Monika STEFFEN  
CNRS Senior Researcher, Institute of Political Studies, Grenoble University, France  
monika.steffen@iep-grenoble.fr

The Europeanization of Public Health: how does it work?  
The seminal role of the AIDS case

Summary: This article analyses the path that led the EU from a somewhat accidental involvement in fighting AIDS to a new and sustainable policy of communicable disease control. It responds to three main questions: Why did an unexpected case lead to the organization of a new sustainable policy? How was this achieved despite national competency over the given policy sector? How did the new policy succeed in covering the enlarged EU?

There are essentially three explanations for this development. First, the AIDS case provided the matrix for further policy developments because of the major threat and the controversial aspects it presented. The unprecedented case made coordination of national policies necessary. Second, the EU enlargement created a political obligation to deal with the major epidemiological risks and poor health conditions in Central and Eastern Europe. The very different levels of health and social care between the old and new member states presented a political challenge to the Union. Third, the policy content and values as well as the policy instruments developed around the AIDS issue match the ways in which Europeanization works and the democratic norms that the EU diffuses in new member states and neighboring regions. The exception became the rule because the AIDS matrix implies more than public health involvement. Whilst the direct effects of historical events like an epidemic are difficult to measure, we can assume that without the AIDS experience EU disease control would not have evolved as it did.

The first section of the article examines selected concepts from the Europeanization literature, pertaining to EU public health involvement. The second section analyses the particular policy problem presented by the AIDS case, and the policy responses initially formalized at national level. The third section retraces the history of the EU's AIDS involvement. It analyses the combined effects of political agendas and trans-border health risks, showing in particular how the sudden outbreak of AIDS in the former communist countries impacted on policy developments at EU level. The fourth section analyses the ways in which AIDS policies were Europeanized and extended towards the new member states. Networking and the harmonization of statistics played a central role in this process, together with peer-coached policy diffusion in initially unfavorable local contexts. The theoretical conclusion is that these patterns of activity constitute the empirical content of “cognitive” Europeanization.

* This paper is currently at the last stages of revision for publication in the Journal of Health Policy, Politics and Law, 2013, in a Special issue edited by Scott GREER: « Bacteria without borders: The European Governance of Infectious Diseases ». The project and an early draft were discussed at an international workshop organized by the Center of European Studies at Michigan University, Ann Arbor, in 2010. I want to thank the three anonymous revisers of the JHPPL as well as the discussants at the workshop for their extremely valuable comments, questions and criticisms.
I – The Europeanization of public health policies: what is Europeanized and how?

The concept of Europeanization describes the processes whereby policies, polities, and politics become “European”, i.e. they either develop at EU level, or apply to all member states, or diffuse throughout Europe. An abundant literature discusses the various models of Europeanization and the role of different actors, in particular the various European institutions involved in Europeanization processes, i.e. the Commission, the Court of Law, the Parliament, the Council, the Council of Ministers, etc., as well as member state governments, NGOs and lobbies. Although it is not within the aims of this article to discuss the different conceptualizations of Europeanization, two theoretical problems should be highlighted, because they help to understand why health is a particularly difficult subject for Europeanization theory. First, it is difficult to isolate the specifically European factor from other international sources and policy transfer, and from national or sub-national inputs. Such blurred boundaries make it impossible to distinguish causes and effects of Europeanization (Saurugger 2005: 292). Furthermore, as policy changes induced by crises have been frequent in European public health policy, independent and dependent factors can become unstable and even reversible categories (Steffen, 2005 b: 286). The second problem is that most of the EU studies focus on the internal functioning of “Europe”, on European policy-making and the EU–member state relationship, without necessarily analyzing how Europeanization works in a specific policy sector, as if all sectors were equal entities from a EU perspective.

It is therefore not surprising that the literature specialized in European health policy provides contrasting interpretations. The main reason is the structure of the health policy field, which comprises very different parts – health insurance, healthcare, and public health –, each calling for a different type of EU involvement. Studies inspired by social policy and welfare state research focus on the financing and regulation of the healthcare sector, and therefore conclude that EU intervention has been both late and weak, compared to the central economic policies of the EU. Investigations of the EU impact on national health policy and delivery of healthcare point out the spillover effects from the major EU policies (free market, free competition, free movement of capital, services and workforce). This has been conceptualized as “uninvited Europeanization” (Greer 2006). Studies generally acknowledge the very complex distribution of competency between member states and EU levels, particularly in fields like safety standards and marketing authorization for pharmaceuticals, biological products and medical goods (Hauray 2006, Farrel 2006, Altenstetter 2008). Because of such multi-level competency, unequal interest by the EU in the different aspects of health governance, and internal conflict within EU institutions, European health policy has been described as “chaotic institutionalization” (Guigner 2003: 31). The rich available data however calls for more explanation.

Although subject to conflict, the complex competence allocation is not necessarily unclear, and may be operational and logical. Lamping (2009) conceptualizes it as a “health policy institutional compound”. The term stresses the “dynamic distribution of authority between Member States and several Community institutions, with shared competency and separate responsibilities, and an issue-specific division of labor” (Lamping and Steffen 2009: 1375-76). The arrangement leaves space for negotiation in case of necessity or opportunity. Consequently, European public health policy is necessarily a patchwork, because it is to a large extent crisis-driven, reactive rather than anticipatory, and addressing specific priorities and sub-sectors. The result is a set of different policies, with different polities, and unequal

---

progress, although all develop under the umbrella of the treaty provision for EU public health competency. This provision was itself written in response to acute crises and trans-border health risks, as Section III will show.

The Europeanization literature offers two useful indications for understanding EU involvement in AIDS and communicable disease control: the concept of cognitive Europeanization and the importance of networking. Following Radaelli’s work on soft Europeanization, Guigner (2007) defines the Europeanization of health policy as “cognitive”, and distinguishes two types of cognitive Europeanization. The one is considered as “rational”, based on persuasion or benchmarking; it is coercive for the participants of networks who therefore have a rational interest in conforming to the benchmarking criteria. The other is considered as “constructivist”, based on information and interiorization of the diffused ideas or practices; it operates on the socialization function of networks. The cognitive dimensions, however, do not explain how ideas become real policies, in the form of institutionalized public health at EU level. Neither does it explain why actors turn to the EU, rather than to other more powerful international actors, and why the EU engages in a field seemingly distant from its primarily economic goals.

The importance of networks is common knowledge for Europeanization specialists (Héritier 1999, Laffan 2002). It is also stressed in national as well as comparative AIDS policy studies (Kirp and Bayer 1992, Berridge 1996, Moatti et al. 2000, Steffen 2004, Pinell 2002). The specific interest of networking however remains unexplained. The study of the European Monitoring Center of Drugs and Drug Addiction, Bergeron (2010) qualified networking as “the power of a weak institution”. Already the first article on EU responses to AIDS revealed the particular weight of networks (Altenstetter 1994). The author insisted on the large number of actors involved, their heterogeneous origin, their presence in several forums, snowballing, cross-fertilizing, etc. Networking even appeared as a “primary raison d’être for members of concerted action-sponsored research networks and community-based networks (…) because they engage simultaneously in networking and the formulation of policy” (Altenstetter 1994: 427). In other words, networking seems essential to EU policy-making in a comparatively weak policy sector such as public health.

II – Problem structure and national policy responses

It may seem paradoxical that it was the AIDS case, known for its “exceptionalism” (Kirp and Bayer 1992), that provided a model for a much larger European policy of communicable disease control. The argument here is that it was precisely the historical uniqueness that made it an issue for the EU as well as a model for transmissible disease control at EU level. To understand the EU's involvement it is important first to analyze the structure of the policy problem and the concerns it entails\(^2\). AIDS aroused public fears because it was so lethal and spread so rapidly. Public debates turned passionate because of the specific routes of transmission and several value-laden issues. The central problem was that the traditional tools for dealing with epidemics were not compatible with current political values, such as freedom, non-discrimination, and the protection of private life. AIDS reminded us that epidemics are not only medical, but also political phenomena. It brought public health back to the center of political science.

\(^2\)The data used in this section are drawn from the author's comparative research conducted in the period from 1990 to 2000 (Steffen, 2004), with follow-up research thereafter.
Initially AIDS appeared as an “ill-structured problem” (Simon 1973). The concept refers to situations where the available knowledge from the initial conditions is insufficient to determine what the future evolution could be and to select solutions. An ill-structured problem confronts institutions and polities with unknown constraints and uncertainty about the rules to apply. Problem definition and solutions depend therefore on the divergent views of interested parties. For the AIDS case, the main issues can be summarized under three headings:

First, AIDS revealed the political challenges of prevention. This unknown disease put pressure on scientific research, care and prevention. Whilst fundamental research and clinical research was developed, no effective medical treatment was available during the first decade. A comprehensive prevention policy was therefore needed, which had to concentrate on behavioral changes since no vaccine existed for the HIV. However, as prevention lacked professional knowledge and institutional support1, it left space for political controversy over the legitimacy and effectiveness of public policies focusing on private behavior, lifestyle and minorities. Controversy concerned the content of the public anti-AIDS campaigns2, especially the extent to which they should be targeted at the specific groups at risk, with a risk of stigmatization, or address the general population, with a risk of losing efficacy. Health and sex education on a large scale, notably in schools, was another difficult issue, since most countries lacked educators in this field.

Second, AIDS revealed the paucity of public health. Communicable disease control was still based on traditional legislation on infectious and sexually transmissible disease, which included case reporting, compulsory treatment, contact tracing, and in certain cases isolation of disease carriers. The AIDS experts deemed these methods to be unsuitable for AIDS, where the active collaboration of the people at risk was needed. When the HIV antibody test became available in 1985, gay activists and public health professionals argued that the application of the traditional procedures would lead to breaches of civil rights and privacy. People with HIV/AIDS, it was argued, would shy away from medical services, and even go underground in order to avoid social consequences of positive test results. The AIDS lobby, composed of public health experts, clinicians and gay activists managed to have AIDS removed from the field of public health legislation. Regulations were consequently replaced by voluntary testing, voluntary partner notification and increased guarantees of confidentiality. Kirp and Bayer (1992: 364-370) conceptualized this issue as the struggle between a “contain-and-control strategy” and a “cooperation-and-inclusion strategy”. The latter also contained political risks. Public authorities had to collaborate with gay organizations and to support the socialization of deviant, even illegal behavior instead of fighting it3. In several countries, the public promotion of new behavioral patterns, known as “safer sex” and “safer shooting”, was little more than lip service for many years.

Third, AIDS revealed governance problems. Coordination, at central government as well as local levels, constituted a major challenge. Care and prevention strategies had to be coordinated over a wide range of policy sectors with no previous links, ranging from sexually transmissible diseases to drug abuse and medical services in prisons, and from specific

---

1 As an example, in France prevention accounted for less than 2% of all health expenditure throughout the 1960s, 1970s and 1980s. It has been upgraded now to 3.5%, thus approaching the European average.

2 For instance, whether condom promotion appeal to the vital risk of AIDS or to the pleasure of sex –France and Great Britain took opposite options–, and whether it should appeal to self-protection or the duty to protect partners –North/South differences–.

3 Such as homosexuality, prostitution and injecting-drug abuse.
counseling for HIV-infected pregnant women to safety standards in the blood and organ donation systems. Hospitals were to collaborate with psychological support and social services. Only well-organized health and social administrations could guide such comprehensive policies. The politically most difficult issue was the shift in drug policy, from a repressive strategy relying on police forces and focusing on abstinence, to health-risk reduction strategy relying on medical and social services. In several countries, including Italy, France and Germany, ministries in charge of the police, home affairs and prison administration fought long battles with health ministries over the issue. Countries were obviously unequally prepared to organize coordination between national government departments, between central and local government, between public and private actors and between different professions. The AIDS challenge made it obvious that good governance constitutes a basic condition for managing transmissible disease. Consequently, the sudden breakdown of the communist states exposed Central and Eastern Europe to sanitary as well as political risks.

At local level, the particular problem was how to extend the “cooperation-and-inclusion” approach, conceived for and by urban middle-class gay communities, to marginalized populations such as intravenous drug users (IDU), sex workers, homeless people and migrants, who lacked the capability to collaborate with public authorities and to promote behavioral changes in their own ranks. As the epidemic spread these populations, policy makers and AIDS experts were confronted with the problem of applying the new public health approach based on inclusion and participation to populations with weak social capital. New modes of intervention had to be developed, based on proximity and outreach strategies, long-term follow-up and free provision of medical attendance, medicines, counseling, psychological support, condoms and syringes. Many Southern, Central and Eastern European countries lacked, and still do lack, political consensus and the appropriate social services and budgets.

New policies to solve the ill-structured problem were shaped at national level, with links to international networks. National differences were considerable and concerned mainly the testing strategies, methadone programs, legal responsibility for HIV transmission, and data collection systems. While epidemiological factors may explain some of the differences, they clearly express differences in the political culture, especially in the divide between the spheres of public policy and private life (Steffen 2005b). The thesis of a relatively common AIDS policy in Western Europe has even been called into question, by Baldwin (2005), who insists on the lasting national differences, in especially concerning the democratic and ethical aspects of the policies.

Epidemiologists had a most difficult mission. The basic concept of their discipline (risk groups) became a politically incorrect term for nearly two decades. Legal rules or political principles could prohibit the use of certain categories in data collection, as in the French

---

6 Reporting of cases was either voluntary or compulsory, depending on the country. Reporting applied to AIDS cases or to HIV infection or to both; methadone as substitution treatment for addicts could be generalized, tolerated or forbidden; HIV tests prior to an insurance contract could be allowed, forbidden or subject to special conditions; partner tracing was compulsory or only permitted if individually agreed to; contamination on purpose or by negligence could be sued in court or not.

7 Southern Europe and Poland continue to suffer from an IDU-induced epidemic, and Northern and Western Europe from predominantly homosexual transmission. During the last decade, however, contact with so-called “high-prevalence countries” (sub-Saharan Africa, Caribbean, Asia) became a main transmission route in a growing number of countries (mainly Great Britain, France, Belgium, and to a growing extent also Germany, Italy, Spain and Portugal).
example where any reference to “ethnic” origin is formally forbidden. As a result, references to “contact with high prevalence countries”, a common statistical category in all other European countries, were banned from the data system. It was only in the early 2000s that data on HIV/AIDS in populations with migration background were published, under the combined pressure from the EU and of the French organizations representing African migrants, often women, living with HIV/AIDS and engaged in better adapted prevention and care strategies (M’Baye 2009).

The arrival of a highly active anti-retroviral therapy (HAART) in 1996-97 reshaped the policy problem. Activist lobbies revised their previous hesitant attitudes towards testing, targeting and data collection, and turned to securing early and general access to the initially very expensive treatment. The new issues were to benefit from EU engagement, because conflict over values slowed down as member states adopted similar priorities around access to the new treatment. However, the medical progress created new crucial policy issues: access to care in poorer healthcare systems in Central and Eastern Europe and the need for a renewal of the data systems in accordance with the new medical situation. Since AIDS as illness could henceforth be nearly eliminated by systematic access to early medication, the data collection on the epidemic needed to shift from “reporting AIDS” to “HIV infection”. Today, only HIV-monitoring allows prognostics on the epidemic and informed policy-making, whilst the old system continues to serve as an indicator for the comparative measurement of effective access to medical care. Together, the two constitute a comprehensive system of public health surveillance and benchmarking.

III – EU involvement: Public health crisis and political agendas

Epidemics are trans-border issues and consequently require multi-level decision-making. In the AIDS case, the problems to be solved have constituted not only pragmatic public health challenges, but also policy issues for European integration.

The EU public health agenda started and developed with trans-border risks and crises. This was illustrated by the first European cancer program, following the explosion of the Chernobyl nuclear power station in Russia in 1986 (Gilmore and Kee, 2004: 219, 224). Although cancer is not transmissible by viral or bacteriological agents, this constituted a precedent at EU level. Like the AIDS epidemic, the Chernobyl accident revealed the lack of epidemiological field data on major trans-border risks. Existing data were incomplete and not comparable. Furthermore, national capacities to organize data systems and adequate care for the victims were unequal. European collaboration was clearly needed. The EU cancer program paved the way, organizing euro-wide networks for research and for data collection (Trubek, Nance and Hervey 2008), first on cancer incidence and then on survival rates, which in turn fostered benchmarking. At national levels, this led the “bad” countries, notably Great Britain, to improve their cancer services (Briatte 2010). At EU level, it led to the prohibition of tobacco advertising. Unlike AIDS however, the cancer case did not enhance larger EU public health policy.

To gather information, the French epidemiologists organized regular and large-scale anonymous testing of birth-giving women in maternity wards, which showed the high concentration of HIV-prevalence in populations with migration background, during the 1990s already. This reality could not be revealed by data limited to “nationality”, since many individuals of this social group are French citizens (parts of the French national territory are situated in “high prevalence” regions).
“Critical junctures” (Krasner 1984, Greer 2008) occurred at the beginning of the 1990s, when political and public health agendas coincided. After the Chernobyl contamination, the fall of the Berlin Wall revealed the onslaught of major epidemics in Central and Eastern Europe: AIDS, IDU, STI, TB and other communicable disease9, whilst the breakdown of communist statehood left already underfinanced healthcare systems and public health institutions without resources. The result was a general decline of life expectancy, of up to 6 years in Russia and Latvia10. Although the “East-West health divide in Europe” had longstanding historical roots (Vägerö 2010), the sudden widening of the gap could not be ignored if the EU was to extend eastwards.

It was in this particular sanitary context that EU enlargement was prepared. The EU has grown from 15 Western member states in 1995 to 25 in 2004 and 27 in 2007, by integrating ten former communist countries (Central Europe and the Baltic Republics) and two Mediterranean islands (Malta, Cyprus). Because of the complication of EU decision-making, without even considering specific policy issues, the growth in membership could induced what Vobruba (2003) called “the enlargement crisis”.

Concerning AIDS, the common belief was that the epidemic would not expand in former communist Europe, which had been preserved from international travel, (homo)sexual promiscuity and intravenous drug addiction. Expert knowledge on how to manage AIDS was moreover available, at least in the West. Indeed, only a small numbers of cases were reported, despite massive HIV testing in these countries. In December 1994, Estonia counted only one case of acute AIDS and 34 cases of HIV-infections. Only twelve new HIV-infections were recorded during the year 1994. In December 1993, Russia had a total of 717 HIV/AIDS cases, of which 250 concerned children contaminated by iatrogenic transmission in the same hospital in Southern Russia (Steffen and FitzSimon 1994). The former communist bloc had, at that time, the same population size as Western Europe, but accounted only for 3% of the reported AIDS cases in the WHO-European region. The epidemic was however to grow quickly11.

In Estonia, the annual number of new infections amounted to nearly 1,500 in 2001. In the Kaliningrad territory, recorded HIV cases jumped from 8 in 1995 to 1,350 in 1997. In the Rostov region, the number of new infections multiplied eightfold between 1995 and 1996, with a further 20-fold increase in 1997, due to intravenous drug addiction. In Ukraine the number of newly identified HIV-infections increased from 1,490 in 1995 to more than 24,000 in 1997. The epidemic was heavily concentrated in the western part of Russia, Ukraine, and, concerning the future EU member states, in Poland, Romania, Estonia and Latvia. The main reason for the sudden expansion was a very rapid spread of injecting drug abuse with extremely risky products and injection habits, in an environment unable, at that time, to deal with a major epidemic. The breakdown of communist state structures compounded a critical fiscal crisis, severe inflation, and a near breakdown of public healthcare and surveillance,

9 Syphilis cases in Belarus jumped from 30 new cases in 1989 up to 21,000 in 1997 (Pimenov and Lavochkin 1998). In Russia, syphilis cases per 100,000 inhabitants jumped from 4.3 in 1989 to 254.2 in 1996 (Pasteur Institute 1997).
10 Male life expectancy in Latvia, a future EU member state, dropped from 66.3 years in 1989 to 60.7 in 1994 (Rajevska 1996). In Russia, male life expectancy dropped to only 57.5 years in 1995 (WHO statistics). The data collected here originate mainly from conference papers, from workshops I personally attended, and from working papers presented by public health experts. During this early period of post-communist transition, data were not available or not easily accessible, partially due to language barriers.
11 Sources of figures used in the following: The European Center for AIDS, Paris; WHO reports; and Steffen 1999b.
before reforms shifted these healthcare systems towards privatization and/or social health insurance (Haggard and Kaufman 2008).

Table 1 here

In Central Europe, the epidemic slowed down from the early 2000s onwards. It was under control by 2005, because risk reduction strategies imported from the EU had been implemented to stop the IDU-driven epidemic in the most affected countries: Poland, Romania and the Baltic Republics (UNAIDS 2005: 72-73). However, at the periphery of the EU the epidemic continued to increase: the annual number of “new HIV-infections” in the Eastern European/Central Asian region reached 270,000 in 2005, before starting to slow down to 130,000 in 2009. The total number of people living with HIV/AIDS is now estimated at 1.4 million in the Eastern European/Asian countries, against 830,000 in Western, Central and Southern Europe together (UNAIDS 2010: 22-23, 38-40). In Central Europe, the main peak of the epidemic spanned the period from the mid-nineties to the early 2000s. The new member states thus entered the EU after having passed their public health exam.

A main difference between the new member states and the more distant neighborhood of the EU is the political and social treatment of the epidemic. Despite revised or new laws, discrimination is still frequent in the Eastern and the Southern Mediterranean. It is grounded in traditional morals and authoritarian administrative practice, poor health and social budgets, poverty and bad living conditions, such as collective apartments with shared sanitary facilities, and a lack of health-related education. As an example, in December 2006, “a fire at a Moscow drug rehabilitation unit killed 44 HIV-positive women and two nurses trapped behind barred doors and windows”12.

Whilst the reasons for EU interest in efficient AIDS management may seem evident, given the large migration flows, including for prostitution, the policy process need explanation. Surprisingly, the literature on the EU has ignored the major event of an epidemic striking Europe at a crucial moment of its history: Eastern enlargement. Only two publications provide accounts of the EU AIDS programs (Altenstetter 1994; Herveyand McHale 2004: 336-43), from which information used in the following is borrowed.

AIDS entered the EU institutions through a backdoor. In 1983 the Commission provided its first modest support for medical investigation into the new disease, under the umbrella of the medical and health research program (MHR3), which ran from 1982 to 1986. The next MHR4 program (1987-91) included a specific AIDS research program, under which the first minimal social science program was funded, in 1989. Since then, AIDS, and later also communicable disease in general, have been part of all European research programs. AIDS research focused on fundamental and clinical research, with the priorities of the time (vaccines, mother-child transmission, emerging drug resistance, etc.). The big European surveys on sexual behaviors have also been conducted within these frameworks. The final evaluation of BIOMED2 called for more “behavioral and socio-economic research in infectious diseases, in which half of the funded projects were HIV/AIDS-related” (European Commission 2000: 313).

On the political level, EU involvement started without a specific legal provision or formal competency. Initiatives originated from the ministers of health of the member states which, within the Council, organized meetings specifically devoted to AIDS, on 29 May 1986, 15

12 RHRN/ITCPru (2006, 11th December) “Inhumane conditions in the Russian drug treatment facilities are the roots of Moscow’s tragedy” (http://www.healthdev.org)
May 1987 and 31 May 1988. Following the request formulated at the summit meeting of heads of states in Venice, in June 1987, for cooperation and the exchange of information on the epidemic, an EU-level Ad Hoc Working Party on AIDS was set up. In May 1989, the Council asked the Commission to prepare a proposal for a coordinated EU program to fight AIDS (Hervey and McHale: 337). The result was the first “Europe against AIDS” program, which ran from mid-1991 to 1993, and was extended until 1995. Its aims were data collection on the epidemic, exchange of information on the different national policies within the EU, especially AIDS prevention amongst IDU and measures for blood safety. A former executive of the program called it a “small” program (interview). Its funding was indeed much less than AIDS research funding during the same period (Altenstetter 1994: 420).

The second program “AIDS against Europe”, running from 1996 to 2000, was more substantial and directly oriented towards control of the epidemic. The overall goal was to contain the spread of AIDS and reduce mortality due to communicable diseases, and to support collaboration between national public policies and NGOs in the field AIDS prevention. The program consisted of four sections (Hervey and McHale 2004: 338-40):

1 – The monitoring of AIDS and communicable disease directly addressed the improvement and coordination of national data collection, and the euro-wide harmonization of statistics on AIDS and other communicable diseases. A 1998 decision set up European networks for the surveillance of several such diseases.\(^\text{13}\)

2 – Combating transmission called for projects which took into account the living conditions and social environments of people at risk. It aimed at the exchange of information on the different national policies and the identification of “best practice” for prevention in precisely targeted populations.

3 – Information, education and training aimed to raise public awareness about AIDS risks as well as tolerant social attitudes. Health and sex education for young people and training for professionals constituted the main activities to be funded.

4 – Support for people living with HIV/AIDS addressed the fight against discrimination and aimed at a code of good testing practice.

To be funded, projects had to include several member states. Priority was given to projects that targeted high-risk groups with difficult access (gay men, IDUs, prostitutes, migrants). The implementation of the program obviously needed the participation of the AIDS associations. Only the latter had access to the specific risk groups, and could therefore collect field data and disseminate knowledge and new behaviors. Since they were essential for AIDS prevention, but divided over many issues, notably the content, style and target of prevention campaigns, it was necessary to organize the terms of their collaboration with national public policies at a more distant and “neutral” EU level. Concerning NGO participation, Hervey and McHale (2004: 337) as well as Altenstetter (1994: 470) note that initially EU levels showed little interest. This may illustrate the bureaucratic functioning of the EU, but may also indicate that it was the national governments that needed an organized public-private partnership most, with EU legitimacy, to share responsibility in the most controversial AIDS issues.

The story contains surprising elements. First, compared to the urgency and uncertainty of the early AIDS years, the “Europe against AIDS” programs came late. Only the second program was a real action plan to fight the epidemic. The first program seemed limited to the exchange of information and some coordination between national governments. Second, AIDS organizations and field experts seemed to be excluded. A contemporary EU policy actor

\(^\text{13}\) Decision 2119/98 EC, OJ 1998 L 268/1.
recalls: “There were EU-attempts, but AIDS was controversial. We were not allowed to do anything. The concern was to respect national competency. Up to 1990, the leitmotif was that it had to stay within governments. Eventually, in 1991, the European Commission was allowed to come in, it is not clear why (interview).” Third, the role of the national health ministers seemed essential. They pushed the EU into action, which seems a contradiction with the vital national competency.

In fact, contrary to the general assumption in European studies, that the EU could not deal with controversial issues or national diversity, the AIDS case shows that its highly controversial dimensions made EU-coordination necessary for national governments. Calling upon the EU is a “two level game” (Putman 1988), which allows blame shifting in case of unpopular measures and shame avoidance in case the national options turn out to be the wrong ones. The first EU-program, with its specific focus on blood safety and coordinating national approaches, was adopted 1990-91, precisely when four senior French government officials stood trial in a penal court and were sentenced to prison for their decisions in the blood transfusion sector. A second court case was running against several government ministers, including the Prime Minister (Steffen 1999a). An attempt was even made, though unsuccessfully, to lay charges for the inadequate handling of AIDS prevention among drug addicts. The French case highlighted the fact that national competency could turn into a political disaster for governments and a personal risk for ministers.

The national differences in AIDS prevention and conflict at national level between various stakeholders, e.g. conservative forces on the one hand and AIDS activists and the political left on the other, pushed the issues onto the European agenda. The main issues at that time were the screening of blood donors, the provision of clean injection equipment to IDU, and sex education in schools. EU involvement on politicized issues with national differences is not in contradiction with national competency. The first “small” EU program responded to immediate uncertainty. In doing so, it prepared the way for the second program, which set out the European AIDS policy, and tested the tools: data harmonization, networking and policy coaching. These approaches could later extend to communicable disease control in general.

The Maastricht Treaty, which entered into force in 1993, provided the EU with competency and responsibility for public health. Article 129 of the Treaty consolidated the institutional environment and financial support for the EU AIDS programs, and the emerging EU networks for communicable disease control. However, the geographical coverage remained “patchy”, networks often depended on motivated individuals, and new public health risks occurred, with a negative impact on the free European market. Examples are the contaminated blood accident, the “mad cow” crisis, the H5N1 virus, and later on SARS (2001-02). Several cases entailed reorganization at EU levels, and even within the Commission. The problem of the Central and Eastern nuclear power stations was transferred from the Directorate General XVII responsible for international trade issues, to the Directorate General XI responsible for environment, nuclear safety and civil protection (Saurugger 2005:301). A European regulatory system for the safety of blood and plasma products was established (Farell 2006). The security of food was transferred from the Agricultural directorate to the new SANCO (Clergeau 2005). In addition, from 1995 onwards the Schengen Space installed free circulation of people without border control, thus creating a growing open sanitary space within the EU. The Amsterdam Treaty, in force since 1999, reflects these and its new Article 152 reinforces the EU public health mandate.
The new legal basis provided by the Treaties allowed for major changes, especially the adoption of the first “EU Public Health Program” (2003-08), under which significant reorganizations were undertaken. The AIDS as well as communicable disease networks, activities and projects have been integrated into the public health program. In 2004, the European Center for Communicable Disease Control was created, and in 2008 it absorbed the EuroHIV data system. A second program covers the period 2008-13. Whilst the first program was directly oriented towards communicable diseases, the second “EU Health Program” has a larger, less specific ambit, including health system governance, cost containment and consumer rights. It has lost the “public” health reference in his title. It remains uncertain, however, to what extent governance and cost control issues of the national healthcare systems are effectively treated in this new framework.

HIV/AIDS as a specific issue and a model of modern communicable disease management continues to develop within the framework of the EU Neighborhood Policy. Since the end of the “Europe against AIDS” program, government representatives, ministers of Health, Education, Social Affairs, and Development of the member states and of the Eastern and Southern neighboring countries, and invited experts have been meeting regularly to discuss AIDS issues and trans-border policy. Several meetings have resulted in an official Declaration, such as the Vilnius Declaration (June 2001), the Dublin Declaration (February 2004), and the Bremen Declaration (March 2007). Two specific AIDS programs, including STI and blood borne infections, have thus been adopted in collaboration with the neighboring countries (2006-09, 2009-13). As the epidemic comes under control in the enlarged Union, EU involvement invests beyond the borders.

The confusing picture of EU programs, action plans, networks and priorities can be understood in the light of the European integration agenda, with three clearly identifiable periods: before, during and after enlargement. This may also answer part of the question concerning the division of labor between the EU and the European Region of the WHO. With the exception of Israel, the Eastern and Southern Mediterranean countries do not belong to the WHO European region, but constitute a very important region for the EU. Collaboration with the WHO Regional office in fighting AIDS was officially agreed upon since the 1st EU AIDS program and has so far been respected, as illustrated by the institutional journey of the European HIV/AIDS data system: initially created as a “WHO collaborating Center” based in Paris, it became a EuroHIV institution and was finally absorbed by the ECDC, whose former director has been appointed as director of the WHO Regional Office.

### Table 2 here

#### IV – Policy style, instruments and diffusion

The crowded path of change can be summarized under three headings: networking, data harmonization, and cross-border policy coaching.

**Networking** developed enormously from the early nineties onwards, integrating the many AIDS organizations into EU-supported networks where they are now participating in common policy formulation and implementation. These organizations' initial function of protest and lobbying was thus transformed into public-private collaboration. Networking engaged four types of partners: EU authorities, national governments and institutions, NGOs, and

---

14 These issues became subject to the Open Method of Coordination (OMC) in 2004.
professional as well as research networks. By 2004, the EU defined the issue of competency and its specific role as follows: “Within the EU, surveillance of HIV/AIDS is the responsibility of Member States. The Commission has to coordinate these efforts and share lessons and best practice widely. For the Union, HIV/AIDS control has been, and continues to be a key public health priority”. The role of the EU is “to improve co-operation and co-ordination at different levels of AIDS governance”.

The main feature is the arrival of organizations from Central and Eastern Europe, from the future new member states, potential candidates (Ukraine, Turkey), and beyond (the Community of Independent States). The political aim here is evident: the Western well-organized and politically trained AIDS organizations will help the emerging and still weak ones from the former communist world to develop. In doing so, the AIDS NGOs play a strategic role for the EU. They export the Western European model of democracy and welfare statehood. The package of technical AIDS assistance contains tolerance towards minorities, participation of citizens in public policy conduct, respect of human rights, social security provisions, etc. The power of the strategy is its apparently apolitical character. These NGOs act locally, engage in practice-oriented field research and do practical work in areas where there is effective need. Occasionally, however, Western initiatives beyond the new EU border meet with clear political refusal.

The evolution on the AIDS front with growing East-West networking and EU support can be traced through the European AIDS congresses specialized in social science, all co-financed by the European Commission. The first pan-European congress was in fact organized as a “Baltic” congress, at the Pasteur Institute in Saint Petersburg in February 1994. The vast majority of participants were public health officials and professionals from all parts of the former Soviet Union and Central Europe. The congress language was Russian, with English translation for the approximately forty Western participants. The event was funded by the EU and the WHO regional office for Europe, with co-financing from the Northern European countries, mainly Germany and the Scandinavian countries. The Western counterpart, with a large Russian participation, was the Berlin congress, labeled as the “First European congress on social aspects of AIDS”, in September 1994. The congress resulted in a six-volume publication in English and German (Friedrich and Heckman 1995), which was widely distributed, free of charge, in Central and Eastern Europe. The “Second European Congress in Social Science on AIDS” was organized in Paris, in January 1998, also generously co-financed by the European Commission, including the English publication (Moatti et al 2000), which again was distributed free of charge in Central and Eastern Europe. A third congress followed in Amsterdam in 2000, with substantial Central European participation. The following European Social Sciences AIDS congresses were all located in new or future member states in Central Europe. It was only in 2007 that a congress returned to Western Europe, directly to Brussels. This event was entirely devoted to access to HAART and the

---

15 For documents and declarations of the EU on HIV/AIDS, cf.: http://www.stopaidsnow.org/downloads_category/political_documents_eu

16 This was illustrated in 2001, when a farmhouse was burned down in the Kaliningrad region. The property was to become a center for the care and social reinsertion of drug addicts with HIV/AIDS, a project financed by the French Embassy in Moscow, headed by a local NGO and a local team of professionals and university psychiatrists, in collaboration with a small team of French professionals specialized in HIV/IDU care (interviews and direct observation).

17 This group accounted for about 250 of the 300 participants (direct observation). The following year (summer 1995), a similar congress was organized, again in St Petersburg, by the same team of partners and organizers, on the subject "Drug-abuse and health risk reduction policies".
social conditions of adherence to the treatment. The subject illustrates the normalization of AIDS, including progress towards normalization in the new member states. In programmatic terms, on the epidemiological front, the EU involvement has been successful. Since 2005, the epidemic is stabilized in Western, Central and Eastern Europe (UNAIDS 2010: 17).

The scientific and professional AIDS networks functioned as well-organized forums for discussion. EU money made East-West traveling and meetings possible, and fostered local experiments in unfavorable Eastern environments. The Pasteur Institute of St. Petersburg, which re-integrated the network of Pasteur Institutes after its long isolation during the Communist era, played a central role in these dynamics. With the help of the Pasteur Institute in Paris, where the HIV virus had first been isolated, it converted its traditional expertise on bacteria to viruses and took the leadership of the AIDS mobilization in the former communist countries. Known as Russia’s most European city, St. Petersburg is situated next to the isolated Kaliningrad region, where AIDS spread with unprecedented speed from a few cases of sailors to a full-fledged IDU epidemic, and to the three Baltic Republics and Poland, all heavily afflicted by AIDS and transmissible disease when applying for EU membership.

On the political front, a new EU strategy appeared from the mid-2000’s onwards. As the EU had taken a global leadership position for the “universal access to HAART” in poor countries, especially in sub-Saharan Africa, under the combined pressure of the French government, French medical NGOs and the UNAIDS organization, the EU developed a similar policy within Europe and neighboring regions, in collaboration with the Regional WHO Office. Internally, the HIV/AIDS involvement became part of the EU’s general framework of communicable disease control and the EU-Health programs. AIDS thus lost its independent status, inherited from its “exceptionalist” past, but the issue entered new levels of EU policy. The Vilnius Declaration (2004, p. 3) on “Europe and HIV/AIDS: new challenges, new opportunities” mentioned not only the usual combined national and EU-funding, but proposed to use the “European Structural Funds” for HIV/AIDS and connected issues, such as risk reduction of IDU and sex/health education strategies. So far, the structural funds had been reserved for the agricultural and economic development the less well-off European regions. With Eastern enlargement and the shift of priority from Southern Europe to Central European regions, public health seems to have been recognized as part of development policies, which is another success of AIDS networking.

AIDS also entered the agenda of the “Civil Society Forum”18. This initiative started with an informal advisory body established by the SANCO in 2001, as “The European Health Forum”. It became fully active only in 2005 following the Dublin Declaration. Members are selected by the Commission, following a call for expression of interest, for a three-year membership. In 2008, membership included around forty representatives of a wide range of NGOs and national networks, from EU member states and “neighboring countries”, including Russia. The current co-chairs (2011) are two NGOs, “AIDS Action Europe” and the “European Treatment Action Group” (ETAG).

With the arrival of the HAART therapy, country differences in access to the then very expensive medicines were considerable, especially between the Eastern and Western parts of Europe. The ETAG, which emerged in 1991 –with the exclusive goal to exert political pressure on all governments and health administrations in order to secure immediate access for all HIV carriers—, is currently the most active one in EU-networks on AIDS. It has nearly

a hundred member organizations in thirty countries. It set up the “AIDS in Europe” initiative, in Brussels in 2007, with the main objective of sharing knowledge and improving evidence on “early testing and early care” and, correlativelly, on “late HIV diagnoses”. These two items require new epidemiological as well as sociological input to the renewed data system, and provide a comprehensive indicator for benchmarking.

With the normalization of AIDS, the multiples issues treated in the networks tend to become both more epidemiological and more political. Topics such as civil society participation, combating discrimination, and free access to medicines are essential for fighting AIDS, but equally important as building blocks for democracy\textsuperscript{19}.

Data collection and harmonization
The first report on the surveillance of AIDS in Europe was issued in April 1984 by the forerunner of EuroHIV, the Paris-based WHO Collaborating Centre on AIDS, both of which were co-financed by the French Institut de Veille Sanitaire, the WHO and the European Commission (DG SANCO)\textsuperscript{20}. Initially, the center presented data on AIDS cases reported in 11 countries, gathered via interpersonal relationships between the first AIDS experts. By 2006, the system included 53 countries, thus covering the entire European WHO Region. Apart from the production of the usual epidemiological statistics (incidence, prevalence, mortality, transmission routes), the center provided analyses of the evolution of the epidemic and annual reports. Initially, the data system was exclusively based on the clinical diagnosis of AIDS cases, identified according to international case definitions that evolved over time. However, since several member states had included HIV-infection in their data systems, and as all former communist countries collected HIV-infection, rather than acute AIDS cases, the European center started to collect and harmonize HIV-data from 1991 onwards. This of course revived controversy over reporting and confidentiality. It took until 1999 for the HIV-based system to be set up officially, with nearly all countries reporting HIV data. The switch from AIDS to HIV monitoring, including the required harmonization, has been a major achievement of the EuroHIV center\textsuperscript{21}. The harmonization effort continued in 2007, when the WHO revised the case definitions, for AIDS as well as for HIV.

The reason for the shift from AIDS to HIV monitoring was the introduction of HAART in 1996, and increasingly widespread use of this highly efficient medication. The clinical diagnosis of AIDS no longer constituted a relevant tool to monitor the epidemic. Henceforth, only the measurement of new HIV-infections could provide useful data for policy-making and evaluation. However, a major criticism still exists. Using HIV diagnoses to monitor the epidemic introduces a bias, since individual take up of HIV testing is influenced by the social environment and the public policy on testing\textsuperscript{22}. France was particularly slow to implement the new system (the 2000-2007 European statistics still do not include French HIV prevalence). In Spain and Italy, countries with considerable regional autonomy, the collection of HIV statistics does still not cover the entire national territory. Central European countries have

\textsuperscript{20} http://ec.europa.eu/dgs/health_consumer/index_fr.htm
\textsuperscript{21} For the final report of EuroHIV, before its transfer to the ECDC, cf.: http://www.eurohiv.org/reports/report_76/pdf/report_eurohiv_76.pdf
been able to rely on their inherited practice and have not necessarily been the latecomers, although they had to rebuild large sections of their health administration after 1989. The European Commission continues to financially support countries and existing structures in adapting their system of collecting data on HIV incidence.

A new demand has been brought forward by the EATG, via its initiative “HIV in Europe”. The organization calls for, and actually works on, a common standard definition for “late HIV diagnosis”. The network has identified twenty different definitions currently in use in the EU. Only a common definition would allow comparative policy evaluation.

Efficient data collection, designed to include qualitative data on social dimensions as well as Euro-wide harmonization, also requires the specialization of certain issues. At least three examples should be mentioned here because of their links to the HIV/AIDS epidemic. In 1996, following massive tuberculosis and AIDS outbreaks in Central and Eastern Europe, with the risk of multi-resistant tuberculosis, the “Euro-TB” data system was set up. The “European Surveillance of sexuality and transmitted infection” (ESSTI) was created in 2001 and has been operational since 2003. It fosters interdisciplinary collaboration and capacity building in countries that are weak in this respect, mainly through collaboration and networking between experts and professionals from all member states.

The third illustration of such specialized data collection networks to support policy-making is the case of “Blood-carried diseases” (BBTD). The European program “Correlation I” (2005-2008) focuses on AIDS and Hepatitis C. It links two main targets: the most vulnerable parts of the population and intravenous drug abuse. AIDS prevention and care with regard to the latter suffered in the past from controversy in Western Europe and still shows significant national differences. Even today, it accounts for the biggest differences between the Western, Southern and Eastern regions of Europe. A specialized agency, the European Monitoring Centre for Drugs and Drug Addiction, was set up in 1995, in Lisbon, to deal with harmonizing health risk-reduction strategy and statistics and data collection practices, among other things (Bergeron 2010). An example of successful data harmonization is the category “death due to drug abuse”. Previously, data varied from a very restrictive definition (“death by overdose” written on the death certificate), which corresponded to a very small numbers of deaths in France, to an extensive definition, including overdose, long-term health damage, accident or suicide under the influence of drugs, which corresponded to a large number of deaths in Great Britain. The huge national differences have been reduced with the use of common statistical categories. The Centre delivers annual reports to the European Commission and provides governments and administrations of member states with comparative policy advice. Best practice and benchmarking are its main instruments.

In January 2008, the EURO-HIV system was transferred to the European Centre for Communicable Disease Control (ECDC), now in charge of coordination of the different systems that have been transferred to it (Euro-TB, ESSTI, BBID), in collaboration with the

---

23 http://bambuser.com/channel/HiWinEurope/broadcast/315042
24 http://www.essti.org/abt_us.php
25 Poland in particular, but many other Central and Eastern European countries as well, have shown difficulties dealing with such issues as multiple partners, prostitution, especially male prostitution, and the public promotion of condoms.
26 National incidence varied from one to over four between countries with the same estimated number of intravenous addicts.
WHO regional office. The reason for transferring surveillance to the ECDC was to operate the surveillance networks “in an integrated way, (and address) overlaps and synergies between surveillance of HIV, tuberculosis, other sexually transmitted infections (STI) and hepatitis B and hepatitis C.”\(^\text{28}\) The other important aim was a “better harmonizing of the reporting methods, systems and practices in use for surveillance”\(^\text{29}\).

Technical collaboration with the WHO European Region also seems to be conducive to more precise data collection and analysis. Subjects that used to be politically sensitive or even taboo are now on the agenda. The main changes as compared to HIV/AIDS data collection prior to 2008 are the implementation of the improved validation rules and the addition of a new pilot variable, the ‘probable country of infection’. In addition to this, several variables have been introduced to recode the cases of infection reported from countries with a generalized epidemic: ‘region of origin’, ‘country of birth’ and ‘country of nationality’ are now distinct categories. In 2008, collecting data on the previously much contested category ‘probable country of infection’ was finally agreed. These data were already available from 17 of the 48 countries that were providing HIV data at the time. Overall, the information was available for 27% of all HIV reported cases. All of this highlights the importance of the human migration factor for communicable disease control, and may inform a possible coordinated EU-immigration policy in the future.

The changes have been actively accompanied. Training courses were set up for HIV data providers in 2008. In 2006 already, the ECDC team for HIV and STI initiated country visits at the request of member states, with the aim of reviewing the state of art concerning HIV and STI surveillance, prevention and control, identifying priority areas where ECDC could provide support, sharing country experiences, and identifying best practices. The first countries visited were Estonia and Romania in 2007, and Bulgaria, Poland and Portugal in 2008.

One of the goals assigned to European harmonized data collection systems is of course benchmarking, which is also a powerful instrument for political integration. The clearest example is the “Euro-HIV-index (EHIVI), which was created under the framework of the EU Public Health Program (2003-2008). The Index combines political, social and epidemiological criteria. Its 28 indicators are based on public statistics, including access to effective treatment for disadvantaged populations (e.g. undocumented migrants), discrimination in the workplace and in schools, and prevention and care in prisons. The Index ranks Luxembourg, Malta, Switzerland and Finland first, whilst the UK, France and Germany are in the middle of the classification (9\(^\text{th}\), 12\(^\text{th}\), and 13\(^\text{th}\) out of 29 countries\(^\text{30}\)), and Bulgaria, Cyprus, Italy, Greece and Romania rank lowest. Such integrated, qualitative and comparative assessment would not have been possible without networking and data harmonization.

**Cross-border issues: Enlargement and neighboring countries**

It was primarily Eastern enlargement that boosted an active EU engagement in AIDS and communicable disease control. The open borders and new neighborhood of the EU implied new trans-border public health issues, as shown in Section III. Large migratory movements from Eastern countries to Western Europe, including prostitution as well as extremely poor populations (Roma), are visible evidence of such cross-border health issues.

\(^{30}\) The 27 EU member states, plus Switzerland and Norway.
The “AIDS and Mobility” program was set up as early as 1992 as an emergency program, with the special aim to secure the delivery of information, prevention and care to migrants and mobile communities across the open intra-European borders. It was co-funded by the Commission, the region of Lower Saxony and the city of Hanover (Germany). It brought together six main member NGOs and a wide network of collaborating NGOs and individual experts, mainly professionals from ethno-medical centers. The task assigned to this network is training and knowledge dissemination.

During the nineties, many regional trans-border actions and networks were initiated by towns, regions, professionals or NGOs. It is not always clear to what extent they should be labeled as “European” initiatives. From 2000 onwards, AIDS has been systematically integrated into the regional policies of the EU. The “Southeastern European Health Network” was the first to be instituted, in 2001, with the aim of fostering the evidence-based ways of fighting AIDS in the Balkans, in Turkey and the Caucasus, all regions suffering from a drug abuse-related HIV epidemic. In 2005, the network extended its ambit to most other infectious disease, with the specific goals of providing assistance to the operation of effective national systems of communicable disease surveillance, including harmonized data collection, early warning systems and European collaboration.

In 2004, in parallel with the beginning of Eastern enlargement, an “Expert Group on HIV/AIDS” for the North of Europe was set up at EU level. Participants of this Expert Group are high-level experts from national ministries and agencies of partner countries, the research community, hospitals, NGOs and other relevant bodies. The Group's main role is to act as the focal point for national inputs from the partner countries and organizations, on all issues concerning HIV/AIDS and STIs. Its ambit reaches from data systems, awareness raising and policy development, to legislation, treatment, and prevention. The practical aims are to share experience and expertise in prevention, health education, case management and testing strategies. Compared to the south-eastern network, the “Northern Partnership in public health and social well-being” is oriented more towards social care and public-private partnerships in providing care – a clearly Scandinavian input.

These regional programs however operate mainly within the enlarged EU, whilst the largest reserve of the HIV and infectious disease is located in Ukraine, Russia and Belarus. AIDS programs have therefore been inserted into the general European Neighborhood Policy (ENP) – with the term “neighborhood” referring to Russia and the sixteen countries\(^{31}\) of the neighborhood program. These “EU Action Plans” included in the first neighborhood program (2006-09) as well as in the second one (2009-2013) emphasize the epidemiological situation and the legal and social handicaps to AIDS management in the EU neighborhood. They insist on the necessary involvement of organizations from civil society and contain detailed objectives in terms of priority groups, priority regions, and access to treatment\(^{32}\). Evaluation, progress and objectives for monitoring actions in the neighboring countries are delivered in meetings bringing together the European Commission and the health ministers and government representatives from the EU member states and the neighboring countries. In the early phase of their engagement (2004), these high-ranking officials declared their willingness to “work towards the collection of biological and behavioral data, and its processing at

\(^{31}\) Algeria, Armenia, Azerbaijan, Belarus, Egypt, Georgia, Israel, Jordan, Lebanon, Libya, Moldavia, Morocco, the Palestinian Authority, Syria, Tunisia and Ukraine.

\(^{32}\) Objective n° 9 of the Dublin Declaration (2004) states: "By 2010 (...) 80 % of the persons at the highest risk of and most vulnerable to AIDS are (to be) covered by a wide range of prevention programs providing access to information, services and commodities (...)."
European level”, in order to “collect reliable evidence to guide national and international HIV/AIDS policy” (Vilnius Declaration, p. 2). At the 2007 meeting, they asked “the European Commission (…) to set up a clearing house for models of good practice” and committed themselves “to provide the political leadership on national, European and international levels to fight the epidemic” (Bremen Declaration, points 23 and 11).

Under the umbrella of the EU, data harmonization and cross-border disease management have extended continuously over the last two decades, to the new member states and beyond, although national competency and policy remain a reality. The explanation is that “policies as such do not leave national territory, actors on the contrary can” (Saurugger 2005:292), especially in a context of intensive networking and of carrier opportunities provided by the institutionalization of public health at EU levels.

V. Conclusion: Public Health Management and European Integration

Finally, why did the story develop as it did, and what are the theoretical lessons from the case study? The answers can be summarized in five points.

1 – The AIDS case constituted a founding event. It created the dynamic and provided the pattern of the activities for a European system of communicable disease control. It was an extremely fertile case, politically, because it involved both powerful, deep-seated fears and potentially anti-democratic policy tools, on the one hand, and modern “new public health” approaches based on democratic norms and values, on the other. A medical emergency developed in the contrasting context of well-established European welfare states and a dramatic post-communist transition process. The question then was less about EU versus national competency, than about how to lower IDU and AIDS incidences in Poland and Ukraine. Initially, AIDS entered the EU as a minor part of medical research programs. Its movement upwards to a major policy issue occurred under the combined pressure of lobbying and crisis. The lobbies constituted around issues of screening, access to care, substitution treatment for IDU, and human rights, have been structured into permanent operational networks linking EU policy-making and local implementation. These networks organized the integration of Central and Eastern European representatives and the exportation of Western European norms to the new member states and beyond, to the neighboring regions.

2 – The EU legitimized the methods that had first been formalized in national arenas and in international forums outside EU involvement. It organized learning from national differences, despite controversy. The Polish Catholic Church continues to fight condoms, few countries have revised their repressive policy toward IDU, and sex education in public schools is still not the same throughout the EU. Yet AIDS prevention and care have become a major sectoral policy. This should be considered as a success for European action in unfavorable environments. Traditional moral arguments and practices subsist, but they have been challenged by the AIDS crisis and have lost their monopoly.

---

33 The harmonization of practice currently continues with standardized protocols on the “preparation” of HIV patients for receiving HAART medication, in order to foster “adherence” to it: in 2009, the European AIDS Clinical Society provided the medical guidelines for diffusion within the enlarged EU and beyond. Similar guidelines were already used by the EU in 2002, concerning the prevention of mother-child transmission of HIV.

34 Several national experts who participated in building up the policy on AIDS in their respective countries, during the rather “hot” eighties and early nineties, currently occupy positions in Oslo (ECDC), Brussels (EU Commission), Copenhagen (WHO Regional Office) and Geneva (UNAIDS, WHO).
3 – The main task of the euro-wide networking has been the production of credible and comparable data from all member states. This has provided the EU with informed expertise for priority setting and has thus changed the evolution of the epidemic, especially in Central and Eastern Europe. Europeanizing public health is an incremental process which is practice-oriented and basically driven by professionals, who are essential to harmonizing and operating data collection systems. Against comparable data, national ideologies have lost their previous self-evidence. The AIDS story in the enlarged EU points to the power of networking: only networking can provide data from “bad” sectors or countries, and it is only then that benchmarking, “the hard way of soft law” (Mossialos et al 2010: 49), can operate and produce change. The efficiency of the EU dynamics and the benchmarking may be difficult to measure, but the progress in access to HAART throughout the EU, including the new member states, is clearly a positive indicator.

4 – The combined analysis of policy timing, partners and content suggest European integration as a factor explaining these developments. Integration is not only an economic process, but also a social and political enterprise (Steffen 2005a, Greer 2009). European involvement in AIDS and communicable disease control evolved together with the European agenda: the Maastricht Treaty and Eastern enlargement. The integration of a large number of former communist countries has involved significant public health issues and policy-making. Successful integration had to include compliance with political values such as non-discrimination and access to prevention and care, including for the most marginalized parts of the population such as HIV-infected drug addicts. The political need has been and still is twofold: preventing the spread of communicable disease, notably towards the old member states, and acting against the major health differences between the richer and the poorer member states.

5 – The treaties provided the legitimacy to EU policy, while the AIDS matrix furnished the practical procedures: participation, networking, and data harmonization, all compatible with the vital national competency. Furthermore, the “new” public health management promoted by the AIDS networks is coherent with the EU principles of free movement for people, anti-discrimination and the protection of private life. The EU had no alternative but to export its democratic ways of managing AIDS, eastwards and southwards. Whilst it has remained national competency to apply existing national legislation on transmissible or infectious diseases to AIDS, or not, the European community of national AIDS experts has networked for the required changes at national level, and continues to do so. Direct EU involvement has thus remained limited to the margin of “added European value”, which does not interfere with national competency.

The EU engagement in AIDS promoted a policy style made up of multi-level networking and trans-border disease management, both of which are dominated by professional experts. The instruments have been data harmonization and peer-conducted policy coaching. These patterns of activities constitute the empirically grounded content of the much used but less defined concept of cognitive Europeanization. The translation of ideas into effective policy and implementation requires the powerful input from politics. Crisis appears to be a necessary factor. By obliging politicians to solve an acute problem, crises create windows of opportunity, with threat and reward for the players. The EU history of public health is indeed a story of crises, and of “soft” power shifting.
References


Table 1. Growth of reported cases

<table>
<thead>
<tr>
<th></th>
<th>AIDS cases, cumulated to 31&lt;sup&gt;st&lt;/sup&gt; Dec. 1994</th>
<th>New HIV infections during 1994</th>
<th>New HIV infections during 2001</th>
</tr>
</thead>
<tbody>
<tr>
<td>UE</td>
<td>24,915</td>
<td>6,937</td>
<td>10,618 (54 per million inhabitants)</td>
</tr>
<tr>
<td>Central Europe</td>
<td>832</td>
<td>1,486</td>
<td>1,502 (8 per million inhab.)</td>
</tr>
<tr>
<td>Eastern Europe and Central Asia*</td>
<td>64</td>
<td>233</td>
<td>99,501 (349 per million inhab.)</td>
</tr>
</tbody>
</table>

* includes the three Baltic Republics

Table 2. EU AIDS involvement and the integration agenda

<table>
<thead>
<tr>
<th>Targeted region</th>
<th>Before Enlargement: Up to the late 1990'</th>
<th>During Enlargement: Early to later 2000s</th>
<th>After Enlargement: From 2006 onwards</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Old” UE-15</td>
<td>Enlarged UE-27</td>
<td>Neighboring countries: action on the Eastern part of the WHO-European region, plus Mediterranean countries</td>
<td></td>
</tr>
<tr>
<td>Changes</td>
<td>Switch-over to data systems on communicable diseases (AIDS integrates a more general category)</td>
<td>Institutionalization of EU-communicable disease control. ECDC in 2004</td>
<td>EU as actor in global public health policy. Priority: access to and pricing of medicines</td>
</tr>
</tbody>
</table>