Since its creation in 2002, the GFATM has provided financial support to three EU MS (Bulgaria, Romania and Estonia), one acceding/candidate country (Croatia), and the three ENP countries (Belarus, Moldova and Ukraine) that have actively participated in the implementation of the EC Communication and its Action Plan. GFATM support to Estonia and Croatia was ceased in 2006 and 2007, respectively, and we therefore do not consider GFATM support for these two counties in the present report, which covers the period 2009–2013.

Figure 6.2 presents the level of GFATM financial support for Romania, Bulgaria, Belarus, Moldova and Ukraine during the period 2009–2013.

Figure 6.2. Level of GFATM financial support for Romania, Bulgaria, Belarus, Moldova and Ukraine, 2009–2013 (in million USD)



SOURCE: GFATM, 2013 [130]

This shows, first, that during 2009–2013, GFATM support was highest for Ukraine, exceeding USD 200 million, while funds granted to Bulgaria, Belarus and Moldova were in the region of about USD 50 million each, and those for Romania were USD 11 million. Second, there was considerable variation in the share of grant funding allocated to HIV/AIDS compared with tuberculosis, ranging from approximately 85 per cent in the Ukraine, to just over 60 per cent in Belarus, about half in Bulgaria, Belarus and Moldova, and one-quarter in Romania.

The total level of GFATM funding remained relatively stable over the period 2009–2013 for the three ENP countries, while it decreased in Bulgaria and Romania (see also Section 6.5).

Table 6.4 presents, for each of the five beneficiary countries, the proportion of financial support by the GFATM that was directly attributable to the EC budget during 2009–2013. The EC pro-rata contribution equated to a total of approximately USD 16 million, of which around 13.5 million were allocated to the three ENP countries. The EC pro-rata contribution allocated to Bulgaria and Romania together amounted to approximately USD 2.5 million. Further detail is provided in Appendix G.

Table 6.4. Total level of GFATM financial support for HIV/AIDS and TB and EC pro-rata contribution, 2009–2013 (in million USD)

Country	GFATM contribution for HIV/AIDS and TB	% EC contribution to the GFATM	EC pro-rata contribution to the GFATM for HIV/AIDS and TB
Ukraine	217.1	4.1%	8.94
Belarus	57.0		2.38
Moldova	55.3		2.24
Bulgaria	45.1		1.96
Romania	11.5		0.48
Total	385.9		16.02

SOURCE: GFATM, 2013 [130]

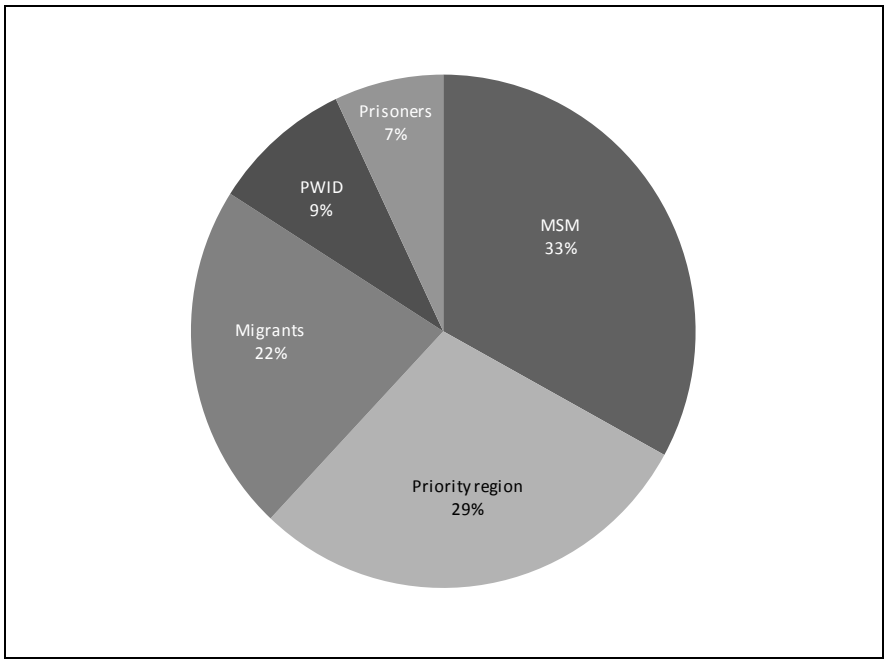
In 2014, the GFATM implemented a new funding model for the period 2014–2016 [131]. As part of this new scheme, the GFATM has set an indicative allocation for HIV/AIDS, tuberculosis and malaria for eligible countries, which was communicated to countries in March 2014 to enable preparation of grant applications by countries. The scheme allows for flexibility in that countries may use the defined allocation by the GFATM for HIV/AIDS, tuberculosis or malaria as they see fit, although any adjustment made will have to be approved by the Global Fund.

6.3. EU spending on main target groups (EQ 13)

In Section 6.1 we reported estimates for annual financial support, at the EU level, for HIV prevention, treatment and care for the period 2009–2013 in Europe by programme, agency and organisation. This subsection explores these figures further, seeking to disaggregate funding by main priority groups. Disaggregation was possible for HIV projects funded through the European Health Programme for the years 2009–2013, but not for the other EU funds described in Table 6.1 (page 83), although this does not mean that (some of) these funds have not contributed to the implementation of projects and activities targeting priority groups.

Considering the period 2009–2013, a total of €12.3 million was spent on HIV prevention, treatment, care and support in the context of the Health Programme. Of this, €5.5 million (45 per cent) targeted specific priority groups, including MSM (33 per cent), migrants (22 per cent), PWID (9 per cent) and prisoners (7 per cent) (Figure 6.3). The remaining 29 per cent of the €5.5 million related to priority regions (€1.6 million).

Figure 6.3. European Health Programme funding allocated to HIV prevention, treatment, care and support, by priority group, 2009–2013



SOURCE: ECDC, 2013 [21]

Funding targeting specific priority groups and regions was delivered through a number of projects, shown in Box 6.2). Further details on the contribution of the EU Health Programme to HIV prevention, treatment, care and support specifically, and on EU-funded research through the Framework Seven Programme, are provided in Chapter 5.

Box 6.2. EU Health Programme projects targeting priority groups and regions, 2009–2013

MSM

- SIALON II: Capacity building in combining targeted prevention with meaningful HIV surveillance among MSM
- EUROHIV EDAT: Operational knowledge to improve HIV early diagnosis and treatment among vulnerable groups in Europe.

Priority regions

- BORDERNETwork: Highly active prevention; scale up HIV/AIDS/STI prevention, diagnostic and therapy across sectors and borders in CEE and SEE
- TUBIDU: Empowering Civil Society and Public Health System to Fight Tuberculosis Epidemic among Vulnerable Groups; contribute to the prevention of an injecting drug user– and HIV-related tuberculosis epidemic.

Migrants

- SRAP: Addiction prevention within Roma and Sinti communities
- EU HEP Screen: Screening for Hepatitis B and C among migrants in the European Union
- Imp.Ac.T: Improving Access to HIV and TB testing for marginalized groups.

6.4. Spending on HIV/AIDS and co-infections treatment in EU Member States (EQ 16)

This subsection explores the proportion of national funding spent on HIV/AIDS and co-infections (viral hepatitis, tuberculosis) treatment among EU Member States, corresponding to evaluation question 16 (Box 6.1, page 81). Data are derived from the ECDC, which collected information on HIV spending from EU MS as part of the 2010 and 2012 rounds of Dublin reporting [124 132]. Eleven EU MS provided relevant information for the period 2009–2011, which is summarised in Table 6.5. We were unable to identify data on HIV/AIDS spending for the remaining EU MS or for more recent years.

Table 6.5. Level of spending on HIV prevention, treatment, care and support by 11 EU Member States, 2009–2011 (in million Euro)

Country	Overall spending on HIV			Per capita (and total) spending on HIV prevention		
	2009	2010	2011	2009	2010	2011
Belgium	96.7	110.0	N/A	0.49 (5.3)	0.49 (5.3)	N/A
Bulgaria	7.9	8.0	9.1	0.59 (4.3)	0.46 (3.4)	0.48 (3.6)
Czech Republic	51.2	N/A	N/A	N/A	0.67 (7.0)	0.67 (7.0)
Estonia	N/A	12.3	N/A	N/A	2.59 (3.4)	N/A
Italy	N/A	N/A	668.2	N/A	N/A	(0.2)
Latvia	4.8	4.3	4.9	0.75 (1.6)	0.48 (1.0)	0.77 (1.6)
Lithuania	N/A	N/A	2.8	N/A	N/A	0.09 (0.3)
Poland	34.1	49.0	55.3	0.05 (2.1)	0.03 (1.2)	0.03 (1.1)
Portugal	7.5	137.7	150.6	0.52 (5.5)	0.52 (5.5)	0.38 (4.0)
Romania	20.0	15.6	19.3	0.04 (0.8)	0.06 (1.2)	0.09 (1.7)
Spain	N/A	N/A	645.8	N/A	N/A	0.35 (16.0)

SOURCE: ECDC, 2013 [124]

Five countries provided data for each year between 2009 and 2011. Among these, Bulgaria, Poland and Portugal reported successive increases in spending over the period, while Latvia and Romania saw a decline from 2009 to 2010, followed by an increase from 2010 to 2011. Total spending on HIV was considerably higher in countries such as Italy and Spain compared with other EU MS for which data were available.

When considering spending on HIV prevention it is interesting to note that at the same time as Bulgaria, Poland and Portugal reported an increase in overall spending on HIV, spending on HIV prevention fell. Romania was the only country among those that did report relevant data that documented a year-on-year increase in HIV spending, whereas Latvia reported a decline from 2009 to 2010, which was followed by an increase in 2011. There was little change in spending on HIV prevention over time in Belgium, the Czech Republic and Poland.

Overall figures shown in Table 6.5 have to be interpreted with caution because of differences in the type of data reported by countries to the ECDC [124].

The ECDC has highlighted the need to better understand national spending on HIV/AIDS in Europe. A meeting of the Dublin Advisory Group in October 2013 considered various options to enhance reporting, such as adapting the UNAIDS Funding Matrix [133]. In light of concerns voiced by EU MS about the value and the feasibility of collecting a comparable and comprehensive set of financial data, with many countries not tracking national HIV spending, the Dublin Advisory Group recommended to continue using the Dublin monitoring process as a means to collect specific data on spending on HIV. Thus, from 2014, the 2014 Dublin Declaration monitoring includes a small set of questions requesting countries to provide data on spending on ART and on prevention, including a breakdown for key populations and an indication of whether HIV spending had increased or decreased. This set of questions will be tested during the next round of Dublin reporting in 2014 and will allow for the collecting of a new set of data for the period 2012–2013 (reporting deadline 31 March 2014).

6.5. Options for the EU to help NGOs to continue HIV work following the phasing out of the Global Fund (EQ 15)

In its 2012 thematic report on civil society, the ECDC highlighted the importance of NGOs in addressing HIV/AIDS in Europe [134]. Among the most important contributions noted was the ability of civil society to strengthen the political commitment of leaders and the development of national policy. It further reported that 83 per cent of respondents from government to a survey of leadership conducted by the ECDC believed that the involvement of civil society in the national response to HIV should be strengthened or expanded. Evidence collected for this evaluation also supports the notion of the value placed on civil society in addressing HIV/AIDS in Europe, with, for example, the Civil Society Forum widely perceived to have helped bring about some changes in combating HIV/AIDS in Europe (see Chapter 4).

The Global Fund has played an important role in helping to strengthen civil society in a number of European countries, in particular in the eastern part of the region, as part of the GFATM's commitment to involve civil society at all levels of its activities. Consequently, where GFATM funding is being phased out, this likely affects the sustainability of NGO work in beneficiary countries where alternative funding streams have not been identified or made available post–GFATM funding.

We have described in Section 6.2 that during 2009–2013 five countries considered in this evaluation received support from the GFATM, namely, two EU MS (Bulgaria and Romania) and three ENP countries (Belarus, Moldova, Ukraine). In this subsection, we focus on Bulgaria and Romania, which experienced a reduction in the financial support granted by the GFATM during 2009–2011. Specifically, we explore the implications of this reduction on the sustainability of HIV/AIDS programmes and of NGOs involved in the delivery of such programmes.

6.5.1. Sustainability of HIV/AIDS programmes following the phasing out of Global Fund support in Romania and Bulgaria

Bulgaria and Romania have been in receipt of Global Fund support from 2003 (award of the grant) [135]. During 2009–2011, which is part of the period under consideration in the

present report, the level of GFATM funding fell substantially in both countries. In Romania, the level of GFATM funding for HIV/AIDS fell from USD 2.5 million in 2009 to zero in 2011 (whereas levels of funding for tuberculosis increased) [130]. Concerns about the sustainability of programmes supported by GFATM funds were already raised in 2008. Key challenges identified at that time included, among others, the absence of a national HIV strategy for 2008–2013, a limited national commitment to take on funding responsibilities, and the capacity-building needs of civil society representatives [136]. Following the discontinuation of GFATM projects from mid-2010, funding for prevention interventions targeting vulnerable populations was not secured and NGOs had to discontinue their activities because of lack of funding [21 134]. These challenges were acknowledged by the government, with the aforementioned 2012 ECDC thematic report on civil society citing a respondent from the Romanian government regarding the funding for civil society organisations, who was quoted to have said that '*currently, the underfunding [of] civil society working in the field of HIV has [the] impact [of] diminishing their active involvement in the national response*' [134]. Among key informants interviewed for this evaluation, one respondent highlighted, however, that some alternative sources of funding had reached Romanian NGOs over the past few years, including international sources, such as the European Social Fund, the EEA and Norwegian grants, as well as national sources, including funds from the Romanian Ministry of Health to purchase materials and a project funded by the city council of the capital, Bucharest.

Bulgaria also experienced a reduction in GFATM support, but because of the country's performance of supported projects during 2004–2008, the grant was renewed through the Rolling Continuation Channel up to 2014 [64]. Continuation of support beyond 2014 remained uncertain for some time because of a funding gap that was experienced by the GFATM and which led the GFATM to redefine of eligibility criteria within a newly created Transitional Funding Mechanism, which would have excluded countries such as Bulgaria to receive further support [137]. The future sustainability of HIV activities was thus flagged as a key issue for Bulgaria by key informants from Bulgaria interviewed for this study, suggesting that the decrease in Global Fund support was already being felt: *'the HIV prevention services are currently funded by the Global Fund, however the funding is being decreased year on year and the national government is expected to complete the budget with national resources. This doesn't happen however and the services are provided with a much decreased budget in the last 3 years'* (BG-KI-1).

This perceived 'lack of preparedness' at the national level observed for countries such as Romania and Bulgaria was recently highlighted as a general challenge in a review by the Global Fund of the sustainability of supported HIV, tuberculosis and malaria programmes [138]. It highlighted that the national response to HIV/AIDS was the primary responsibility of national governments and that governments were thus expected to assume financial responsibility for services previously supported by the Global Fund. However, the GFATM found that among the six countries considered in their review, which included Romania, there had been no deliberate development of sustainability plans to guide their transitioning from Global Fund support.

Regarding future support through GFATM, it may be worth noting that most recently the GFATM has described Bulgaria and Romania as eligible (again) for support for the period 2014–2016, covering HIV/AIDS and tuberculosis for Bulgaria and tuberculosis for

Romania[12] [131]. This implies that the further financing of HIV/AIDS programmes in Bulgaria is likely to be sustained. However, for Romania it is not known whether any of the allocations defined by the GFATM can also be used for HIV/AIDS.

6.5.2. Options for the EU to help NGOs continue their HIV work

The preceding section indicated that while Bulgaria and Romania continue to be eligible for (some) support through the GFATM in the foreseeable future, the uncertainty and funding shortfall experienced by both countries over recent years means that they will have to engage in efforts to plan for transitioning when they may no longer qualify for GFATM funding. This will be particularly important to ensure sustainability of the work and services currently provided by NGOs in these countries, with shortfalls in funding likely to undercut preventative efforts targeting vulnerable groups in particular, as experienced in Romania. While sustaining financial support is key, it will be equally important to support strengthening capacity among NGOs to enhance their involvement in national policy development and decisionmaking and their participation in EU-level projects.

Based on the evidence collected in this evaluation, including interviews with key informants (KI-1, KI-3, KI-4, KI-7 and KI-9), we identified a set of options for the EU to support NGOs in continuing their work, which can be described as follows:

- Supporting the involvement of civil society and people living with HIV/AIDS through:
  - Continuing to include them as key actors in the next EU-level HIV/AIDS policy framework
  - Maintaining the HIV/AIDS Civil Society Forum
- Supporting NGOs in accessing European structural funds to implement their activities.

  A position paper by advocacy NGOs asked EU institutions to reduce health inequalities among Member States using structural funds, requesting in particular that social inclusion activities of the European Social Fund (ESF) integrate HIV components and that ESF funds be accessible to small NGOs and community-based groups [137].
- Strengthening the capacity of NGOs

  The EU could fund activities such as training or mentoring schemes between organisations that help build the capacity of these NGOs, for example, in the following fields:
  - Advocacy
  - Fundraising
  - Drafting proposals/Project management, etc.
- Integrating NGOs in EU-level projects through:
  - Ensuring that different funding streams such as the EU Health programme are accessible to NGOs though, for example, defining criteria that encourage their

[12] For Bulgaria: 9.2 million USD has been indicatively allocated for HIV and 10.3 USD million for tuberculosis. For Romania: 12.8 million USD has been indicatively allocated for tuberculosis.

participation. While NGOs can already access funding under the EU Health programme in principle, currently representing 56 per cent of the main beneficiaries and 53 per cent of the associated partners [110], our consultation found that some NGOs face difficulties in acceding such funds, a situation that was mostly attributed to the co-financing requirement: *'to apply directly to […] funds (such as EU Health Programme) is nearly impossible, because this programme provides huge grants and requires 40 per cent co-financing, which makes it inaccessible for most of the Bulgarian NGOs' (BG-KI-2).*

- Simplifying the process of applying and managing EU projects.

6.6. Impacts of the financial crisis on national responses to HIV/AIDS (EQ 14)

6.6.1. Effects of the financial crisis on national HIV responses (EQ 14-1)

A number of studies have sought to assess the impacts of the global economic crisis on population health and the wider health system in Europe [139 140]. The European Observatory on Health Systems and Policies has launched a 'Health and Financial Crisis Monitor' that aims to collate the available evidence on the impact of the crisis on a range of health domains, including infectious diseases, and on health system financing, coverage, efficiency and cost [141]. The Observatory found that 10 EU Member States – Bulgaria, Croatia, Greece, Hungary, Ireland, Italy, Latvia, Portugal, Romania and Spain – had reported cuts in their national health budgets in response to the financial crisis and that Bulgaria and Latvia had reduced their budgets by more than 20 per cent between 2008 and 2010, which, in Latvia, affected public health and control and epidemiological surveillance in particular [139].

However, there is as yet little systematic assessment of the direct and long-term consequences of the 2008 financial crisis on EU MS responses to HIV/AIDS across Europe specifically. A small number of country-specific studies have highlighted challenges related to the crisis, with, for example, HIV outbreaks reported among injecting drug users in Greece [142 143] and Romania [144], which have been associated with cutbacks in prevention and treatment programmes for illicit drug use [145].

The ECDC, as part of its monitoring of the implementation of the Communication and the Action Plan for combating HIV/AIDS, undertook an assessment of the consequences of the financial crisis by reviewing data collected from countries which had reported to the Dublin Declaration monitoring process and participated in Think Tank meetings in 2011 and 2012, alongside information obtained from responses to additional questions posed in 2012 on the effects of the financial crisis [21]. These data provide insights into the effects of the financial crisis on national responses to HIV/AIDS, although not all EU MS responded to the requests for information. In the following we briefly reflect on the findings reported by the ECDC, which we complement with data collected as part of this evaluation, drawing on information obtained from desk research, key informant interviews and country case studies.

Evidence of the consequences of the financial crisis on national responses to HIV

National spending on HIV/AIDS

In Chapter 3 we reported on the findings of our surveys of Think Tank and CSF members on the main (perceived) barriers to the implementation of policies on HIV/AIDS (see Section 3.4). Lack of financial resources was identified as an important obstacle, and some respondents linked this lack of resources to the financial crisis. It is challenging, however, based on available published data, to assess with certainty the impacts of the crisis on the availability of funding for HIV/AIDS. Indeed, earlier in this chapter (Section 6.4), we noted that among five countries for which national-level data on year-on-year spending are available for the period 2009–2011, Bulgaria, Poland and Portugal reported successive increases in spending, while Latvia and Romania saw a temporary decline from 2009 to 2010, followed by an increase in 2011. At the same time, countries reduced spending on HIV prevention, however, and we have described above that both Bulgaria and Romania have been facing increasing challenges in sustaining preventative services following reductions in the support granted by the Global Fund.

The aforementioned consultation by the ECDC of EU MS as part of Think Tank meeting in December 2012 found that, of those participating, countries such as Austria, Denmark, Finland, Luxembourg, the Netherlands and Sweden, reported that there had been little effect of the crisis on their funding for national HIV responses [21]. At the same time, countries had expressed concerns about the potential sustainability of services, in particular where funding had remained stable vis-à-vis an increase in demand. Also, as one key informant interviewed for this evaluation noted, data available only reflect spending to the year 2012, with further cuts experienced during 2013 not yet documented (KI-4).

Importantly, as indicated above, while overall spending on HIV might not have been affected, several countries reported considerable reductions in spending on prevention activities targeting HIV, or spending in areas that are not directly related to the health or HIV budget but that will also impact on vulnerable at-risk groups and people living with HIV, such as cuts in housing or employment services. The ECDC (2013) reported that this latter point was emphasised in particular in their survey of civil society organisations referring to the respective countries they were working in. This found reports of reduced funding for preventative activities in Finland (municipal budgets), Germany (national AIDS organisation budget), Italy (harm reduction services in prisons or targeted at PWID), and Spain (National AIDS Strategy Secretariat [SPNS] budget cuts and plans to close the SPNS, with implications for programmes delivered by NGOs) [21]. According to the ECDC, reduced spending on HIV prevention was also reported by Think Tank members, including France (national prevention campaigns and NGOs).

Restructuring health services

A number of European countries introduced health reforms that involved a considerable restructuring of the way health services are governed, organised and delivered and that may have influenced the delivery of HIV services. However, it is difficult to conclude with certainty whether such changes came about in response to the financial crisis or whether the crisis merely accelerated ongoing reform processes (or, indeed, the crisis provided an opportunity to introduce reforms that in other circumstances would have been difficult to pursue) [139]. Examples include England, the Czech Republic, Latvia and Lithuania. For example, according to the key informant interviewed for the England case study in the context of this evaluation, although the financial crisis as such does not appear to have had

an impact on the response in England to HIV/AIDS, it is likely that a major healthcare reform introduced in 2012 will. Thus, from 2013, responsibility for sexual health services and HIV prevention (including HIV testing) was transferred from the National Health Service (NHS) to local authorities (councils), and there have been concerns that where council budgets are under pressure this might affect the ability to sustain funding of HIV services [146]. Similarly, the health sector in Latvia has undergone considerable change, involving the closure, in 2009, of the Public Health Agency and the reorganisation of other agencies. Budget cuts in healthcare were shown to have reduced access to services, as well as the proportion of out-of-pocket payments in healthcare financing [147], and there is evidence that access to HIV services has been affected, which we describe below.

Affordability of HIV treatment

In Chapter 3 we documented a perceived lack of financial resources reported by respondents to the Think Tank and CSF surveys undertaken as part of this evaluation. Although it is difficult to generalise from the findings, reports pointed to a potential link between the financial crisis and the ability of countries to sustain antiretroviral therapy in the context of financial constraints (Section 3.4). There is some evidence from the aforementioned ECDC monitoring report and data collected within case studies conducted for this evaluation, highlighting efforts of countries to reduce the costs of ART in order to ensure continued treatment. Examples include a reported use of generic drugs in Italy, or the negotiation of the cost of drugs with manufacturers, as reported for France and Latvia [21]. For the latter it is worth reiterating the experiences we have already documented in Section 3.4 (Box 3.2). Thus, from 2010, ART was included in the national reimbursement list, and, based on cost-effectiveness analysis and negotiations with pharmaceutical companies, the Latvian Centre for Health Economics was able to achieve price reductions based on international comparisons of between 3 and 49 per cent in 2010 compared with 2009 [139]. This resulted in a reduction on the cost of treatment per person of over 50 per cent, thus freeing up funds to cover a wider range of people with HIV [148].

Coverage of HIV services

The ECDC (2013), in its monitoring report of the Communication and Action Plan, reported on comments provided by stakeholders, including national governments (through the Think Tank) and civil society, concerning impacts of the financial crisis on the availability of HIV services. This report found that countries generally reported maintaining the provision of testing, treatment, care and support services [21], and key informants interviewed for this evaluation thought that (their) countries had been able to sustain of even expand their level of HIV/AIDS treatment and care services (KI-4, KI-6, KI-10 and KI-11). There was a notion that, in general, in the EU, people who are diagnosed with HIV and considered to be in need of treatment would be receiving it. However, there is also evidence of some countries having experienced cases of service disruption or, indeed, a redefinition of eligibility for services, resulting in a reduction in the number of people accessing HIV services. For example, there were reports of stock-outs of ART supplies in countries such as Latvia (LV-KI-1) and the Czech Republic [139]. A statement issued by the Civil Society Forum in 2012 highlighted, *'We also note with great concern reports from a significant number of European countries of ARV stock-outs resulting in dangerous interruptions to treatment for people living with HIV'* [149].

Evidence of a redefinition of eligibility criteria for the receipt of ART was reported for Latvia and Spain. We described the case of Latvia earlier in this report (Section 3.4). In brief, as part of the government's austerity measures in response to the global financial crisis, funding allocated to HIV treatment and care was frozen in 2010. Specifically, restrictions were placed on the number of PLWHIV provided with ART free of charge and new treatment guidelines stipulated that the threshold for treatment initiation was to be set at a lower than internationally recommended CD4 cell count [73]. In Spain, NGOs expressed concerns about legislation which, in August 2012, revoked healthcare coverage for migrants without a residence permit [21]. There is an expectation that, to the contrary, the law '*will have a negative impact on public health and especially on that of patients infected with HIV who will remain untreated; this will increase health costs in the medium to long term and leave us in default of internationally-agreed health objectives*' [150]. These concerns were supported by key informants from Spain who were interviewed in the context of this evaluation. A recent study by Perez-Molina et al. (2012) estimated that there were between 2,700 and 4,600 HIV-positive undocumented migrants in Spain, of whom some 1,800 to 3,220 would likely be aware of their infection and of whom 80 per cent could receive antiretroviral treatment [151]. The authors argued that reducing access to treatment for this group would increase morbidity and mortality among this group and lead to a greater cost in patient care, in particular for those who are more likely to present late, with consequences for the wider public health system.

Evidence from other countries also points to the likely impacts of the crisis on vulnerable population groups, such as migrants and people who inject drugs, as a consequence of cuts in service provision [152], with anecdotal reports concerning Italy [153] and the Czech Republic [154].

Potential health impacts of the financial crisis

The long-term consequences of financial crises on population health outcomes remain inadequately understood [139]. A recent systematic review of the impacts of economic crises on communicable disease transmission and control found evidence of worse infectious disease outcomes during a recession, which often resulted from higher rates of infectious contact under poorer living conditions, reduced access to therapy or reduced retention in treatment [144 155]. It further identified a small number of population groups at particular risk of contracting infectious diseases during periods of economic strain, including migrants, homeless people, and prison populations.

In the introduction to this section we highlighted the experiences of Greece and Romania, which both recorded localised HIV outbreaks among intravenous drug users in 2011 [156]. As noted, the outbreaks in Greece have been associated with low levels or, indeed, a reduction in the provision of prevention services, in particular around the treatment of illicit drug use and including needle exchange programmes [145]. More recent evidence also points to the importance of wider support mechanisms, such as housing, highlighting how the HIV outbreak in Greece, with homeless PWID more than two times more likely to contract HIV than those with housing [157]. In Romania, the increase of HIV among IDUs coincided with the phasing out of Global Fund support, which was associated with a temporary reduction in the level of provision of prevention services [158].

Conversely, other countries that were also severely affected by the financial crisis did not report similar outcomes. For example, Regidor et al. (2014), in a recent assessment of the impacts of the crisis on health outcomes in Spain, did not find evidence of negative impacts on the number of cases diagnosed with HIV [159]. It may be worth noting that the aforementioned systematic review highlighted that the long-term impacts of economic crises on communicable disease transmission and control are not inevitable and that there is also evidence suggesting that the magnitude of the impact would depend, to a considerable extent, on budgetary responses by government [155]. Such considerations offer the potential to alleviate the detrimental effects of an economic recession.

6.6.2. Options for the EU to address the consequences of the financial crisis on HIV/AIDS (EQ 14-2)

We here present options offered by a small set of key informants interviewed for this study on how the EU could help address the consequences of the financial crisis on HIV/AIDS in Europe (KI-4, KI-5, KI-6, KI-8, KI-9 and KI-10):

- Maintain HIV/AIDS high on the political agenda in EU Member States.
- Strengthen the tracking of EU Member States' financial expenditures on HIV/AIDS. This is necessary in order to be able to monitor the evolution of the levels spent on HIV/AIDS in Europe and to allow stakeholders (national governments, CSF members, EC, etc.) to take corrective actions if needed.
- Support projects that assess links between the crisis and health outcomes as they relate to HIV in Europe.[13]
- Considering the concerns of sustainability of ART provision in some EU Member States, initiate a debate on pricing for drugs to support countries in lowering ARV costs. This was mentioned by two key informants (KI-9 and KI 10) and is also advocated by the CSF (see Box 6.3.).
- Continue supporting targeting resources to key services and at-risk populations. The focus placed by the 2009–2013 EC Communication on priority groups (i.e. MSM, PWID and migrants and mobile populations) was mentioned by key informants (KI-3 and KI-9) as one of the major contributions of the EC Communication.
- Engage with EU Member States in need (e.g. the EU intervention in Greece).
- Explore how the new legal framework on serious cross-border threats to health [161] could be used by the EC to support EU Member States in need (e.g. countries experiencing HIV outbreaks or problems of discontinuation of services, such as ART stock-outs).

[13] For example, in 2009 UNAIDS and the World Bank monitored the impact of the global economic crisis in developing countries affected by HIV and AIDS [160]. UNAIDS/WB. Update on the Impact of the Economic Crisis: HIV Prevention and Treatment Programmes. UNAIDS and the World Bank 2009 .

Box 6.3. The call of the EU HIV/AIDS Civil Society Forum to secure affordable drug prices

In a statement published in 2012, the EU HIV/AIDS Civil Society Forum acknowledged the current financial crisis and the pressure it placed on budgets. It called on governments and the European Commission to maintain and increase ARV treatment access, through price reductions and differentiated prices for ARVs in the European region:

'We call on the governments of the EU Member States and neighbouring countries, the European Commission and the pharmaceutical industry to keep their promise and meet as soon as possible to discuss how to secure affordable drugs prices across the European region, an essential precondition if our commitments to universal health access are to be met'.

In addition, it called on the European Commission *'to initiate the extension of Council regulation 953/2003[14] to countries in need of price-reduced drugs for people living with HIV/AIDS'.*

SOURCE: AAE, 2011 [149]

6.7. European added value (EQ 3)

During 2009–2013, financial resources were made available at the EU level to support the implementation of the EC Communication. EU funding was distributed through multiple actors, such as international organisations, EU programmes, and agencies that had the necessary legal basis and competence to reach a wide range of stakeholders. These agencies included national, regional and local authorities, as well as non-state actors, such as civil society, researchers and academia, and industry, involved in combating HIV/AIDS in the MS and neighbouring countries. In addition, attention seems to have been paid to allocate these funds to those activities that have the potential to contribute, through their outputs and impacts, to achieving the general objectives of the Communication, that is, improving the quality of life for PLWHIV, improving access to key services and reducing new HIV infections, and addressing the main areas addressed by the Communication, including political leadership, prevention, priority regions, priority groups, knowledge and monitoring.

We have identified some variations in the level of annual EU spending on HIV/AIDS during 2009–2013, especially regarding FP7 projects and the Health Programme.

6.8. Summary

The evaluation sought to understand (i) the amount of EU funds allocated to HIV/AIDS and the EC's contribution to the Global Fund; (ii) the amount of EU funds allocated to priority groups; (iii) spending on HIV/AIDS and co-infections by Member States; (iv) the way in which the EU could support NGOs; and (v) the effects of the financial crisis in Europe on HIV/AIDS and the potential ways of addressing these effects.

[14] Council Regulation (EC) No 953/2003 of 26 May 2003 to avoid trade diversion into the European Union of certain key medicines.

Spending on HIV/AIDS prevention, treatment, care and support (including the contribution to the Global Fund)

The exact total amount spent by the EU on HIV/AIDS could not be reported because such data are not monitored in a centralized way across the different EC services. On the basis of the available data, it has been estimated that around € 150 million was allocated to HIV/AIDS during the period 2009–2013.

During that same period, the EU contribution to the funding of the Global Fund amounted to approximately USD 683.7 million (approximately € 510 million), which represents 4 per cent of the total donor contributions. Besides this contribution, individual EU Member States are major contributors to the GFATM, with a total invested of around USD 6,464.9 million (approximately € 4,800 million), representing about 40 per cent of total donor contribution to the GFATM.

EU spending on main target groups

For the period 2009–2013, a total of € 12.3 million was disbursed through the Health Programme on HIV projects, out of which € 5.5 million was allocated to 10 different projects targeting MSM, priority regions, migrants, PWID and prisoners. The evaluation study did not yield any additional information regarding the EU spending on HIV/AIDS per main target group.

Funding at the Member State level to fight HIV/AIDS

The evaluation study could not draw a complete picture regarding the EU MS spending on HIV/AIDS during the period 2009–2013, since the reporting of expenditures by countries to the ECDC provided only partial and fragmentary information. From data collected by the ECDC in 11 MS for the period 2009–2011, the following can be concluded: € 2,115 million has been spent on HIV, out of which circa € 83 million was allocated to HIV prevention.

ECDC explores several options on how to improve the future reporting of HIV expenditure and included a small set of questions in the 2014 Dublin Declaration monitoring asking countries to provide whatever data they have on ART and prevention spending. This option is currently being tested, with a reporting deadline end of March 2014.

Options for the EU to help NGOs continue their work following the phasing out of the Global Fund

The evaluation identified several options to further support at the EU level those national NGOs which have experienced difficulties in continuing their HIV activities after the phasing out of the Global Fund, and to also continue to help the civil society groups that face technical and financial capacity problems in implementing their activities. These options include keeping the civil society involved in the next EU-level HIV/AIDS strategy, facilitating their access to structural funds, continuing the implementation of capacity-building activities and simplifying the mechanisms for applying to and managing EU programmes.

Impacts of the financial crisis on national responses to HIV/AIDS

Data on the impact of the 2008 global financial crisis on HIV prevention, treatment, care and support are not readily available. A small number of country-specific studies have highlighted challenges related to the crisis, with HIV outbreaks reported among injecting

drug users in Greece and Romania, and these have been associated with cutbacks in prevention and treatment programmes for illicit drug use. There was variation among countries for which national-level data on year-on-year spending on HIV were available for the period 2009–2011, suggesting that while overall spending on HIV may have remained fairly stable, countries appeared to have reduced spending on HIV prevention, with implications for sustaining preventative activities. Countries generally reported maintaining the provision of testing, treatment, care and support services, although some experienced cases of service disruption or a redefinition of eligibility for services, thus reducing the number of people accessing HIV services. Overall, it remains challenging to establish direct links between the financial crisis and changes in HIV prevention, treatment, care and support where these occurred.

European added value

The EC Communication has brought European added value by ensuring that financial resources were made available at the EU level to support (i) actions implemented by a wide range of multiple stakeholders involved in the combat against HIV/AIDS and (ii) activities able to contribute to the EC reaching its objectives and addressing the main thematic issues. Despite this, several elements have impacted the level of funding available for HIV/AIDS, including the phasing out of the Global Fund and the financial crisis.

7. EU HIV policy coordination and monitoring

In this chapter we present key findings on two aspects of policy making in the EU: (i) the relationship between the Communication and its Action Plan and other EU policies and (ii) the monitoring of the policy-making process and the use of indicators to measure the implementation of EU policy on HIV at the national level (hereafter referred to as policy process indicators). This chapter answers evaluation questions 2, 3 and 4 (see Box 7.1).

Box 7.1. Evaluation questions addressed in Chapter 7

Evaluation question 2
What are the relevant policy process indicators in order to obtain complete outcome data?
Evaluation question 3
What is the European added value of the Communication?
Evaluation question 4
What is the relation of the Communication to other EU policies?

7.1. Relation of the HIV Communication to other EU policies (EQ 4)

7.1.1. Extent to which the Communication is aligned with other EU policies

HIV/AIDS is one of the 17 vertical health policies [162][15] and falls under the broad umbrella of the EU Health Strategy 2008–2013, 'Together for Health' [163]. The Communication called on the EC to promote the mainstreaming of HIV/AIDS-related issues across EU policies, legislation and agreements [14]. The Communication and its Action Plan reference a number of policies, including the following [16]:

- Foreign policy: including the European Neighbourhood Policy (ENP), Northern Dimension, Development and Cooperation, and cooperation with international and regional organisations.

[15] The definition of vertical health policies, as proposed by PHEIAC (2012), applies to distinct policy areas, for example, Alzheimer's; health of the elderly; tobacco; nutrition; illicit drugs; cancer; rare diseases; HIV/AIDS; preparedness planning; chemical, biological, radiological and nuclear security; patient safety; and telemedicine. This is in contrast to horizontal health policies, which apply – when relevant – to the entire body of specific health policies; for example, 'shared health values', 'health is the greatest wealth' and 'global health'.

- Human rights, tolerance and non-discrimination: pointing to equal treatment policies in relation to racial equality [164] and employment equality [165]
- Social policy and migration: denoting social inequalities and social inclusion of the most at-risk populations and demanding better public health and social services for migrant populations
- Education and research: calling for more resources to improve health research (in particular, vaccine and microbicide development, preventive and therapeutic interventions, and social science research); aiming at improved education, knowledge and awareness on HIV/AIDS, especially among young people
- Drug policy: calling for the provision of harm reduction measures, such as sterile needles and injecting equipment and substitution treatment
- Regional policy: discussing the possibilities of structural and social funds to scale up HIV/AIDS-related health services.

Based on a review of EU policies and their relation to the Communication, existing policies can be broadly divided into the following categories:

(1) EU policies that are closely aligned with the Communication and Action Plan (e.g. research policy [166] and development and cooperation [167]) that declare HIV/AIDS to be either their top priority or one of the key health issues that need to be addressed by the policy in question
(2) EU policies that reference HIV/AIDS to substantiate the importance of their policies but are not directly aimed at combating HIV/AIDS (e.g. drug control policy [168])
(3) EU policies that are directly related to public health but do not explicitly target HIV/AIDS (e.g. regional policy [169] or employment rights [170]) and that do incorporate health issues among their core activities
(4) EU policies that are less explicitly related to public health and that do not explicitly refer to HIV/AIDS, such as ENP [171], education [172], justice and home affairs (fundamental rights [173][16] or migration [174]) where the prominence of health is somewhat limited.

7.1.2. Mechanisms of coordination between public health, HIV and other EU policy areas

In the area of health the Commission maintains collaboration across a number of policies through various channels, which can be briefly summarised as follows [175]:

- Inter-service group on public health that gathers more than 20 departments across the EC that work through several thematic subgroups, dealing with dynamic health systems, global health, health and environment, and HIV/AIDS
- Health in social and regional policy, where the collaboration takes place through the Social Protection Committee that deals with healthcare among other issues and through the Committee of the Regions

[16] Article 35 (Health Care) of the Charter of Fundamental Rights of the European Union states: '*Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices. A high level of human health protection shall be ensured in the definition and implementation of all the Union's policies and activities.*'

- Council working party on public health at a senior level that considers the strategic importance of health in all policies
- Research and new technologies, mainly through the FP7 funding
- Education and healthy environments, which include the youth health initiative and cross-cutting issues, such as indoor air and water quality, noise and pesticides.

The evidence gathered through the interviews and email exchanges with key stakeholders provides more insight into this general picture and also provides more contextual information and views on the links between the Communication and its Action Plan and other EU policies.

One of the key informants reported various mechanisms of coordination between different services in the area of HIV/AIDS (KI-2). These coordination mechanisms include regular briefings and meetings organised by relevant agencies and Directorate-Generals (DG) (including Think Tank and CSF meetings), conferences, and the work of the Inter-service Group on Global Health. According to the same key informant, the Inter-service Group on Global Health, and, more specifically, its working group on HIV/AIDS (which that includes DG SANCO, DG RTD, the Directorate-General for Justice [DG JUSTICE], the Directorate-General for Home Affairs [DG HOME], DG DEVCO and DG Communications), has been involved in the formulation and launch of the Communication, its recent update and future developments.

7.1.3. Assessment of the coordination

According to three key informants, in many areas, the EU policies were coherent and mutually supportive of different EC directorates, which, effectively, resulted in collaboration on combating HIV/AIDS (KI-1, KI-2, and KI-5). Specific examples of constructive cooperation include the drug policy and harm reduction strategies with DG JUSTICE (KI-5) and sexual health education packages on HIV prevention among young MSM, PWID, migrants with DG EAC (KI-3).

One key informant noted a discrepancy between the expected results as set out in the Communication and Action Plan and the actual outcomes (KI-4). The key informant stated that the outputs of the work of the Inter-service Group on HIV/AIDS had been somewhat disappointing. The key informant pointed to the area of antidiscrimination, where in the informant's view, activities and their outcomes have been underwhelming (KI-4). Another key informant noted that, while discussions at the Inter-service Group on HIV/AIDS show political commitment, they often miss operational and practical aspects regarding how different services will be responsible for the priorities and actions and who will be responsible for funding these actions (KI-3).

A number of key informants indicated areas where coordination between EU policies could still be improved:

- Affordability of medicines: The cost of medicines is high in Europe (particularly in the central and eastern parts of the WHO European Region), compared with other parts of the world (KI-3, KI-8, KI-10 and KI-12). One key informant suggested that DG ENTR and DG TRADE could increase collaboration on efforts to reduce the price of medicines (KI-12).

- Harm reduction and human rights: Overall, two key informants stated that they would like to see greater involvement of DG JUSTICE in relation to these policies (KI-12, KI-4).
- Education: According to one key informant, collaboration on HIV/AIDS should be extended to DG EAC (KI-3).

One key informant also noted some specific recommendations for DG SANCO (KI-3):

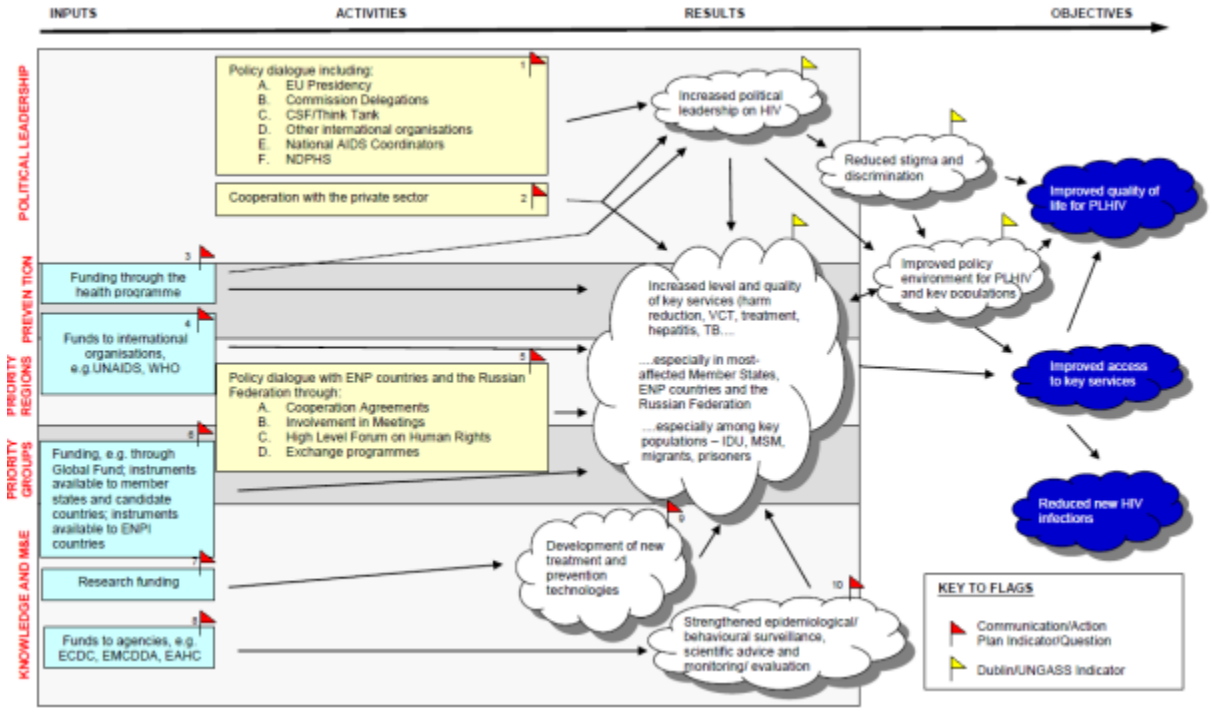
- Provide an internal forum to monitor the implementation of the Communication and its Action Plan within the EC and its agencies (currently, these discussion take place at the Think Tank and CSF meetings)
- Strengthen coordination of HIV funding among different EU programmes, including the European Neighbourhood and Partnership Instrument, the Health Programme, FP7 and others, to ensure greater continuity of funding.

7.2. Monitoring the uptake of the EU HIV policy at the national level (EQ 2)

In 2010, the EC mandated the ECDC to develop a monitoring and evaluation framework for the Communication and its Action Plan [108].[17] This framework (Figure 7.1) aims to capture the added value of Europe-wide and Commission actions in response to HIV. The ECDC developed 10 sets of indicators that correspond to different elements of the framework (supplementary to the UNGASS/Dublin Declaration reporting indicators). These ECDC indicators are grouped into four categories: (1) financial inputs, (2) non-financial inputs, (3) effects, and (4) contributions to Europe's response to HIV.

[17] Note that the Action Plan defined more than 40 indicators to monitor the implementation of specific actions contributing to the Communication's objectives.

Figure 7.1. Framework for monitoring and evaluating the Communication and its Action Plan

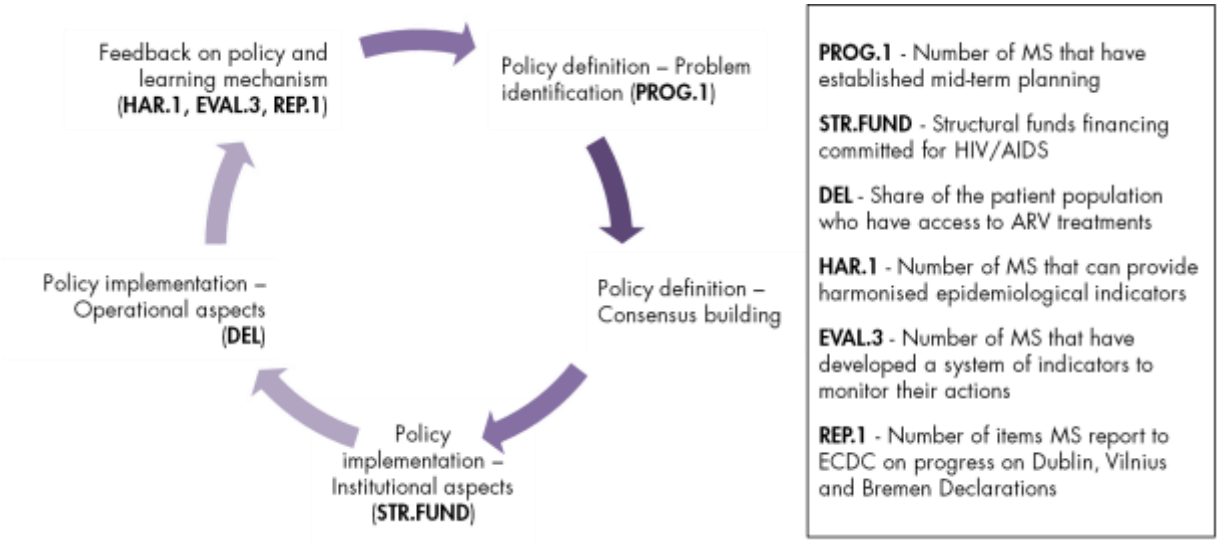


SOURCE: ECDC, M&E Framework, 2011 [108]

While these indicators measure the inputs, activities and results of policy interventions, they do not report on the delivery process and the extent to which EU policy has been taken up by Member States.

An assessment of the utility of both the existing and proposed indicators to measure the implementation of EU health policies at the national level was presented in the PHEIAC study in 2012 [162]. This assessment proposed a non-exhaustive list of indicators to measure the extent of policy uptake for a number of health policies, including HIV/AIDS. The indicators on HIV/AIDS policy implementation comprised six indicators that cover the entire policy cycle, from the policy definition, through to implementation, feedback and learning mechanisms (see Figure 7.2).

Figure 7.2. Proposed indicators for the HIV/AIDS policy area



SOURCE: Adapted from PHEIAC, 2012 [162]

The terms of reference for this evaluation further narrowed PHEIAC's list of indicators to the following four indicators:[18]

(1) Number of MS that have established *or reviewed* mid-term planning *from 2009–2013 and have mentioned the EU policy*
(2) Structural funds*/national funds/EU funds* financing *invested against* HIV/AIDS *and associated co-infections*
(3) Share of the *people in need, as defined in WHO guidelines, with* access to *HIV/AIDS* treatment
(4) Number of items MS report to ECDC on progress on Dublin, Vilnius and Bremen Declarations*, HIV/AIDS communication monitoring*.

The relevance and feasibility of these indicators are discussed in turn in the sections below. Where appropriate, alternative indicators have been suggested.

7.2.1. The number of Member States that have established or reviewed mid-term planning from 2009–2013 and that have mentioned EU policy

Data on the number of Member States that have established or reviewed mid-term planning are not currently collected by the ECDC, and the collection of these data would add to the reporting burden of Member State representatives.

As currently formulated, this indicator would likely capture a change in policy at the national level. However, the indicator also has some important limitations. First, it does not measure the extent to which a given EU policy has been implemented. If there was a policy change, the fact that an MS mentioned the EU in relation to the policy change might not fully explain reasons for the policy change. For example, the policy change may have been triggered by a change in the HIV/AIDS epidemic in a given MS, a shift in national priorities or an expiry of

[18] Note that the modifications to the PHEIAC wording are marked in italics.

the old policy. Second, the indicator does not report on the nature of the policy changes, and consequently recorded changes may not necessarily reflect priorities set out in the Communication and Action Plan.

The Think Tank and CSF surveys sought to establish whether national strategic plans for HIV/AIDS have changed in the period 2009–2013 and, if so, whether they reflect the specific priorities set out in the Communication and its Action Plan and the extent to which these changes can be attributed to the Communication and its Action Plan. Hence, the survey aimed to explore the nature and reasons for these changes, which addressed the shortcomings of the proposed indicator. However, it is important to note that the implementation of this survey increased the reporting burden for the individuals who were targeted by the survey. Given this reporting burden, it is unlikely that such an approach would be feasible for regular monitoring and evaluation; rather, it is more appropriate for periodic evaluation. Please see Section 7.3.1 for the survey results.

Only two key informants commented on the proposed indicator, and neither of them found this indicator relevant (KI-4, KI-10).[19] One key informant thought that all Member States had plans for HIV/AIDS, and was of the opinion that what was of more importance to understand was the extent to which these policies had been implemented (KI-10). Another key informant felt that the policy indicators should reflect the activities undertaken by the EC, rather than the MS (KI-4). The same key informant also doubted whether MS would mention the EU policy in their plans, as MS had not received funding from the EC to implement the Communication and its Action Plan.

7.2.2. Structural funds/national funds/EU funds invested to fight HIV/AIDS and associated co-infections

The challenge of defining and measuring the level of spending on public health actions is well documented in the literature [176]. However, where data exist,[20] this indicator is regularly monitored and reported on by the ECDC (see Figure 7.1). The ECDC has repeatedly called for improvement in the quality of information reported on financial and non-financial inputs used in the implementation of the Communication and its Action Plan [21].[21] See Chapter 6 for an overview of findings regarding the funding for HIV/AIDS-related activities.

One key informant thought that this indicator would provide useful information but that it was not always feasible to track HIV funding (KI-10). For this reason, the key informant believed that this indicator could only be used as a supplementary measure to monitor implementation of the Communication and Action Plan. Another key informant felt that it

[19] The negative view of this indicator may stem from the difficulty for the key informants to understand the objective of the proposed indicator, as well as the likely minimal relevance of the indicators to them.

[20] There is no information about the EU structural funds' contribution or funding through the European Neighbourhood Partnership Instrument.

[21] Currently, there is no system/process in place to collect data at the EU level that would provide a global view on EU spending on HIV/AIDS. At the national level the ECDC collected data on funding in EU Member States for the years 2009–2011, but the information was incomplete and not always comparable (it covered only 11 Member States). The ECDC is working on setting an approach to collect a new set of data for the period 2012–2013.

would be useful to obtain more accurate data on EU funds invested in combating HIV/AIDS from both the EC and its delegations (KI-4).

7.2.3. Share of the people in need, as defined in WHO guidelines, with access to HIV/AIDS treatment

An indicator that reports on the share of people in need (as defined in WHO guidelines) who have access to HIV/AIDS treatment aims to capture the delivery aspects of the policy implementation, which directly relates to one of the objectives of the Communication and its Action Plan (i.e. improving access to prevention, treatment, care and support). However, the current wording of the indicator is ambiguous. The research team understood the aim of this indicator to be to capture ARV drugs coverage, as defined by the new WHO consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection [177].

The guidelines recommend initiating HIV treatment earlier and further scaling up the provision of ARV drugs for treatment and prevention in resource-limited settings. The new guidelines have a number of implications for monitoring of the new recommendations (including such areas as when to start ART, which ART regimen to start, response to ART and diagnosing treatment, service delivery and more). The guidelines also recommend the use of viral load testing to monitor ART success and to identify treatment failure, which should complement the clinical and immunological monitoring of people receiving ART (see Table 7.1 for indicators recommended by new WHO guidelines and Table 7.2 for the current scope of reporting on the coverage of ARV treatment to different organisations).

Table 7.1. Overview of data areas for monitoring and evaluating the HIV treatment cascade

Step in the cascade	Indicator
Linkage and enrolment in HIV care	Percentage of people newly diagnosed with HIV infection enrolled in HIV care
	Profile of PLWHIV initiating HIV care
	Retention in care of PLWHIV not yet initiating ART, including HIV-exposed infants
ARV drugs: coverage	Number of people receiving ART (and coverage)
	Number of people receiving ARV drugs for PMTCT [prevention of mother-to-child transmission] (and coverage)
ARV drugs: drug supply	Percentage of ART facilities with ARV drug stock-outs in a given period
ARV drugs: adherence and retention	Adherence
	Percentage retained on ART and PMTCT
Viral suppression	Percentage of viral suppression
Impact	Mortality; incidence and the number of adults and children acquiring HIV infection; mother-to-child transmission rate; survival

SOURCE: WHO, Consolidated Guidelines, 2013 [177]

There is an ongoing a debate about guidelines, especially related to the cost effectiveness of different monitoring strategies. For example, Keebler et al. (2014) propose that, due to high costs of viral load monitoring, countries should prioritise the expansion of ARV coverage using lower-cost clinical or CD4 cell count monitoring instead of viral load monitoring [178]. Monitoring viral load could be considered in countries that have achieved close to full

coverage of ART. However, Brown et al. (2014) argue that despite an ART coverage rate of 84 per cent among the diagnosed population, '*[i]n the UK, it is unlikely early treatment will reduce HIV transmission unless the undiagnosed population is substantially reduced*' [179].

It should also be noted that the ECDC has explored alternative approaches to tracking ART coverage in the Dublin Declaration monitoring process. The reason was that many MS expressed concerns about the relevance of modelling methods used by UNAIDS to estimate the number of PLWHIV needing ART [67]. (These estimates were considered to be less relevant for the high-income countries and for countries where HIV epidemics concentrated among particular subpopulations; the estimates could also result in the incorrect impression that providing ART coverage to all in need is the problem, while the main issue is to identify all those who need treatment [67].)

This debate among experts and academics was reflected by two key informants who believed that it is too early to determine whether or not this indicator would be of relevance (KI-10, KI-4).

7.2.4. Number of items Member States report to ECDC on progress on Dublin, Vilnius and Bremen Declarations, and HIV/AIDS Communication monitoring

The main limitation of this indicator is its ambiguity about the target value, which could range from over 50 indicators (total number of indicators used for ECDC, UNAIDS and WHO monitoring, which is considered a significant reporting burden) to zero (if a country does not report), neither extreme of which is desirable. It is important to note that any reporting by Member States to ECDC takes place on top of their reporting to UNAIDS and the WHO. According to the ECDC, HIV monitoring and reporting has improved, which is reflected in the higher reporting rates by countries in the region on implementation of the Dublin Declaration and on UNGASS indicators [21 67]. For Dublin Declaration reporting in 2010, responses were received from 49 countries, which included 12 countries that did not comply with UNGASS reporting in 2008 [21]. For the Dublin Declaration reporting, responses were received from 50 countries in 2012 and from 51 countries in 2013, out of a total of 55 countries [21].

The ECDC also reports progress made towards developing a set of regionally specific, harmonised indicators that combine ECDC, UNAIDS and WHO reporting into a single process, in order to reduce the reporting burden [21]. However, there is room for further improvements because the ECDC collects information on 24 indicators, the UNAIDS on 28 and the WHO on 33. Among the 50 indicators used in the 2012 round of ECDC reporting, only 14 were fully harmonised across the three agencies. However, given the different remits of the three organisations involved, full harmonisation is unlikely [180].

Nash et al. (2009) noted some shortcomings in current monitoring and evaluation of HIV programmes, including the existence of parallel systems for various donor organisations whose indicators and reporting requirements are not always harmonised [181]. The authors proposed including a number of methods to improve the current monitoring systems: developing web-based systems with capability for decentralised data entry and real-time access to summary reporting; timely feedback and dissemination of information to national, regional, and local staff; integrating monitoring and evaluation systems across different programmes and interventions, and more. The recent efforts of the ECDC seem to be in line

with the recommendations of Nash et al. (2009) and, according to the ECDC, have received positive feedback from the stakeholders involved in the process of data collection [180]. For example, as opposed to separate requests from the ECDC, UNAIDS and WHO, most of the data in 2012 were submitted electronically via the UNAIDS online reporting tool. The overlap between these three reporting systems is shown in Table 7.2.

Table 7.2. Sample of indicators used in combined reporting, 2012

	Dublin Declaration (ECDC)	Global AIDS Response Progress (UNAIDS)	Universal Access (WHO)
Target 4. Have 15 million people living with HIV on antiretroviral treatment by 2015			
ART among people diagnosed with HIV infection			
HIV treatment: 12 months retention			
HIV treatment: survival after 12 months on ART, PWID			
HIV treatment: 60-month retention			
PWID on treatment: 60 months retention			
ART stock-outs			
Late HIV diagnosis			

NOTE: The shading represents indicators used by a given institution and included in combined reporting

SOURCE: ECDC, Thematic report: Combined reporting, 2013 [180]

7.3. The European Surveillance System

An important component of current monitoring activities is the European Surveillance System (TESSy), which is managed by the ECDC [59]. Data gathered through the TESSy system are currently used to '*contribute to the evaluation and monitoring of prevention and control programmes targeted at HIV/AIDS to provide the evidence for recommendations to strengthen and improve these programmes at the national and European level*' [182]. Although TESSy was not a component of this evaluation, a number of key informants commented on TESSy when discussing EU monitoring activities. The key informants' comments are summarised below.

Key informant interviews provided important insights into, and views on, the current approach to HIV surveillance across Europe and the ECDC's role in surveillance. The majority of the key informants (8 out of 13) believed that HIV surveillance data collection had improved across Europe since 2009 and, of these, 4 thought that the Communication had been crucial to this improvement. Five key informants thought that the Action Plan provided the policy framework for a continued pan-European system and tasked the ECDC to provide regular reports (KI-1, KI-5, KI-8, KI-12, KI-13). Three other key informants did not make and/or consider there to be a link between the Communication and ECDC (KI-4, KI-3, KI-10). There was a general consensus among key informants that the TESSy system, and the ECDC more generally, provided valuable information for informing policy makers on the current status of the epidemic in Europe (see also Box 7.2).

Box 7.2. Key informant views on the further development of HIV surveillance at the European level

Key informants representing different stakeholders at the European level provided a range of views on how the current approach to HIV surveillance across Europe, and the role of ECDC in it, might be developed further. These can be summarised as follows:

Data completeness and comparability. Key informants acknowledged the high levels of completeness of data on the main indicators of HIV/AIDS across the European region. However, selected indicators for at-risk groups, particularly sex workers and migrants, and measures such as CD4 cell count, have remained incomplete and difficult to compare (KI-5). Key informants noted how EU funding through the Health Programme had made an important contribution in supporting and improving data collection within countries; one example listed was the COBATEST project (KI-10). However, there was concern about the level of reporting for some countries, and the quality of data, especially from non-EU countries, was questioned. And it was highlighted that some countries, such as Russia, do not report to TESSy (KI-1, KI-5).

Data presentation. Key informants noted that the style and regularity of ECDC reports, such as surveillance reports, thematic reports and country missions, had made the epidemiological data collected through TESSy more accessible to policy makers (KI-1, KI-12). However, one informant noted that, as a result of individual research projects, there was a risk of policy development to be biased towards the focus of these projects and initiatives. The informant further highlighted that accessibility of the dataset should to be increased, through, for example, an open source mechanism permitting general access (KI-5).

Data linkage. One key informant noted that collaboration between EMCDDA and ECDC had improved, and that the two agencies conducted a joint risk assessment for HIV among PWID (KI-5). One other key informant suggested that there could be a better linkage of the various data sets, for example, '*combining ECDC data with the FRA survey would enable a more sophisticated understanding of what's going on among MSM*' (KI-12).

Behavioural risk surveillance. Behavioural data are not routinely collected by the ECDC and understanding of behaviours of at-risk groups using secondary surveillance data is currently limited. A mapping review of behavioural surveillance in EU/EEA countries conducted in 2008 commissioned by the ECDC found that 16 out of 28 countries had established a behavioural surveillance system, but that these varied widely with regard to indicators and methods used [183]. One key informant noted that system development should be at the national level but that '*these should be harmonised in order to ensure data that is collected is comparable at the EU level*" (KI-9). At the same time key informants highlighted the value of research projects funded by the Commission, such as SIALON, which are thought to have provided substantial added value to increasing knowledge in this area among MSM (KI-3, KI-4).

Real-time monitoring and projection. Data that are available typically report on data with a time lag of at least one year, and there is a need for more timely reporting to inform priority setting, in particular in the case of outbreaks (KI-4, KI-8, KI-12). Key informants recommended the development of projection and other tools that would, for example, allow for the timely assessment of the potential for an outbreak (KI-5), or for longer-term projections of the likely development of the epidemic, and so inform appropriate action: '*there is a need for a unified European surveillance system and estimation system to account for predicting the spread of the epidemic for at least five years* [ahead]' (BG-KI-1).

7.4. European added value (EQ 3)

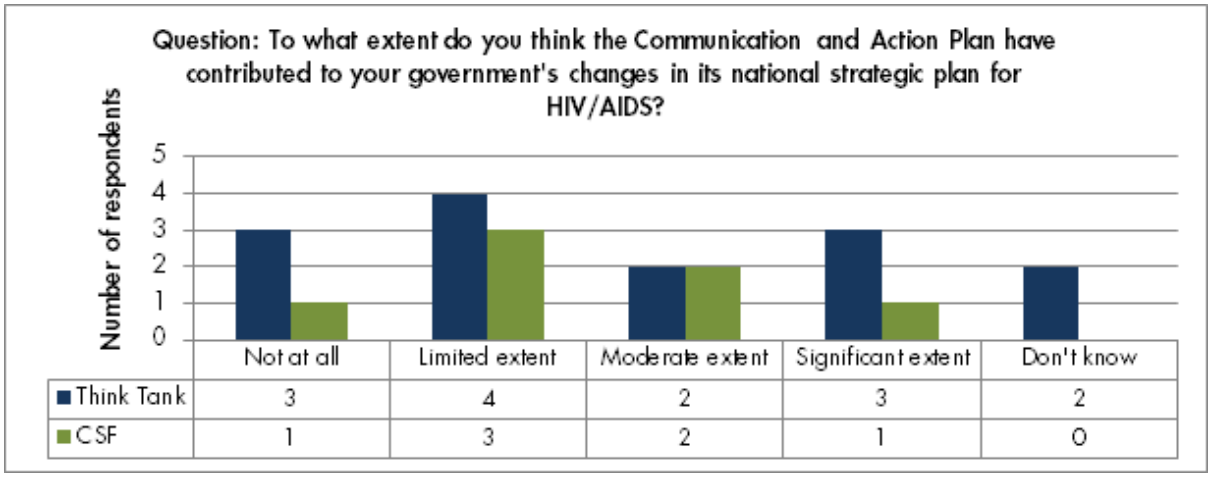
7.4.1. Impact on policy definition

In the survey, the majority of the respondents to the Think Tank survey (14 out of 17) and about half of the respondents to the CSF survey (5 out of 11) confirmed that their government had either adopted a new national strategic plan or had revised an existing plan for HIV/AIDS between 2009 and 2013. Nearly all respondents (see below) stated that these changes reflected the specific priorities defined in the Communication and its Action Plan:

- Protection of human rights (Think Tank: 12 out of 13; CSF: 4 out of 6)
- Promotion of timely diagnosis (Think Tank: 12 out of 13; CSF: 5 out of 6)
- Prevention among the priority target groups (Think Tank: 11 out of 12; CSF: 5 out of 6)
- Integration of HIV prevention with sexual health (Think Tank: 11 out of 12; CSF: 4 out of 6)
- Provision of ARV to PLWHIV (Think Tank: 13 out of 13; CSF: 6 out of 6)
- Treatment of co-infections (Think Tank: 11 out of 13; CSF: 5 out of 6)
- Surveillance (Think Tank: 13 out of 13; CSF: 6 out of 6)

However, 11 out of all 21 survey respondents believed that the Communication and its Action Plan had contributed to these changes to a limited extent or not at all (Figure 7.3). There were no clear geographical patterns in the survey responses: significant or moderate impact was reported by three Western, three Central and one Eastern European counties, whereas limited or no impact was recognised by five Western, three Central and two Eastern European counties.

Figure 7.3. National policy definition resulting from the Communication and its Action Plan



SOURCE: Surveys with Think Tank and CSF members

While only some changes in Member States' national strategic plans on HIV/AIDS can be attributed to the Communication, the importance of the Communication is seen by key informants (UK-KI-1, KI-3 and KI-7) to be of greater political importance in:

- Setting out expected actions
- Defining priority areas and groups
- Using the Communication as an advocacy tool to influence stakeholders at the national level.

7.4.2. Monitoring policy implementation – use of indicators and targets

While the use of health targets as a policy tool to improve health outcomes has been widely discussed in the literature [184-186], there is limited evidence that target setting and monitoring lead to improved outcomes if there are no implementation mechanisms in place to achieve these targets [176]. Allin et al. (2004) highlighted three general goals of health targets [176]:

- To initiate the development of health policy strategies within a country or region
- To help shift in healthcare (e.g. focus on treatment as prevention, prioritising certain groups or regions)
- To contribute to the improvement of population health.

The four proposed indicators to monitor the EU policy implementation process are process-driven (as opposed to outcome-oriented) and provide little information about the expected outcomes of the policy (e.g. new infections, coverage of ART and harm reduction programmes, and more). However, for those outcome-oriented indicators the EC could rely on the already existing and very extensive reporting system.

Given the limited competences of the EU in public health and the involvement of global organisations in target and goal setting, it may not be expected or necessary for the EU to formulate targets and determine relevant policy indicators. The research team found that the area where the EU could bring greatest added value in monitoring responses to the HIV

epidemic would be in further streamlining reporting processes and further harmonising the current system of indicators.

7.4.3. Reducing HIV reporting burden

The research team found that reducing the reporting burden is one area where the ECDC has already started making progress and where the EU could further add significant value. The ECDC's current efforts to harmonise and streamline HIV reporting with other international organisations seem to be addressing some of the problems. This evaluation confirmed that there is a high degree of 'survey and reporting fatigue' among key stakeholders and that, unless this issue is addressed, efforts to establish new indicators to monitor and evaluate policy implementation could be counterproductive and undermine the position of the ECDC and the EC among the key stakeholders.

7.5. Summary

In this chapter the evaluation sought to understand (i) the relation of the Communication to other EU policy areas and (ii) the indicators that are necessary to monitor the process of the implementation of the Communication.

Alignment with other EU policies

The Communication and its Action Plan are clearly in line with other EU policies (such as research, development and cooperation, drug control). However, there are areas where coordination and proximity with other policies could be further strengthened (e.g. the prominence of public health and HIV issues is somewhat underrepresented in the field of fundamental rights, migration and the ENP). Some key informants thought there is room for improvement in a number of areas, such as reducing the price of medicines, fighting stigma and discrimination, education of young people, as well as in the way objectives are operationalised and responsibilities are assigned in the proceedings of the Inter-service Group on HIV. Providing leadership in internal monitoring of the Commission's efforts to implement the Communication and its Action Plan and providing an adequate platform for this activity could help further improve the collaboration and coordination of the EU policies around combating HIV/AIDS.

EU HIV policy monitoring and added value

At the national level, only a few changes in strategic plans on HIV/AIDS can be attributed to the Communication. However, the Communication did give political weight to HIV/AIDS issues and set out expected actions, defined priority areas and groups, and provided an advocacy tool to influence stakeholders at the national level. The current monitoring and evaluation framework that was developed by the ECDC provides limited insight into the delivery process and extent of implementation at the Member State level. Given the complexity and breadth of HIV reporting that is required from the European countries, the scope for EU added value lies in continuing and reinforcing efforts to reduce, harmonise and streamline existing indicators, rather than in developing new indicators.

Finally, some key informants believed that HIV surveillance data collection had improved across Europe since 2009, although further improvements were possible. These

improvements include completeness and comparability of data (especially in the case of non-EU countries), presentation of data (permitting general access and linking ECDC data with other datasets), behavioural data (that should be harmonised and more routinely collected than at present), and real-time monitoring and projection (to reduce the time lag in reporting and allow for the timely assessment of HIV outbreaks and likely developments of the epidemic).

8. Summary, conclusions and recommendations

The report documents the findings of an independent evaluation of the implementation of the European Commission Communication 'Combating HIV/AIDS in the European Union and the neighbouring countries, 2009–2013' and its Action Plan. It sought to explore the extent to which the Communication and Action Plan have achieved their expected outcomes, in line with a series of 18 evaluation questions set by the commissioner of the evaluation. The evaluation focused primarily on the 28 EU Member States, but it also included non-EU countries that are represented in European fora, namely, member countries of the HIV/AIDS Think Tank, which represents EU Member States, Candidate Countries and EEA Countries; member countries of the Civil Society Forum, which brings together non-governmental organisations and networks; and countries from the wider WHO European Region where appropriate and relevant.

In this concluding chapter we synthesise the findings presented in this report, bringing together the key observations in relation to the five thematic areas of the evaluation. These were (i) changes in the HIV epidemic and access to key services; (ii) role and impact of the Civil Society Forum; (iii) contribution of EU-funded research and public health projects; (iv) funding to support HIV prevention, treatment, care and support; and (v) EU HIV policy coordination and monitoring. We draw conclusions and suggest suitable actions and specific recommendations for the relevant stakeholders for each of the themes, which we report on. Building on lessons learnt through this evaluation, we conclude with a discussion of options for shaping the design of a future European policy framework on HIV/AIDS and for a suitable approach to an evaluation thereof. Before presenting the findings it is, however, important that we first highlight some of the limitations of the work presented in this report.

8.1. Limitations of the evaluation

This evaluation faced a number of important limitations, which can broadly be grouped into the following categories: scope and time frame of the evaluation, availability and collection of data, and establishing attribution.

8.1.1. Scope and time frame of the evaluation

The terms of references for this evaluation defined a broad scope for the evaluation, involving 18 distinct evaluation questions. The evaluation was to be undertaken within the relatively short time frame of eight months to ensure timely input into further developments in HIV/AIDS policies at the EU level. This meant that the evaluation had to cover a large number of countries and a wide range of stakeholders. The geographic scope of the evaluation included the 28 EU Member States, as well as non-EU countries represented in

the Think Tank and CSF forum and countries from the wider WHO European Region, subject to data availability. The relevant stakeholders included academics, Think Tank members, CSF members and representatives of European institutions and international organisations. The depth of the evaluation was therefore necessarily constrained by the broad scope and tight time frame of the evaluation.

8.1.2. Data availability and collection

The evaluation drew on a wide range of data, some of which are routinely collected as part of ongoing monitoring activities at the European level, including data from ECDC surveillance reports, DG RTD and DG SANCO. However, the ability to fully address all evaluation questions was restricted by the at times patchy nature of the data (e.g. availability of reports on projects supported by the Health Programme between 2009 and 2013); its timeliness (the most recent data were typically available to 2012 only, so covering only parts of the period covered by the Communication and the Actions Plan); its lack of comprehensiveness (e.g. data on CD4 cell count at diagnosis); its uncertain quality (e.g. national level funding on HIV); or its lack of specificity (e.g. number of new HIV diagnoses as a proxy for incidence). Furthermore, the scope to collect new primary data was restricted. This was in part because of the timeline within which data had to be collected. However, there was also a need to minimise the duplication of data collection efforts such as those undertaken by the ECDC in order to reduce the reporting burden of the providers of data at the national and NGO levels.

Surveys

The evaluation used three surveys, two of members of the Think Tank and the CSF, and one of researchers of FP7 projects (using the *ImpactFinder* tool). The extent to which the findings of the CSF and Think Tank surveys can be generalised remains uncertain due to the relatively low response rate of, respectively, 40 per cent (14/35 CSF members) and 44 per cent (17/ 39 Think Tank members). There was also a risk of self-reporting bias because many of the respondents were from organisations under evaluation; they may therefore have had a vested interest in the evaluation. For both surveys, we attempted to minimise the impact of self-reporting bias by consulting additional stakeholders with no vested interest.

The response rate to the *ImpactFinder* survey that was used to inform the evaluation of the impact of EU research was at 43 per cent (30/77), also leaving some degree of uncertainty as to the robustness of the results. An additional limitation of the *ImpactFinder* survey was that the survey was limited to six FP7 projects and thus may not have captured all of the potential impacts of FP7 research.

Key Informant Interviews

Similarly, the number of key informants interviewed for this study was relatively small. The initial aim was to conduct three key informant interviews for each of the country case studies and two key informant interviews for the two research case studies to complement the information gathered through desk research. However, it was not possible to secure the intended number of interviews because of unwillingness to participate by some and an inability to establish contact with others. Thus, we secured one expert in the United Kingdom, two from Bulgaria and two from Latvia; for the two research case studies, we interviewed two experts for EuroCoord and one for microbicides.

For the overall evaluation, we sought to interview four Think Tank members, four CSF members and seven representatives from the European Commission services, EU agencies and international organisations. We were able to interview these as planned, except that we interviewed only two Think Tank members instead of four.

8.1.3. Attribution

A core challenge of any evaluation of complex policy processes is the attribution of observed effects to the policy in question, as it is often not possible to establish a plausible counterfactual. In this evaluation, it is possible that policies that were implemented before the Communication and the Action Plan of 2009 or other exogenous developments may have contributed to the findings observed in this evaluation. It is also possible that much of the impact of the Communication and its Action Plan on the HIV epidemic in Europe occurs indirectly as a result of its impact on the actions of Member States, which have a direct impact on the epidemic at a national level, such that it may not be possible to assess with certainty the precise contribution of the Communication and its Action Plan on the observed changes. Finally, the evaluation was undertaken at the end of the period covered by the Communication, and it is conceivable that selected impacts of the Communication and its Action Plan may occur at some later stage, in particular where funding instruments such as the FP7 or Health Programme are concerned, with many projects ongoing at the time of writing.

8.1.4. The evaluation presented in this report was prescriptive and task-driven

The commissioning of the evaluation presented in this report was guided by a set of pre-specified evaluation questions that covered a large number of topics to be explored within a comparatively short time frame. While this provides a broad overview of a range of issues of importance in relation to the Communication, this breadth will inevitably be at the expense of the depth of the analysis.

Also, underpinning this evaluation was an assumption that relevant stakeholders are aware of and understand the objectives of the Communication and its Action Plan. However, as we have shown, this does not unequivocally appear to be the case. Some key informants and survey respondents found it difficult to link the Communication and its Action Plan with the mechanisms intended, including the CSF and Think Tank platforms, EU-funded research, and activities of the EC and ECDC. There also appeared to be a lack of clarity about the geographical reach of the Communication and Action Place, with representatives from neighbouring countries not considering the Communication to be applicable outside the EU.

This indicates that a renewal of the HIV/AIDS policy at the EU level would benefit from a clearer formulation of the intended outcomes and the definition of the causal pathways that are thought to result in the desired outcomes ('theory of change'). Such an approach would clarify the roles and responsibilities of individual stakeholders tasked with the delivery of the objectives set out in the policy, which should also aid in the communication of the policy. Considering the evaluation of the renewed policy, it may be important for the EC to consider reducing the scope or commissioning a series of studies that explore particular aspects in more detail, thereby providing a level of granularity that was not possible to deliver in the context of this evaluation. Furthermore, there is a persuasive argument to reconsider the approach to evaluation towards one that builds on the monitoring and evaluation framework

for the Communication, as described in Section 7.2, and that is informed by theory, setting out the different elements of the 'intervention' logic – from inputs, processes, outputs, and outcomes to impacts – and that seeks to understand how and why the desired change is expected to come about. This would facilitate both the implementation process (by considering contextual factors, assumptions and risks) and the future evaluation of the next framework.

8.2. Key observations and recommendations

8.2.1. Changes in the HIV epidemic and access to key services

The evaluation sought to (i) assess the contribution of the Communication to reducing the number of new infections, improving access to key services and improving the quality of life for PLWHIV; (ii) identify barriers to the uptake of HIV testing and treatment; and (iii) identify challenges in the implementation of HIV-related policies and programmes.

Before discussing observed trends and the potential contribution of the Communication and its Action Plan to these trends, it is important that we note that current approaches to HIV surveillance in Europe (and indeed elsewhere) rely primarily on proxy measures of the burden of HIV, such as new diagnoses of HIV (and AIDS) cases, and the numbers of those accessing HIV-related treatment and care services. However, these measures provide only limited insight into the nature of the epidemic; an observed change in the number of newly diagnosed cases can mean that there has been a change in HIV transmission (that is, new infection) or a change in testing of undiagnosed infections, or both. It is against this background that observed trends, and associated impacts of the Communication, have to be interpreted. Keeping this in mind, available data suggest that the rate of new diagnoses per year fell between 2009 and 2012 across the EU/EEA. The rate remained highest in the eastern part of the WHO European Region and lowest in the central part. The most common routes of transmission in the EU/EEA overall continued to be through MSM, although heterosexual contact has become more important, while in the East transmission tends to occur among PWID and their sexual partners.

Turning to access to HIV services, available data suggest that there was an increase in the number of tests performed in the EU/EEA since 2009, but that that there was considerable variation in the rate of testing among countries. Available data on CD4 cell count as an indicator for access to and uptake of HIV testing suggest that the number of people who present late for testing has remained high across the region. Although the number of countries reporting indicators of access to and uptake of HIV testing has increased during 2009–2013, overall data on HIV testing services have remained patchy across the region. Similarly, there is little systematic data collection on access to ART and on ART coverage at the European level. An observed decline in the rate of newly diagnosed AIDS cases in EU/EEA countries during 2009–2013 suggests improved access to treatment. Non-EU/EEA counties saw an increase in the number of recorded new AIDS cases during the same period, mostly driven by a rise in cases in the eastern part of the region, which only reversed in 2011. Although improvements in access to treatment have been achieved, increasing ART coverage, especially among undiagnosed populations, remains a concern.

Overall, and as indicated earlier, while HIV surveillance data that are being collected across Europe provide some insight into the HIV epidemic, the nature and scope of data that are

available do not provide sufficient granularity to allow for a robust assessment of the extent to which the Communication and Action Plan may have contributed to any observed change in HIV incidence and access to key services. Key informants in the field of HIV consulted for this evaluation by means of interviews and surveys highlighted that such a contribution would, if anything, be largely indirect, because the development and implementation of policies on HIV/AIDS is a national-level competency. At the same time, key informants highlighted the importance of the Communication and its Action Plan in emphasising the need to focus on groups most at risk for HIV, including MSM, PWID and migrants, providing political support for the delivery of services and for these groups.

Considering barriers to the uptake of HIV testing and treatment, the evaluation identified a series of factors – including lack of awareness of HIV; lack of knowledge of HIV; entitlement status, an issue of particular relevance for migrants; and stigma – and factors relating to the attitudes and motivations of healthcare staff and the wider system to ensure provision of appropriate services for hard-to reach groups in particular, and the provision of counselling and support to facilitate access to and uptake of services by those at risk.

Reported barriers to the implementation of HIV-related policies and programmes included lack of resources, both human and financial; lack of capacity (and oversight), mentioned in particular for the central and eastern parts of the European Region; as well as legislative, regulatory and policy issues more broadly. Here, key informants highlighted measures that would exclude certain at-risk populations from accessing HIV services, and which they linked to ineffective anti-discrimination laws and suboptimal service coverage provisions, mainly affecting undocumented migrants. Respondents raised concerns about the long-term sustainability of HIV services in resource-constrained settings and where the number of PLWHIV is rising. These points will be revisited below in the context of funding for HIV/AIDS (Section 8.2.4).

Based on our observations under the first thematic area of the evaluation, which considered (i) changes in the HIV epidemic, (ii) access to key services, (iii) barriers to access and uptake of HIV services and (iv) barriers to the implementation of HIV/AIDS policies and programmes, we recommend that the European Commission consider:

- **Adopting a new European policy framework on HIV/AIDS** in order to ensure that HIV/AIDS remains on the policy agendas and to reinforce stakeholders' commitment to implement policies and programmes to address HIV/AIDS prevention, treatment, care and support at the national and regional levels. The evaluation showed that while activity at the EU level is unlikely to directly impact on trends in HIV infections (except where the EU directly funds related activity) the 2009–2013 Communication has formed an important political backdrop against which to help stimulate activity at the national level, in particular with regard to the most at-risk populations.
- **Supporting activities to strengthen the primary prevention of HIV/AIDS**. While based on limited data from key informants, the evaluation confirmed that there is a continued need to enhance awareness and understanding of HIV among key population groups, and the options for HIV testing at the community level, in order to reduce the number of undiagnosed cases – and the proportion of people

diagnosed late– in order to improve prognosis and, through ensuring timely treatment, reduce transmission.

- **Supporting activities targeting the most at-risk populations**, in particular working with relevant stakeholders to address the needs of migrants and developing guidance on the financing and delivery of prevention, treatment, care and support services for this group. Considering the particularly vulnerable situation of migrants, in particular those with uncertain legal status, support action at the European level, bringing together the European Commission, the HIV/AIDS Think Tank and the Civil Society Forum, may be particularly suited to help improve countries' responses to enhancing access to information and key services for this group specifically.

8.2.2. Role and impact of the Civil Society Forum

The evaluation sought to assess (i) the contribution of the Civil Society Forum (CSF) to the objectives of the Communication; (ii) the effectiveness of the CSF in providing relevant information to the EC and the Think Tank; and (iii) the adequacy of resources dedicated to the CSF in relation to its objectives and needs. The evaluation found that the role of the CSF was considered important by key informants, who reported that it facilitated interactions, discussions and best practice exchanges among various stakeholders. The evidence collected pointed to activities by the CSF which key informants regarded as successful. The informants singled out activities around stigma and discrimination and the uptake of key HIV services by at-risk population groups, in particular MSM and PWID. Overall, the data collected were not sufficient to enable attribution of observed changes solely to CSF actions.

We found that the CSF had established regular interactions between its members and the HIV/AIDS Think Tank, mainly through biannual meetings and email exchanges. The communication and the information disseminated by the CSF were judged as helpful by key informants and survey respondents in raising awareness of meeting participants and of Think Tank members on development in HIV/AIDS at the EU level.

The evidence collected for this evaluation suggests that there is, however, some room for further improvement.

Drawing on limited evidence, we further found that the financial resources allocated to the running and management of the CSF were rated as being sufficient, at present, to carry out its mandate and the activities it is currently implementing.

Overall, the evaluation found that by assigning the CSF a role in the implementation of the Communication, the European Commission empowered the organisations representing civil society and strengthened its role in influencing policymakers at the national and European levels. The contribution of the EC Communication was seen to be particularly important in Member States that have joined the EU more recently, as a means to strengthen the civil society movement.

It was outside the scope of the evaluation to consider the role and impact of the HIV/AIDS Think Tank and its interactions with the CSF. However, we believe it to be important to briefly reflect on this issue, given the importance apportioned by key informants interviewed for this study to the Think Tank. This is further described in Box 8.1.

Box 8.1. The HIV/AIDS Think Tank and collaboration with the CSF

The HIV/AIDS Think Tank was established in 2004, in the light of the growing HIV/AIDS epidemic in the eastern part of the European region in particular and the recognised need for a 'dedicated working group or Think Tank on HIV/AIDS' that would represent Member States, Candidate Countries and the EEA Countries [187]. While the Think Tank was established before the period covered by the 2009–2013 Communication, which is the subject of the present evaluation, key informants interviewed for this study highlighted the importance of the Think Tank as a mechanism for the implementation of the Communication. The Think Tank was seen not only to have formed a platform for regular meetings between country representatives, the EC and international organisations, but also to have established informal channels of communication and collaboration among its participants. This was considered as important added value by a number of key informants.

Evidence collected for this evaluation suggests that the CSF and Think Tank appear to best serve their own members: respondents to the Think Tank survey highly valued their meetings, while respondents to the CSF survey reported to be largely unfamiliar with Think Tank member meetings (with the possible exception of the CSF co-chairs, who attend Think Tank meetings).

It is uncertain whether the level of interactions between the CSF and the Think Tank should and could be enhanced. While the role of the civil society in combating HIV/AIDS and its collaboration with national authorities has been seen as critically important, at the European level these two platforms might work more effectively by focusing their collaboration on transferring effective practices between countries.

Based on our observations under the second thematic area of the evaluation, which considered the role and impact of the Civil Society Forum, we recommend that the European Commission considers:

- **Continuing to support the CSF** to further enhance the involvement of civil society in the development of HIV/AIDS policies, programmes and activities across Europe and to strengthen advocacy for at-risk populations and people affected by HIV/AIDS, in particular where civil society advocacy is not (yet) well established. The evaluation found that the legitimacy awarded by the European Commission in the 2009–2013 Communication to the CSF was seen to be crucial to empower stakeholders involved in combating HIV/AIDS. It empowered them by increasing their knowledge and informing their actions at the national level and by influencing perceptions of stakeholders on the added value of the civil society perspective on the development of HIV/AIDS policies at the EU level.

We also recommend that the CSF considers:

- **Focusing its work on the sharing of experience and transferring of good practices among countries** to combat HIV/AIDS in Europe. The evidence showed that, through its activities and website (the clearinghouse), the CSF has facilitated access to good practices that might be transferred to other countries. The CSF (or, indeed, the Think Tank) might serve as a platform where these opportunities could be pro-actively and more effectively exploited. This could be effected by involving a wider group of stakeholders in dedicated sessions or working groups focused on the transfer of knowledge and the review of evidence on what works, for whom and under what conditions.

8.2.3. Contribution through EU-funded research and public health projects

The evaluation sought to explore (i) the extent to which FP7 funding has led to the development of novel preventive tools and therapeutic options and how these have

contributed to the Communication's objectives; (ii) the effects of EU-funded projects on the level of awareness of HIV; (iii) the extent to which the Health Programme has contributed to the objectives set out in the Communication; and (iv) the extent to which the EU-funded programmes facilitated an exchange of experience between countries in the area of HIV. Data collected as part of this evaluation refer to two areas of HIV/AIDS research, (i) microbicide development and (ii) HIV progression and the long-term effects of antiretroviral therapy (ART) (EuroCoord). EU-funded research in the area of microbicides has yet to lead to the development of novel preventive tools. Work in this area is still in the early stages of development, and this is reflective of the global situation regarding microbicide research. Conversely, the EuroCoord study was shown to have contributed to HIV surveillance methods, national surveillance strategies and the type of data that are collected across Europe, as well as research infrastructure and policy and treatment guidelines. It is difficult to generalise from these two cases to the overall impact of FP7-funded projects; overall, evidence on the extent to which FP7 projects contributed to reducing the number of new infections, improving access to key services and improving the quality of life of PLWHIV during 2009–2013 is weak.

At the same time, we identified supportive evidence that FP7 projects considered did contribute to activities raising awareness of HIV prevention and treatment, through improving knowledge through education and training of future researchers and decisionmakers. However, as before, it difficult to generalise from evidence collected to the overall impact of FP7-funded projects on the level of awareness of and knowledge about HIV/AIDS or, indeed, to establish causal effects.

Turning to the EU Health Programme 2008–2013, we found that projects on HIV that were supported through this funding stream were largely aligned with the objectives set out in the Communication. The Health Programme was shown to have enabled epidemiological and behavioural research across various EU countries, the exploration of screening for HIV and co-infections among at-risk groups in participating Member States, and the development of training material. However, as is the case with research funded under the FP7 programme, it is as yet not possible to determine with certainty the extent to which these projects have contributed to the attainment of Communication's objectives, with the project ongoing at the time of writing.

One area where EU-funded research was found to be rated highly was around networking and exchanging experience at the European level, although these benefits were not widely recognised by respondents to the survey. This suggests that there may be a need to facilitate communication among academics, researchers and those working in HIV surveillance, and to disseminate the research findings to a broader range of stakeholders across Europe.

Although the overall contribution of EU-funded research and public health projects to combating HIV/AIDS in Europe remains to be established, key informants interviewed for this evaluation viewed the availability of such funding as a considerable added value of EU action at this level. There was also some suggestion that there may be a larger role for the EU to play in terms of coordinating and funding HIV research across the different directorates that support research efforts, in order to enable a 'more cohesive' approach to addressing conditions such as HIV/AIDS.

Based on data collected within this evaluation, it is difficult to draw firm recommendations on the contribution of EU-funded research and public health projects to the objectives of the Communication. Where the evidence permits, we suggest that the European Commission:

- **Continues to develop mechanisms that facilitate communication between scientists and practitioners** and that better address the translation gap between basic and applied research. Mechanisms may include continuing funding streams that (i) systematically require the collaboration of basic science and applied research to ensure that research is translatable into practice; (ii) incentivise the conduct of implementation research alongside studies that develop strategies for HIV/AIDS prevention, treatment, care and support, so providing insights into the scalability of 'good practice'; or (iii) specifically focus on developing (and evaluating) research dissemination formats that effectively communicate HIV research findings to different audiences, including vulnerable population groups. Other mechanisms include the systematic involvement of key stakeholders representing HIV surveillance and monitoring, public health agencies, social services and other stakeholders in the further development of the HIV/AIDS research agenda across the relevant EU agencies (DG SANCO, DG RTD and the Directorate-General for Development and Cooperation [DG DEVCO]).
- **Considers establishing mechanisms within the new Health Programme** that enable access to EU-funded interventions by organisations, such as NGOs, that are currently unable to meet the matched funding requirements and to so encourage their participation in pan-European projects.

8.2.4. Funding to support HIV prevention, treatment, care and support

The evaluation sought to understand (i) EU funds allocated to HIV/AIDS and the EC's contribution to the Global Fund; (ii) EU funds allocated to priority groups; (iii) spending on HIV/AIDS and co-infections by Member States; (iv) the way in which the EU could support NGOs; and (v) the effects of the financial crisis in Europe on HIV/AIDS and the potential ways of addressing these.

Any assessment of overall spending at EU-level on HIV/AIDS in Europe is poses a challenge because of a lack of centralised monitoring. However, drawing on data derived from a range of sources, we estimate that overall spending at the EU level on HIV prevention, treatment care and support during 2009–2013 was approximately €150 million.

When considering spending on HIV prevention, treatment, care and support by priority group, we were only able to draw on published data from the EU Health Programme. This indicated that during 2009–2013 one-third of projects supported through this funding stream addressed MSM, followed by priority regions (29 per cent), migrants (22 per cent), PWID (9 per cent), and prisoners (7 per cent).

The EU contribution to the Global Fund to Fight AIDS, Tuberculosis and Malaria during 2009–2013 was around €508 million, equating to about 4 per cent of total donor contributions to the GFATM. During the same period, two EU MS, Bulgaria and Romania, and three ENP countries, Belarus, Moldova and Ukraine, received support through the Global Fund. GFATM budget reductions for HIV/AIDS in Bulgaria and Romania during 2009–2013 meant that, in Romania, funding for prevention interventions targeting vulnerable populations was not secured and NGOs had to discontinue their activities because

of lack of funding. The future sustainability of HIV activities was also flagged for Bulgaria. We identified a set of options that might be considered by the EU to further support NGOs in countries facing the phasing out of the Global Fund or NGOs that experience capacity issues in the EU MS and neighbouring countries, and we provide recommendations below.

Data on the impact of the 2008 global financial crisis on HIV prevention, treatment, care and support are not readily available. A small number of country-specific studies have highlighted challenges related to the crisis, with HIV outbreaks reported among injecting drug users in Greece and Romania, and these have been associated with cut-backs in prevention and treatment programmes for illicit drug use. There was variation among countries for which national-level data on year-on-year spending on HIV were available for the period 2009–2011, suggesting that overall spending on HIV may have remained fairly stable, but countries appeared to have reduced spending on HIV prevention, with implications for sustaining preventative activities. Countries generally reported maintaining the provision of testing, treatment, care and support services, although some experienced cases of service disruption or a redefinition of eligibility for services, which had the effect of reducing the number of people accessing HIV services. Overall, it remains challenging to establish direct links between the financial crisis and changes in HIV prevention, treatment, care and support where these occurred.

Against the reported limitations of data, which prevented the assessment of EU-level spending on HIV/AIDS, we recommend that the EC considers introducing a centralised system to record and monitor information on the level of EU funds spent on HIV/AIDS by various DGs and EU agencies. Work currently undertaken by the ECDC to monitor national expenditures on HIV/AIDS might enable the EC follow the trends at the EU and national levels with greater accuracy [133].

With regard to civil society, we further suggest that the European Commission considers:

- **Continuing facilitating access by NGOs to EU structural funds and EU-funded programmes**, by providing capacity-building components and by further simplifying rules and regulations
- **Prioritising health investments through EU-level funds**, in particular in the European Social Fund (ESF) allocation for social inclusion
- **Supporting training for or mentoring of schemes between organisations** that help build their capacity in the areas of advocacy, fundraising and project management.

8.2.5. EU HIV policy coordination and monitoring

The evaluation sought to understand (i) the relation of the Communication to other EU policy areas and (ii) the indicators that are necessary to monitor the process of the implementation of the Communication.

Based on the evidence collected as part of the evaluation, HIV policy appears to be well embedded in other EU policies, although there are areas where coordination could be further strengthened, in particular in the area of human rights, affordability of medicines, and operational aspects of the EU funding to combat HIV. This study highlighted that there is already a substantial HIV reporting burden and concluded that additional and process-

driven indicators to monitor the uptake of EU policy at the national level might not add significant value. In this context, the evaluation concluded that the area where the EU could add most value is to continue the ECDC's efforts to harmonise and streamline HIV reporting. Exploring changes to the European surveillance system, the evaluation found evidence that suggests that the HIV surveillance data collection has improved across Europe since 2009. However, the data collected are insufficient to unambiguously attribute these changes to the Communication.

Based on our observations, we suggest that the European Commission considers:

- **Strengthening coordination between HIV policy and the areas of justice, human rights and non-discrimination** to more effectively address the issue of stigma and the situation of migrants in the EU.
- **Improving coordination of HIV funding among different EU programmes**, including EU-funded scientific research, the Health Programme, the European Neighbourhood and Partnership Instrument, and other instruments, to ensure greater continuity of funding.
- **Further advancing existing mechanisms to monitor the implementation of the Communication and its Action Plan by the EC and EU agencies** in order to take corrective action and/or resolve coordination issues when required. The Inter-service Group on HIV/AIDS in Europe, chaired by DG SANCO, could provide a suitable forum for reviewing the effectiveness of the implementation at the EU level.
- **In collaboration with the ECDC, continuing efforts to harmonise and streamline HIV reporting** to reduce the burden on national authorities and the civil society, who continue to report to multiple funders and organisations on progress in combating HIV.
- **In collaboration with the ECDC, developing actions to further improve completeness, comparability and availability of TESSy data.** While it was outside the scope of this evaluation to assess the existing surveillance system and therefore the evidence we collected to support these recommendations is limited, our evaluation did reveal a number of areas in which improvements seem possible.

8.3. Reflections on the evaluation: Lessons learned and implications for the further development of HIV/AIDS polices at the EU level

In this section we draw general conclusions on the implementation of the Commission Communication and its Action Plan based on the specific topic areas discussed throughout the report. We also reflect on lessons learnt through this evaluation to inform the formulation of a renewed policy at the EU level to replace the Action Plan on HIV/AIDS adopted in 2014, which extended the existing framework [3].

The Communication provided political backing to and strategic leadership in combating HIV/AIDS in Europe

As illustrated in this evaluation, the Communication and its Action Plan were seen by stakeholders to have provided a necessary stimulus, continuous pressure and leverage for various stakeholders to advocate for and take action against HIV/AIDS in Europe. While such action did not automatically translate into new policies at the national level, in the

current economic context it was important that issues related to HIV/AIDS remained high on the political agendas. For this reason it will be important that the Commission retains the momentum and seeks to develop a renewed policy framework addressing HIV/AIDS in Europe for the coming years.

Given the at times rapidly changing context, in terms of economic or societal context as well as scientific advances in HIV research, it appears necessary to consider a mechanism that builds in an element of 'flexibility' to a new policy framework and that thus would permit greater responsiveness to changes that may occur within the time horizon of the policy framework.

The Communication's objectives preceded developments in HIV surveillance systems

Of crucial importance for the systematic monitoring of the impacts of any policy development at the EU level is the availability of data that are aligned with the objectives of the given policy. The three core objectives of the 2009–2013 Communication were to reduce the number of new HIV infections in all European countries by 2013; to improve access to prevention, treatment, care and support; and to improve the quality of life of people living with, affected by, or most vulnerable to, HIV/AIDS in the EU and neighbouring countries. Yet, relevant data that would allow for a robust assessment of the extent to which these objectives have been achieved are as yet lacking. This is in part because of challenges inherent in measurement as such, for example, the incidence of HIV or the quality of life of PLWHIV. However, other indicators are more amenable to routine collection, such as the number of HIV tests performed or the CD4 cell count at diagnosis.

It is against this background that it will be important for the Commission, in collaboration with the ECDC, to define future surveillance priorities and develop a sustainable and systematic approach to collecting epidemiological and behavioural surveillance data at the EU level. This may require, as part of a renewed HIV/AIDS policy, incorporating mechanisms suitable to support countries that currently lack the capacity for data collection, in order to enhance the comprehensiveness and comparability of data across the region. Any policy objectives set for combating HIV/AIDS in Europe should also consider the time frame within in which it will be realistic that desired outcomes, such as the reduction of new infections, can be achieved and, more importantly, set targets against which to judge success.

Identified areas of high added value build on key competencies of the EU

The evaluation found that the Communication was perceived to have added value in a number of areas, including focusing efforts and resources on priority regions and groups; strengthening civil society in contributing the setting of the policy agenda on HIV/AIDS at the European and national levels; facilitating collaboration and exchange of experience among countries; and supporting collaborative projects in the area of research and public health.

Building on these key areas of activity and competency, it appears to be important for the EC to focus on the following areas for developing further HIV/AIDS polices at the EU level:

- **HIV research**: Building on a small number of recommendations presented in Section 8.1, there is an opportunity for the EC to revisit its approach to the funding and organisation of HIV research in order to strengthen the cohesiveness between

research areas and to continue to promote the combination of basic science and applied research to enable swifter translation of research findings into practice.

- **Primary prevention of HIV**: There is considerable opportunity to strategically focus available (research) funding to increase awareness of and knowledge about HIV/AIDS among at-risk groups and to systematically communicate findings among key stakeholders involved in HIV/AIDS policies and practice, in order to facilitate cross-national learning. Given the competencies of the EU in the field of public health in particular, there may also be a role for DG SANCO, in collaboration with other directorates – such as DG JUSTICE, DG HOME or DG EMPL – to consider supporting a joint campaign on stigma and discrimination against people living with HIV. Such a campaign would crucially require involvement of the CSF and the Think Tank to ensure that messages are culturally sensitive and acceptable.
- **Health security**: The EC, in cooperation with the Think Tank, could further explore if and how the Decision on serious cross-border threats to health could be used to support EU Member States in combating HIV/AIDS.

References

1. McManus H, O'Connor CC, Boyd M, et al. Long-term survival in HIV positive patients with up to 15 years of antiretroviral therapy. PloS one 2012;7(11):e48839
2. EC. A European Programme for Action to Confront HIV/AIDS, Malaria and Tuberculosis through External Action (2007-2011). Communication from the Commission to the Council and the European Parliament. European Commission 2005;COM (2005) 179 final
3. EC. Commisison Staff Working Document. Action Plan on HIV/AIDS in the EU and neighbouring countries: 2014-2016. European Commission 2014;SWD(2014) 106 Final
4. EC. Fight against HIV/AIDS: launch of enhanced Action plan in EU and neighbouring countries for 2014-2016. European Commission 2014;IP/14/267(14/03/2014)
5. EC. Bremen Declaration on Responsibility and Partnership – Together Against HIV/AIDS. European Commission 2007;online: http://www.eu2007.de/en/News/download_docs/Maerz/0312-BSGV/070Bremen.pdf [accessed 31 March 2014]
6. EC. "Vilnius Declaration" on Measures to Strengthen Responses to HIV/AIDS in the European Union and in Neighbouring Countries European Commission 2004;online: http://ec.europa.eu/health/ph_threats/com/aids/docs/ev_20040916_rd03_en.pdf [accessed 31 March 2014]
7. Council of the European Union. Council conclusions on Combating HIV/AIDS - Outcome of proceedings. 2005
8. Council of the European Union. Council Conclusions on Progress on the European Programme for Action to confront HIV/AIDs, Malaria and Tuberculosis through External Action (2007-2011). 2009
9. UNICEF. Dublin Declaration on Partnership to fight HIV/AIDS in Europe and Central Asia. 2004;online: http://www.unicef.org/ceecis/The_Dublin_Declaration.pdf [accessed 20 March 2014]
10. United Nations General Assembly Special Session on HIV/AIDS (UNGASS). Declaration of Commitment on HIV/AIDS. 2001
11. United Nations General Assembly Special Session on HIV/AIDS (UNGASS). Political Declaration on HIV/AIDS. 2006
12. United Nations General Assembly Special Session on HIV/AIDS (UNGASS). Political Declaration on HIV and AIDS: Instensifying Our Efforts to Eliminate HIV and AIDS. 2011
13. United Nations. Investing in Development: A Practical Plan to Achieve the Millennium Development Goals. 2005
14. EC. Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions. Combating HIV/AIDS in the European Union and neighbouring countries, 2009-2013. European Commission 2009;COM(2009)0569 final
15. EC. Communication from the Commission to the Council and the European Parliament on combating HIV/AIDS within the European Union and neighbouring countries, 2006-2009. European Commission 2005;Luxembourg

16. EC. Commission Staff Working Document. Action Plan Accompanying document to the Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the regions Combating HIV/AIDS in the European Union and neighbouring countries, 2009 - 2013. European Commission 2009;SEC(2009) 1403 final
17. European Commission. HIV/AIDS Think Tank (working group with Member States). 2014
18. European Commission. HIV/AIDS Civil Society Forum (CSF). 2014
19. EU. Decision No 2119/98/EC of the European Parliament and of the Council of 24 September 1998 setting up a network for the epidemiological surveillance and control of communicable diseases in the Community. Official Journal of the European Union 1998; L 268(03/10/1998):1-7
20. EU. Regulation (EC) No 851/2004 of the European Parliament and of the Council of 21 April 2004 establishing a European centre for disease prevention and control Official Journal of the European Union 2004;L 142/1(30.4.2004)
21. ECDC. Monitoring implementation of the EC Communication and Action Plan for combating HIV/AIDS in the European Union and neighbouring countries, 2009-2013. Final Report. European Centre for Disease Prevention and Control 2013;Stockholm
22. SANCO D. Terms of Refrence: SANCO framework contract on evaluation, impact assessment and related services, Ref. Ares(2013)2764082. European Commission 2013;unpublished
23. ECDC. Monitoring recently acquired HIV infections in the European context. European Centre for Disease Prevention and Control 2013;Stockholm
24. Contandriopoulos D, Lemire M, DENIS JL, Tremblay É. Knowledge exchange processes in organizations and policy arenas: a narrative systematic review of the literature. Milbank Quarterly 2010;88(4):444-83
25. Europe AA. The NGO partnership on HIV and AIDS in Europe and Central Asia. AIDS Action Europe;online: http://www.aidsactioneurope.org/about-us/who-we-are [accessed 31 March 2014]
26. Wooding S, Nason E. Mapping the impact: exploring the payback of arthritis research. RAND Europe 2009(MG-862-ARC)
27. Gené-Badia J, Gallo P, Hernández-Quevedo C, García-Armesto S. Spanish health care cuts: penny wise and pound foolish? Health Policy 2012;106(1):23-28
28. Smith MK, Powers KA, Muessig KE, Miller WC, Cohen MS. HIV treatment as prevention: the utility and limitations of ecological observation. PLoS medicine 2012;9(7):e1001260
29. ECDC/WHO. Surveillance Report: HIV/AIDS surveillance in Europe - 2008. European Centre for Disease Prevention and Control/WHO Regional Office Europe 2009;Stockholm
30. ECDC/WHO. Surveillance Report: HIV/AIDS surveillance in Europe 2009. European Centre for Disease Prevention and Control/WHO Regional Office Europe 2010;Stockholm
31. ECDC/WHO. Surveillance Report: HIV/AIDS surveillance in Europe 2010. European Centre for Disease Prevention and Control/WHO Regional Office Europe 2011;Stockholm
32. ECDC/WHO. Surveillance Report: HIV/AIDS surveillance in Europe 2011. European Centre for Disease Prevention and Control/WHO Regional Office Europe 2012;Stockholm
33. ECDC/WHO. Surveillance Report: HIV/AIDS surveillance in Europe 2012. European Centre for Disease Prevention and Control/WHO Regional Office Europe 2013;Stockholm
34. Birrell PJ, Gill ON, Delpech VC, et al. HIV incidence in men who have sex with men in England and Wales 2001–10: a nationwide population study. The Lancet infectious diseases 2013

35. Shelton JD, Cohen M, Barnhart M, Hallett T. Is antiretroviral therapy modifying the HIV epidemic? The Lancet 2010;376(9755):1824-25
36. Laga M, Piot P. Prevention of sexual transmission of HIV: real results, science progressing, societies remaining behind. Aids 2012;26(10):1223-29
37. Phillips AN, Cambiano V, Nakagawa F, et al. Increased HIV incidence in men who have sex with men despite high levels of ART-induced viral suppression: analysis of an extensively documented epidemic. PloS one 2013;8(2):e55312 doi: 10.1371/journal.pone.0055312[published Online First: Epub Date]|.
38. van Sighem A, Vidondo B, Glass TR, et al. Resurgence of HIV infection among men who have sex with men in Switzerland: mathematical modelling study. PloS one 2012;7(9):e44819 doi: 10.1371/journal.pone.0044819[published Online First: Epub Date]|.
39. McDonald SA, Hutchinson SJ, Wallace LA, et al. Trends in the incidence of HIV in Scotland, 1988-2009. Sexually transmitted infections 2012;88(3):194-9 doi: 10.1136/sextrans-2011-050132[published Online First: Epub Date]|.
40. van der Knaap N, Grady BP, Schim van der Loeff MF, et al. Drug users in Amsterdam: are they still at risk for HIV? PloS one 2013;8(3):e59125 doi: 10.1371/journal.pone.0059125[published Online First: Epub Date]|.
41. Jansen IA, Geskus RB, Davidovich U, et al. Ongoing HIV-1 transmission among men who have sex with men in Amsterdam: a 25-year prospective cohort study. AIDS 2011;25(4):493-501 doi: 10.1097/QAD.0b013e328342fbe9[published Online First: Epub Date]|.
42. Heuker J, Sonder GJ, Stolte I, Geskus R, van den Hoek A. High HIV incidence among MSM prescribed postexposure prophylaxis, 2000-2009: indications for ongoing sexual risk behaviour. AIDS 2012;26(4):505-12 doi: 10.1097/QAD.0b013e32834f32d8[published Online First: Epub Date]|.
43. Blome MA, Bjorkman P, Flamholc L, Jacobsson H, Molnegren V, Widell A. Minimal transmission of HIV despite persistently high transmission of hepatitis C virus in a Swedish needle exchange program. Journal of viral hepatitis 2011;18(12):831-9 doi: 10.1111/j.1365-2893.2010.01400.x[published Online First: Epub Date]|.
44. Xiridou M, van Veen M, Prins M, Coutinho R. How patterns of migration can influence the heterosexual transmission of HIV in The Netherlands. Sexually transmitted infections 2011;87(4):289-91 doi: 10.1136/sti.2010.048512[published Online First: Epub Date]|.
45. Cowan SA, Gerstoft J, Haff J, Christiansen AH, Nielsen J, Obel N. Stable incidence of HIV diagnoses among Danish MSM despite increased engagement in unsafe sex. Journal of acquired immune deficiency syndromes (1999) 2012;61(1):106-11 doi: 10.1097/QAI.0b013e31825af890[published Online First: Epub Date]|.
46. Uuskula A, McMahon JM, Kals M, et al. Risk for Heterosexual HIV Transmission Among Non-Injecting Female Partners of Injection Drug Users in Estonia. AIDS and behavior 2013;17(3):879-88 doi: 10.1007/s10461-011-0078-9[published Online First: Epub Date]|.
47. Salado-Rasmussen K, Katzenstein TL, Gerstoft J, et al. Risk of HIV or second syphilis infection in Danish men with newly acquired syphilis in the period 2000-2010. Sexually transmitted infections 2013;89(5):372-6 doi: 10.1136/sextrans-2012-050580[published Online First: Epub Date]|.
48. Ndawinz JD, Costagliola D, Supervie V. New method for estimating HIV incidence and time from infection to diagnosis using HIV surveillance data: results for France. AIDS 2011;25(15):1905-13 doi: 10.1097/QAD.0b013e32834af619[published Online First: Epub Date]|.
49. Gouws E, Cuchi P. Focusing the HIV response through estimating the major modes of HIV transmission: a multi-country analysis. Sexually transmitted infections 2012;88 Suppl 2:i76-85 doi: 10.1136/sextrans-2012-050719[published Online First: Epub Date]|.

50. Case KK, Ghys PD, Gouws E, et al. Understanding the modes of transmission model of new HIV infection and its use in prevention planning. Bulletin of the World Health Organization 2012;90(11):831-38A
51. Aghaizu A, Murphy G, Tosswill J, et al. Recent infection testing algorithm (RITA) applied to new HIV diagnoses in England, Wales and Northern Ireland, 2009 to 2011. Euro surveillance: bulletin Europeen sur les maladies transmissibles= European communicable disease bulletin 2013;19(2)
52. Le Vu S, Le Strat Y, Barin F, et al. Population-based HIV-1 incidence in France, 2003–08: a modelling analysis. The Lancet infectious diseases 2010;10(10):682-87
53. Romero A, Gonzalez V, Esteve A, et al. Identification of recent HIV-1 infection among newly diagnosed cases in Catalonia, Spain (2006-08). European journal of public health 2012;22(6):802-8 doi: 10.1093/eurpub/ckr179[published Online First: Epub Date]|.
54. Re MC, Bon I, Grandi N, et al. Recent and long-lasting infections: the need for avidity testing in HIV-1 infected subjects. The new microbiologica 2012;35(4):407-14
55. Mammone A, Pezzotti P, Angeletti C, et al. HIV incidence estimate combining HIV/AIDS surveillance, testing history information and HIV test to identify recent infections in Lazio, Italy. BMC infectious diseases 2012;12(1):65
56. Le Vu S, Velter A, Meyer L, et al. Biomarker-based HIV incidence in a community sample of men who have sex with men in Paris, France. PloS one 2012;7(6):e39872 doi: 10.1371/journal.pone.0039872[published Online First: Epub Date]|.
57. Niccolai LM, Verevochkin SV, Toussova OV, et al. Estimates of HIV incidence among drug users in St. Petersburg, Russia: continued growth of a rapidly expanding epidemic. European journal of public health 2011;21(5):613-9 doi: 10.1093/eurpub/ckq115[published Online First: Epub Date]|.
58. UNAIDS/WHO. When and how to use assays for recent infection to estimate HIV incidence at a population level. UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance 2011
59. ECDC. European Network for HIV/AIDS Surveillance. European Centre for Disease Prevention and Control;online: http://www.ecdc.europa.eu/en/activities/surveillance/hiv/Pages/index.aspx [accessed 17 March 2014]
60. EMCDDA. HIV outbreak among injecting drug users in Romania. European Monitoring Centre for Drugs and Drug Addiction 2012;Lisbon
61. EMCDDA. HIV outbreak among injecting drug users in Greece. European Monitoring Centre for Drugs and Drug Addiction 2012;Lisbon
62. EMCDDA. Outbreaks of HIV among IDUs in Greece and Romania: Preliminary data suggest no signs of a slowing down in 2012. European Monitoring Centre for Drugs and Drug Addiction 2012;online: http://www.emcdda.europa.eu/news/2012/HIV-outbreaks [accessed 28 April 2014]
63. Oguntibeju OO. Quality of life of people living with HIV and AIDS and antiretroviral therapy. HIV AIDS (Auckl) 2012;4:117-24
64. UNGASS. Republic of Bulgaria country progress report on monitoring the 2011 political declaration on HIV/AIDS, the Dublin Declaration and the universal access in the health sector response. Reporting Period: January 2010-December 2011: United Nations General Assembly Special session on HIV/AIDS, 2012.
65. Sniedze I. HIV/AIDS and TB Surveillance and Prevention System in Latvia. The Centre for Disease Prevention and Control of Latvia 2012;Riga
66. Mocroft A, Lundgren JD, Sabin ML, et al. Risk factors and outcomes for late presentation for HIV-positive persons in europe: results from the collaboration of observational HIV epidemiological research europe study (COHERE). PLoS medicine 2013;10(9):e1001510
67. ECDC. Thematic report: HIV treatment, care and support. Monitoring implementation of the Dublin Declaration on Partnrship to Fight HIV/AIDS in Europe and Central Asia: 2012 progress. European Centre for Disease Prevention and Control 2013;Stockholm

68. Girardi E, Sabin CA, Antonella d'Arminio Monforte M. Late diagnosis of HIV infection: epidemiological features, consequences and strategies to encourage earlier testing. JAIDS Journal of Acquired Immune Deficiency Syndromes 2007;46:S3-S8
69. European Centre for Disease Control (ECDC). EMIS 2010: The European Men-Who-Have-Sex-With-Men Internet Survey. 2010
70. Kaai S, Bullock S, Burchell AN, Major C. Factors that affect HIV testing and counseling services among heterosexuals in Canada and the United Kingdom: an integrated review. Patient education and counseling 2012;88(1):4-15 doi: 10.1016/j.pec.2011.11.011[published Online First: Epub Date]|.
71. Fakoya I, Prost A, Burns F, Hart G. Increasing the uptake of HIV testing to reduce undiagnosed infection and prevent transmission among black African communities living in England: Barriers to HIV testing. National Institute for Health and Care Excellence 2010
72. ECDC. Country mission Latvia: HIV, sexually transmitted infections and hepatitis B and C. European Centre for Disease Prevention and Control 2011
73. ITPC. Rationing Funds, Risking Lives: World backtracks on HIV treatment. On-the-ground rsearch in India, Kenya, Latvia, Malawi, Swaziland, and Venezuela. International Treatment Preparedness Coalition; Treatment Monitoring & Advocacy Project 2010;Missing the Target 8(April 2010)
74. van Ginneken E, Habicht J, Murauskiene L, Behmane D, Mladovsky P. The Baltic states: building on 20 years of health reforms. BMJ: British Medical Journal 2012;345
75. Behmane D, Innus J. Pharmaceutical policy and the effects of the economic crisis: Latvia. Eurohealth 2011;17(1):8
76. Altice FL, Kamarulzaman A, Soriano VV, Schechter M, Friedland GH. Treatment of medical, psychiatric, and substance-use comorbidities in people infected with HIV who use drugs. Lancet 2010;376(9738):367-87 doi: 10.1016/s0140-6736(10)60829-x[published Online First: Epub Date]|.
77. Sylla L, Bruce RD, Kamarulzaman A, Altice FL. Integration and co-location of HIV/AIDS, tuberculosis and drug treatment services. International Journal of Drug Policy 2007;18(4):306-12
78. Culley DM, Taylor J, Rubin J, Hoorens S, Disley E, Rabinovich L. Assessment of the Implementation of the EU Drugs Strategy 2005-2012 and Its Action Plans. 2012(TR-1228-EC)
79. Busch M, Grabenhofer-Eggerth A, Weigl M, Wirl C. Report on the Current state of play of the 2003 Council Recommendation on the prevention and reduction of health-related harm, associated with drug dependence, in the EU and candidate countries. Gesundheit Osterreich 2013;online: http://ec.europa.eu/eahc/documents/health/report-drug-dependence_en.pdf [accessed 10 June 2014]
80. Alvarez-Del Arco D, Monge S, Caro-Murillo AM, et al. HIV testing policies for migrants and ethnic minorities in EU/EFTA Member States. European journal of public health 2014;24(1):139-44 doi: 10.1093/eurpub/ckt108[published Online First: Epub Date]|.
81. EC. Call for the expression of interest to become a member of the EU HIV/AIDS Civil Society Forum. European Commission website;Online: http://ec.europa.eu/health/sti_prevention/hiv_aids/civil_society_forum/call_en.htm [accessed 10 June 2014]
82. AAE. Civil Society Forum Meeting Reports. AIDS Action Europe website;online: http://www.aidsactioneurope.org/our-work/advocacy-work/civil-society-forum-meeting-reports [accessed 10 June 2014]
83. Spicer N, Harmer A, Aleshkina J, et al. Circus monkeys or change agents? Civil society advocacy for HIV/AIDS in adverse policy environments. Social Science & Medicine 2011;73(12):1748-55
84. EC. "Right to health, right to life" - High Level Meeting on HIV and Human Rights in the European Union and its neighbouring countries, 27-28 May 2013. European Commission 2013;online:

http://ec.europa.eu/health/sti_prevention/events/ev_20130527_en.htm [accessed 8 May 2014]
85. RTD D. Survey of FP7 funded projects. Data provided courtesy of European Commission 2014;unpublished
86. EuroCoord. Enhancing clincial and epidemiological HIV research in Europe through cohort collaboration. EuroCoord website;online http://www.eurocoord.net/ [accessed 28 April 2014]
87. EuroCoord. Partners. EuroCoord website;online: http://www.eurocoord.net/partners.aspx [accessed 20 May 2014]
88. EuroCoord. Aims. EuroCoord website;online: http://www.eurocoord.net/aims.aspx [accessed 31 March 2014]
89. AIM-HIV. Anti-Inflammatory Microbicides against HIV. AIM-HIV project website;online: http://aim-hiv.isciii.es/ [accessed 28 April 2014]
90. CORDIS. EU Research Projects. APO-HSV-2/HIV: Double infection by HSV-2 and HIV: how does HSV-2 infection facilitate for HIV infection? . European Commission; Community Research and Development Information Service;online: http://cordis.europa.eu/projects/rcn/88711_en.html [accessed 16 May 2014]
91. CORDIS. EU Research Projects. FUTURE-PHARMA: Exploiting plants for the production of future generation recombinant pharmaceuticals. European Commission; Community Research and Development Information Service;online: http://cordis.europa.eu/projects/rcn/99830_en.html [accessed 16 May 2014]
92. CHAARM. Combined Highly Active Anti-Retroviral Microbicides. CHAARM website;online: http://chaarm.eu/ [accessed 28 April 2014]
93. MOTIF. Microbicide Optimization Through Innovative Formulation for vaginal and rectal delivery. MOTIF website;online: http://www.motifproject.eu/web/ [accessed 28 April 2014]
94. WHO. Microbicides. World Health Organization;online: http://www.who.int/hiv/topics/microbicides/microbicides/en/ [accessed 20 May 2014]
95. Karim QA, Karim SSA, Frohlich JA, et al. Effectiveness and safety of tenofovir gel, an antiretroviral microbicide, for the prevention of HIV infection in women. science 2010;329(5996):1168-74
96. EuroCoord. Publications & presentations. EuroCoord website;online: http://www.eurocoord.net/publications__presentations.aspx [accessed 28 April 2014]
97. CHAARM. Publications. CHAARM website;online: http://chaarm.eu/microbicides/publications-0 [accessed 28 April 2014]
98. MOTIF. Scientific publications. MOTIF website;online: http://www.motifproject.eu/web/scientific-publications/ [accessed 20 May 2014]
99. EuroCoord. Policy Brief 2013. EuroCoord website 2013;online: http://www.eurocoord.net/pdf/EuroCoord_Policy_Brief_2013.pdf [accessed 23 May 2014]
100. CHAARM. Project objectives. CHAARM website;online: http://chaarm.eu/project/project-objectives [accessed 20 May 2014]
101. AIM-HIV. Objectives. AIM-HIV project website;online: http://aim-hiv.isciii.es/index.php/the-project/objectives [accessed 20 May 2014]
102. MOTIF. Objectives & Expected Outcomes. MOTIF website;online: http://www.motifproject.eu/web/objectives-results/ [accessed 20 May 2014]
103. Kirby DB, Laris BA, Rolleri LA. Sex and HIV Education Programs: Their Impact on Sexual Behaviors of Young People Throughout the World. Journal of Adolescent Health 2007;40(3):206-17
104. EC. Periodic Report Summary 1 - EUROCOORD (European Network of HIV/AIDS Cohort Studies to Coordinate at European and International Level Clinical Research on HIV/AIDS). European Commission. CORDIS 2013;online: http://cordis.europa.eu/result/report/rcn/56019_en.html [accessed 28 April 2014]

105. Chafea. HIV funding 2003-2013. data provided courtesy of Consumer, Health and Food Executive Agency 2014;unpublished
106. Chafea. Project No 20101211 under EU Health Programme 2008-2012. Capacity Building in Combining Targeted Prevention with Meangingful HIV Surveillance Among MSM (SIALON II). European Commission; Consumer, Health and Food Executive Agency website;online: http://ec.europa.eu/eahc/projects/database.html?prjno=20101211 [accessed 31 March 2014]
107. Chafea. Overview of the EU Health Programme Support to Tackle HIV/AIDS and co-infections. European Commission; Consumer, Health and Food Executive Agency 2014;available online: http://ec.europa.eu/chafea/documents/health/hiv-infopack_en.pdf [accessed 31 March 2014]
108. ECDC. M&E Framework; Proposed Framework to Monitor the EU Commission Communication & Action Plan to Combat HIV/AIDS in the EU and Neighbouring countries 2009-2013. European Centre for Disease Prevention and Control 2011;Stockholm
109. EAHC. M&E framework. Questions for EAHC on the Implementation of the EU Commission Communication & Action Plan to Combat HIV/AIDS. data provided courtesy of Executive Agency for Health and Consumers 2012;unpublished
110. Chafea. EU Contribution to a reinforced prevention and improved care in times of HIV epidemic resurgence; Health Programme 2008-2013 support to the implementation of the COM(2009)569 Combating HIV/AIDS in the European Union and neighbouring countries, 2009-2013, Infopack for the Cluster meeting on HIV prevention, 12-13 June, Athens. European Commission; Consumer, Health and Food Executive Agency 2014
111. COBATEST. Cross-national survey on the implementation of community based voluntary counselling and testing (CBVCT) programmes – Quantitative Report. HIV Community-based testing practices in Europe 2012;online: http://www.cobatest.org/news.php [accessed 5 November 2014]
112. SRAP. SRAP Final Publication. Addiction and Prevention within Roma and Sinti Communities. Why it matters. . Addiction and Prevention within Roma and Sinti Communities 2013;online: http://srap-project.eu/2013/09/04/srap-final-publication-addiction-and-prevention-within-roma-and-sinti-communities/ [accessed 10 June 2014]
113. BORDERNETwork. Bridging research on HIV/STI prevalence and risks to evidence-based effective practice. Final Report: HIV/STI Sentinel-Surveillance. BORDERNETwork Package 5 2012
114. TUBIDU. Assessment on HIV and TB knowledge and the barriers related to access to care among vulnerable groups. Report on a cross-sectional study among injecting drug users. National Institute for Health Development, Estonia 2014
115. Dudareva-Vizule S, Marcus U. Formative research report. SIALON II 2013
116. ECDC. Mission Report. Joint technical mission: HIV in Greece 28-29 May 2012. European Centre for Disease Prevention and Control 2013;Stockholm
117. Action Q. Joint Action on Improving Quality in HIV Prevention. Quality Action website;online: http://www.qualityaction.eu/ [accessed 31 March 2014]
118. SIALON-II. Capacity building in combining targeted prevention with meaningful HIV surveillance among men who have sex with men. SIALON II website;online: http://www.sialon.eu/en/ [accessed 31 March 2014]
119. EuroCoord. EuroCoord Methodology. EuroCoord website;online: http://www.eurocoord.net/contact_us/eurocoord_methodology_subgroup.aspx [accessed 10 June 2014]
120. AAE. Final report SANL_FY2012. data provided courtesy of CHAFEA;unpublished
121. AAE. The Clearninghouse on HIV and AIDS in Europe and Central Asia. AIDS Action Europe;online: http://www.aidsactioneurope.org/clearinghouse [accessed 10 June 2014]

122. PHEIAC. Specific Contract: Mid-Term Evalusation of the Health Programme. Case Study Report. Public Health Evaluation and Impact Assessment Consortium 2011;9th August 2011
123. AAE. Joint Actions and Projects. Final Report. Call for Proposals 2008-2013. data provided courtesy of CHAFEA 2013;unpublished
124. ECDC. Thematic Report: Leadership and resources in the HIV response. Monitoring implementation of the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia: 2012 Progress Report. European Centre for Disease Prevention and Control 2013;Stockholm
125. GFATM. About. The Global Fund to fight Aids, Tuberculosis and Malaria website;online: http://www.theglobalfund.org/en/about/ [accessed 10 June 2014]
126. EU. Decision No 36/2002/EC of the European Parliament and of the Council of 19 December 2001 concerning the Community contribution to the Global Fund to fight HIV/AIDS, tuberculosis and malaria. Official Journal of the European Union 2001;L 007(11/01/2002):001-02
127. EU. Financing for Global Health. Action for Global Health. Guide to Global Health in Europe website;online: http://www.globalhealthguide.eu/?site=policies-and-funding&sub=financing-for-global-health [accessed 10 June 2014]
128. GFATM. Funding and Spending. The Global Fund to fight Aids, Tuberculosis and Malaria website;online: http://www.theglobalfund.org/en/about/fundingspending/ [accessed 5 November 2013]
129. GFATM. Pledges and Contributions. The Global Fund to fight Aids, Tuberculosis and Malaria 2013;online: http://www.theglobalfund.org/en/about/fundingspending/ [accessed 5 November 2013]
130. GFATM. Grant Portfolio. The Global Fund to fight Aids, Tuberculosis and Malaria website;online: http://portfolio.theglobalfund.org/en/Home/Index [accessed 26 November 2013]
131. GFATM. Country Allocations 2014 -2016. The Global Fund to fight Aids, Tuberculosis and Malaria 2014;online: http://www.theglobalfund.org/en/fundingmodel/allocationprocess/allocations/ [accessed 15 March 2014]
132. ECDC. Implementing the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia: 2010 progress report. European Centre for Disease Prevention and Control 2010;Stockholm
133. ECDC. Meeting report: monitoring the HIV response in Europe: Report of the 1st Dublin Declaration Advisory Group Meeting, Zagreb, 14-15 October 2013. European Centre for Disease Prevention and Control 2013;Stockholm
134. ECDC. Thematic Report: Civil society Monitoring implementation of the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia: 2012 progress. European Centre for Disease Prevention and Control 2012;Stockholm
135. GFATM. Global Fund grants US$ 60 million to Romania, Bulgaria, Cuba and East Timor. The Global Fund to fight Aids, Tuberculosis and Malaria 2014;Online: http://www.theglobalfund.org/en/mediacenter/newsreleases/2003-06-06_Global_Fund_grants_USD_60_million_to_Romania_Bulgaria_Cuba_and_East_Timor/ [accessed 10 June 2014]
136. ITPC. Making Global Fund Country Coordinating Mechanisms work through full engagement of civil society. On-the-ground research in Argentina, Cambodia, Cameroon, India, Jamaica, Romania and Uganda. International Treatment Preparedness Coalition; Treatment Monitoring & Advocacy Project 2008;October
137. Kuehne J, Finch K, Voitzwinkler F. Bridging the gap – How the European Union can address the funding crisis for TB and HIV programmes in Eastern Europe and Central Asia. Position Paper. UK and Global Health Advocates France 2013;September 2012
138. GFATM. Sustainability Review of Global Fund Supported HIV, Tuberculosis and Malaria Programmes. The Global Fund to fight Aids, Tuberculosis and Malaria 2013

139. Mladovsky P, Srivastava D, Cylus J, et al. Health policy responses to the financial crisis in Europe. Policy Summary 5. 2012
140. Karanikolos M, Mladovsky P, Cylus J, et al. Financial crisis, austerity, and health in Europe. The Lancet 2013;381(9874):1323-31
141. EOHSP. Health & Financial Crisis Monitor. European Observatory on Health Systems and Policies;online: http://www.hfcm.eu/ [accessed 10 June 2014]
142. Bonovas S, Nikolopoulos G. High-burden epidemics in Greece in the era of economic crisis. Early signs of a public health tragedy. Journal of preventive medicine and hygiene 2012;53(3):169-71
143. Nikolopoulos G, Tsiodras S, Botsi C, Malliori M, Kremastinou T. HIV surveillance and injecting drug users in Greece. The Lancet 2014;383(9918):693-94
144. Pharris A, Wiessing L, Sfetcu O, et al. Human immunodeficiency virus in injecting drug users in Europe following a reported increase of cases in Greece and Romania, 2011. Euro Surveill 2011;16(48):1-5
145. Kentikelenis A, Karanikolos M, Reeves A, McKee M, Stuckler D. Greece's health crisis: from austerity to denialism. The Lancet 2014;383(9918):748-53
146. Kirby T, Thornber-Dunwell M. England's HIV services face complex new environment. The Lancet 2014;383(9911):17-18
147. Mitenbergs U TM, Misins J, Mikitis E, Martinsons A, Rurane A, Quentin W. Latvia: Health system review. Health Systems in Transition 2012;14(8):1-191
148. Laukamm-Josten U, De Colombani P, De Joncheere K, et al. Mid-term evaluation of the Latvian National HIV Programme: 2009-2013. World Health Organization and United Nations Office on Drugs and Crime 2011
149. AAE. Accelerating progress in Europe to universal access to HIV treatment during a time of financial crisis. AIDS Action Europe 2012;online: http://www.aidsactioneurope.org/news/archive/accelerating-progress-europe-universal-access-hiv-treatment [accessed 10 June 2014]
150. EATG. The impact of economic austerity on the HIV response in Spain: a community perspective. Working Paper European AIDS Treatment Group 2014
151. Perez-Molina JA, Pulido Ortega F. [Assessment of the impact of the new health legislation on illegal immigrants in Spain: the case of human immunodeficiency virus infection]. Enfermedades infecciosas y microbiologia clinica 2012;30(8):472-8 doi: 10.1016/j.eimc.2012.07.004[published Online First: Epub Date]|.
152. ECDC. Meeting Report. Responses to HIV and migration in western industrialised countries: current challenges, promising practices, future directions. 22 July 2012. European Centre for Disease Prevention and Control 2013;Stockholm
153. CSF. Report of the 16th HIV/AIDS Civil Society Forum Luxembourg, 3-4 December 2012. Meeting convened by the European Commission Health & Consumer Protection Directorate-General with co-chairing of AIDS Action Europe and the European AIDS Treatment Group The EU HIV/AIDS Civil Society Forum 2012
154. CSF. Report of the 14th HIV/AIDS Civil Society Forum, Luxembourg, 6/7 December 2011. Meeting convened by the European Commission Health & Consumer Protection Directorate-General with co-chairing of AIDS Action Europe and the European AIDS Treatment Group The EU HIV/AIDS Civil Society Forum 2011
155. Suhrcke M, Stuckler D, Suk JE, et al. The impact of economic crises on communicable disease transmission and control: a systematic review of the evidence. PloS one 2011;6(6):e20724
156. EMCDDA/ECDC. HIV in injecting drug users in the EU/EEA, following a reported increase of cases in Greece and Romania. European Monitoring Centre for Drugs and Drug Addiction and European Centre for Disease Control 2012;Lisbon
157. Sypsa V, Paraskevis D, Malliori M, et al. Homelessness and Other Risk Factors for HIV Infection in the Current Outbreak Among Injection Drug Users in Athens, Greece. American journal of public health 2014(0):e1-e9

158. Botescu A, Abagiu A, Mardarescu M, Ursan M. HIV/AIDS among injecting drug users in Romania. Report of a recent outbreak and initial response policies European Monitoring Centre for Drugs and Drug Addiction 2012;Lisbon
159. Regidor E, Barrio G, Bravo MJ, de la Fuente L. Has health in Spain been declining since the economic crisis? Journal of epidemiology and community health 2014;68(3):280-82
160. UNAIDS/WB. Update on the Impact of the Economic Crisis: HIV Prevention and Treatment Programmes. UNAIDS and the World Bank 2009
161. EU. Decision No 1082/2013/EU of the European Parliament and of the Council of 22 October 2013 on serious cross-border threats to health and repealing Decision No 2119/98/EC. Official Journal of the European Union 2013;L 293(05/11/13)
162. PHEIAC. Study to measure the implementation of EU health polices at national, regional and local levels, assessing the utility of existing indicators for this task and developing new indicators as necessary. Final Report. Public Health Evaluation and Impact Assessment Consortium 2012;Volume I - Main Text
163. EC. White Paper. Together for Health: A Strategic Approach for the EU 2008-2013. European Commission 2007;COM(2007) 630 final
164. EU. Council Directive 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin. Official Journal of the European Union 2000;L 180(29/06/2000)
165. EU. Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation. Official Journal of the European Union 2000;L 303(02/12/2000):0016 - 22
166. EC. Research & Innovation. Health, Infectious Diseases, HIV/AIDS research under FP7. European Commission;online: http://ec.europa.eu/research/health/infectious-diseases/poverty-diseases/aids_en.html [accessed 14 February 2014]
167. EC. Development and Cooperation - EuropeAid. Health. European Commission;online: http://ec.europa.eu/europeaid/what/health/index_en.htm [accessed 14 February 2014]
168. EC. Justice. Drug control policy. European Commission;online: http://ec.europa.eu/justice/anti-drugs/index_en.htm [accessed 14 February 2014]
169. EC. Regional Policy - Inforegio. Health. European Commission;online: http://ec.europa.eu/regional_policy/activity/health/index_en.cfm [accessed 14 February 2014]
170. EC. Employment, Social Affairs & Inclusion. Rights at Work. European Commission;online: http://ec.europa.eu/social/main.jsp?catId=82&langId=en [accessed 14 February 2014]
171. EC. Joint communication to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions. A new response to a changing Neighbourhood. European Commission 2011;COM(2011) 303 final(Brussels 25/05/2011)
172. EC. SPORT. Health and Participation. European Commission;online: http://ec.europa.eu/sport/policy/societal_role/health_participation_en.htm [accessed on March 2014]
173. EU. Charter of Fundamental Rights of the European Union. Official Journal of the European Union 2012;2012/C 326/02
174. EC. Home Affairs. Immigration. European Commission;online: http://ec.europa.eu/dgs/home-affairs/what-we-do/policies/immigration/index_en.htm [accessed 14 February 2014]
175. EC. Public Health. Coordination among policy areas. European Commission;online: http://ec.europa.eu/health/health_policies/coordination/index_en.htm [accessed 14 February 2014]
176. Allin S, Mossialos E, Mckee M, Holland W. Making decisions on public health: a review of eight countries. European Observatory on Health Systems and Policies 2004

177. WHO. Consolidated Guidelines on the use of antiretroviral drugs for treating and preventing HIV infection. Recommendations for a public health approach. World Health Organisation 2013(June 2013)
178. Keebler D, Revill P, Braithwaite S, et al. Cost-effectiveness of different strategies to monitor adults on antiretroviral treatment: a combined analysis of three mathematical models. The Lancet Global Health 2014;2(1):e35-e43
179. Brown A, Nardone A, Delpech V. WHO 'Treatment as Prevention'guidelines are unlikely to decrease HIV transmission in the UK unless undiagnosed HIV infections are reduced. AIDS 2014;28(2):281-83
180. ECDC. Thematic report: Combined reporting. Monitoring implementation of the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia: 2012 Progress Report. European Centre for Disease Prevention and Control 2013;Stockholm
181. Nash D, Elul B, Rabkin M, et al. Strategies for more effective monitoring and evaluation systems in HIV programmatic scale-up in resource-limited settings: implications for health systems strengthening. JAIDS Journal of Acquired Immune Deficiency Syndromes 2009;52:S58-S62
182. ECDC. European Network for HIV/AIDS Surveillance; Descritption of the network. European Centre for Disease Prevention and Control;online: http://www.ecdc.europa.eu/en/activities/surveillance/hiv/Pages/description.aspx [accessed 21 May 2014]
183. Dubois-Arber F, Jeannin A, Spencer B, et al. Mapping HIV/STI behavioural surveillance in Europe. BMC infectious diseases 2010;10(1):290
184. Wismar M, McKee M, Ernst K, Srivastava D, Busse R. *Health targets in Europe: learning from experience*: World Health Organization, 2008.
185. Holm L-E. Setting targets for health 2020. The European Journal of Public Health 2012;22(4):453-53
186. Smith P, Busse R. Peer Reviewed: Learning From the European Experience of Using Targets to Improve Population Health. Preventing chronic disease 2010;7(5)
187. EC. Mandate for the Think Tank on HIV/AIDS in Europe European Commission 2004;online: http://ec.europa.eu/health/archive/ph_threats/com/aids/docs/ev_20040614_md_en.pdf [accessed 31 March 2014]

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