

DRAFT

The Whys and Ways of European Community-Wide Responses to AIDS

by

Christa Altenstetter  
Ph.D. Program in Political Science  
Graduate School--City University of New York  
33 West 42 Street  
New York, New York 10036  
Tel.: (212) 642-2386  
Fax: (212) 642-1980

May 1993

Paper prepared for delivery at the Third Biennial International Conference of the European Community Studies Association (ECAS), May 27-29, 1993, at the Omni Shoreham Hotel, Washington, D.C.

Panel "The Social Dimension--Social Policy--Health Policy"

I greatly acknowledge financial support of the Stifterverband der Deutschen Wissenschaft, the Mannheim Centre for European Social Research (MZES), and the Institut für Medizinische Informatik und Systemforschung (MEDIS) within the Research Center on Health and the Environment (GSF) in Neuherberg near München. A PSC-CUNY Award of the Research Foundation of the City University of New York facilitated field work in Brussels during September and October 1991.

## Introduction

This paper reviews the major decisions and activities of the European Community with regards to AIDS/HIV<sup>1</sup> over the last ten years, the complex extra- and intra- Community policy making processes and policy networks from which these actions resulted, and the factors which have allowed the Community to act in some areas but not in others.

A Community AIDS strategy "covers any measure which is established on the grounds of AIDS, for example, public information campaigns, legislation, regulations and practices enacted, enabled or carried out by governments and/or initiated by specially appointed committees. An AIDS strategy is an expression of a public health policy."<sup>2</sup>.

This paper follows Laswell's definition of policy as a projected program of values (ends and ultimate goals; methods and means)<sup>3</sup> and is mindful of Dror's call for cross-field research.<sup>4</sup> Analytical-theoretical guidance is therefore drawn from the comparative policy-literature and research on policy networks, rather than from the study of domestic, comparative and international politics, or European integration.<sup>5</sup> From a comparative policy perspective the causal links between (1) political structure, the (2) European Community's AIDS policy and the (3) con-

sequences of these actions need to be explored.<sup>6</sup> Such an approach also calls for special attention to the particular problem structure of AIDS/HIV as a major cause of agenda setting, policy deliberations and strategies globally, across Europe and within the European Community. By political structure I include both the more enduring and formal aspects of government, public administration, decision making rules and the political culture of each member state (influencing national responses) and the institutional arrangements for EC-policy making as well as the dynamics of power-sharing and influence between EC-institutions and the member states based on the Treaty of Rome, subsequent amendments, EC-legislation and court rulings.

In consequence, this paper is primarily an exploration of how and whether the institutional arrangements for Community policy making impact upon the scope of policy choices, and is also a study of the consequences of such arrangements on the final policy choices. It is not an analysis of AIDS/HIV per se. A vital step in understanding specific policy responses is to bring historical and institutional context, law and culture back to the study of public policy and policymaking processes. This would apply to the global, the EC and the national level. By problem structure I mean the objective and subjective dimensions of AIDS/HIV and its distribution among the population of the member states of the European Community.

The point of departure of this paper is this proposition: historically developed circumstances and practices in regard to health care and public health in the member states have conditioned the range of policy options and their political feasibility at the Community-level.<sup>7</sup> With the member states having retained full control over public health and medical and health care for patients with AIDS/HIV/ACR<sup>8</sup>, leaving the European Community lacking specific powers in the area of medical care and public health (with the exception of work-related health and since 1987 environmental health matters), the range of policy options which the European Community could pursue in response to AIDS was indeed limited.<sup>9</sup> Symbolic politics and symbolic Community policymaking seem to have prevailed over interest politics, as they have in social policy.<sup>10</sup>

Policy environments and the objective and subjective dimensions of AIDS.

The objective dimensions. The facts about the spread of the virus, the incidence rates and the evolution of the infection are well known and need not be repeated. New insights regarding the disease are being continually gained and almost instantaneously shared with a world-wide audience through professional and scientific journals, mass media, international data banks and many research networks. At least nine international conferences on AIDS/HIV and the AIDS/HIV activities of interna-

tional and intergovernmental organizations have generated a worldwide agenda for debates and research with multiplier effects on Community and global discussions within the United Nations system (notably the World Health Organization), and the Council of Europe.

Countries differ in their total number of AIDS cases and in their respective rate of increase. Less clear is how many seropositive individuals or others who have displayed ACR-symptoms will eventually come down with the disease within a predictable time span. The number of individuals needing diagnosis and treatment as well as social support services is projected to go up further, as are the costs for treating patients and financing research to find a cure or a vaccine. The European Community and its member governments may have only seen the tip of the iceberg.<sup>11</sup>

Several trends are observed in all EC-countries: an increase in drug-related deaths and morbidity; an increase in treatment demands; an increase in first time users; a high proportion of prisoners who are drug users; and, finally, a growing concern over HIV-related problems among drug users, their families and others in the Community.<sup>12</sup>

Table 1 about here

The subjective dimension. As a highly "value laden epidemic"<sup>13</sup> AIDS conjures up many subjective reactions and poses barriers to a policy on AIDS, prevention and cure. Differences in perception of the problematique AIDS have been documented ever since the first case was discovered. But these will not be discussed here. Instead, reference is made to this summary:

Subjective reactions and barriers		
Death	Sex	Isolation
Dying	Illness	Bereavement
Prejudice	Discrimination	Risk
Disfigurement	Dependence	Loss of employment
Sexism	Prostitution	Promiscuity
Anger	Pain	Conflict
Disability	Uncertainty	Racism
Drugs	Despair	Fear

Hilary Dixon and Jane Springham, Aids prevention through health promotion: facing sensitive issues. World Health Organization, Geneva, 1991, p. 9.

Contrary to widespread beliefs and prejudices, we now know that the virus makes no distinction between age or sex, drug users or sexual workers, social or ethnic groups, rich or poor. But scapegoating and moral finger have done much to hinder the rapid coordination of action at the Community level. A wide gulf continues to exist between the analytical definitions in scientific research--medical, epidemiological, psychological and social science--and the political definitions of and responses to AIDS.<sup>14</sup>

The objective and subjective conditions of the disease, and the subsequent policy responses to AIDS in each member state<sup>15</sup> are

widely documented and need not be repeated here. The chronology of Recommendations, Resolutions, and Conclusions adopted every six months by the EC-Council of Ministers and the ministers for health is evidence for their presence in the multilevel and multi-actor intra-Community policy processes from 1983 onwards, when the Commission of the European Communities began to support AIDS research. It also mirrors the influence of the international policy environment as a major source of inspiration and controversy.

European Community policy actors have treated AIDS/HIV as a deadly but not a contagious disease. Because AIDS/HIV is an epidemic it is ill suited for arguments that the death rates from cardiovascular disease or cancer in the member states are higher.

Why study AIDS/HIV in the context of the European Community?

AIDS/HIV is a good entry point to the study of European Community policy processes and responses. These will continue beyond 1993. Comparative policy studies remind us that problem structures seldom coincide with established decision-making structures. AIDS transcends all boundaries--territorial, jurisdictional-legal, political and administrative. Migration of workers, tourism and free mobility of persons has been at the heart of European integration since the 1950s. A study on policy responses to AIDS, it was felt, would register an array of

diverse factors--social, cultural, ethical, moral and religious values which are observable in the reactions of politicians, governments, professionals and lay people to AIDS/HIV.

Such a study would contrast with the on-going research in the area of medical devices and pharmaceutical products and health care services and health protection schemes. A comparison of EC-policy responses in three different areas--products, services, travellers/people/patients--generated within the same institutional context would seem to offer a firm ground for generalizing about the effects of institutional arrangements on policy choices. The three case studies for the comparison are not yet completed.

The absence of explicit, treaty-based Community legislative authority over public health, health care, health care organizations and health protection schemes (with the exception of workplace-related health matters) has gone hand in hand with an observable involvement of the European Community in diverse health-related activities. This has raised a plethora of issues that deserve scholarly attention. The original Treaty of Rome of 1957, as amended and expanded in the Single European Act of 1987 (SEA) and the new draft treaty on European Union adopted by the heads of state or governments of the Twelve in Maastricht on 12 December 1991, is thought to be the root cause for the limited EC response.



According to an apparent international consensus, AIDS and HIV raises human rights issues: the right to privacy, liberty and security, freedom from inhuman and degrading treatment, freedom of movement, the right to marry and found a family, to free association, health care, and the right to work. These rights are protected in variable degrees in international conventions and treaties. The intersection of international law and politics with national law and politics in the area of human rights is clearly established.<sup>16</sup> Yet on the national level, there is no consensus on how much, if at all "the inalienable principle of non-discrimination and these rights need to be protected." All twelve EC-member states are reported to have taken measures which violated one or several rights.<sup>17</sup>

Recent observers of the European Community have reiterated the insights gained from comparative public policy research on the importance of legal, constitutional and institutional dimensions as setting the perimeters for playing the "political games" when decisions are made and actions taken. These observers have also added another range of issues. As B. Guy Peters plausibly argues, European policymaking processes are not simply two-level games.<sup>18/19</sup>

This explanation is reinforced by observations made by Alberta M. Sbragia. She concludes: "The six founding members of

the Community signed the Treaty of Rome rather than attend a constitutional convention. That fact has meant that the evolution of the Community is intrinsically tied to how national governments view their role in the Community... "Yet the very framework within which the Commission was established... was destined to undergird the power of national governments as decisionmakers"... "Second, a treaty allows national governments to segment the process of institution building. Although some legal scholars argue that the Treaty of Rome has been "constitutionalized" in the legal arena, it is important to note that the use of treaty mechanisms allows such constitutionalization to be limited, very explicitly, by the member states"... Thus the practice of judicial review can be segmented by treaty in a way that is extremely difficult by constitutional means. In a similar vein, it is only because the national governments decided that Jacques Delors should chair the committee which wrote the Delors Report on Economic and Monetary Union that the Commission was involved at all.... Finally, national governments can disregard developments in one area of policy when they negotiate treaties in other areas. "Third, the process of creating institutions by treaty maximizes the power of the executive within all the national governments concerned. Treaties are negotiated by executives, even though they are ratified by legislatures."<sup>20</sup>

Research on EC-policymaking in three illustrative health care cases suggests that her observations apply not only in gen-

eral terms but also in terms of policy-specific interpretations. Ample evidence has been found of similar constraints operating on EC-institutions as a result of the dominance of national representatives in those EC-legislative policy processes that matter for the adoption of Community-wide action. Figure 1 schematically identifies the international and national influences that affected the policy responses to AIDS in the European Community.

Figure 1 about here

#### The European Community as international actor

As a legal and political entity, the European Community participates in many international, intergovernmental and transnational processes through its representatives: ranging from the participation of President Jacques Delors and his Commissioners at the top EC-level to permanent or even a temporarily delegated EC-nationals.

The EC-member states are signatories of many legally binding international conventions. They have signed the European Convention on Human Rights (ECHR) and related protocols (The EC is not yet a party to the Convention), the European Social Charter of the Council of Europe (ESC), and twenty-three international social and labor conventions (ILO). These last have become Community law. Further, some have signed the International Covenant

on Economic, Social and Cultural Rights (ICESC). For information on those countries which signed these international policy tools, see Annex 1.<sup>21</sup>

International consensus documents, standards and norms, models of good medical and other practices, protocols, and guidelines exert a great deal of influence on the issues that are discussed in the EC-context. In the field of health policy and health care these seem to have more significance than in other policy areas. Even though some are controversial among the policy and the scientific communities, we need to recognize that international policymaking on AIDS has endorsed them, and they supercede EC-policymaking on AIDS/HIV. EC-reporting on AIDS even follows categories used by the international community, governments, researchers, statistical offices or data banks and people alike.<sup>22</sup>

The EC-member states are members of the 32-country European Office of the World Health Organization (WHO) and members of the 25-country Council of Europe. These organizations are pursuing very different, if not entirely opposite goals. The WHO's mission places health considerations above all else, whereas the European Community under the Treaty of Rome seeks trade and economic strategies and technological development and research (Articles 100-100A) with health not figuring prominently at all until the early 1990s. As for the transeuropean Council of Europe,<sup>23</sup> it

has a long and impressive history of involvement in the area of health, health services, manpower, training, health education, biomedicine, drugs and drug addiction, blood transfusion, organ transplantation, ethical aspects of health, the collection of blood and human plasma, good manufacturing practices, good health care practices, quality assurance, quality control in blood transfusion centers, blood donors and blood donations, post-collection information and so on.<sup>24</sup> The work of the Council in the health area is highly regarded by the European and the international community.

Despite the different missions and goals of these transeuropean institutions and the European Community, they have co-sponsored pilot projects in such fields as health education in several European cities<sup>25</sup>. Other co-sponsored projects include cooperation concerning drug addiction, training courses, the development of a strategy to achieve self-sufficiency in Europe on the basis of voluntary, that is, non-commercial, and non-remunerated donations of blood and organs, the preparation of a European Guide on the preparation and use of blood products and the development of European priority lists for organ recipients and other subject matters.<sup>26</sup>

Cooperative arrangements between the EC and WHO exist in the fields of AIDS, cancer, health education and drugs.<sup>27</sup> The formulation and implementation of cooperation involves senior or

junior members of the relevant public authorities, professionals and scientists nominated by the relevant executive agencies.

Executive dominance through the national AIDS coordinators and national officials is manifest in the composition of the Council of Europe's Comité Européen de Lutte Anti-Drogues (European committee to fight drugs). CELAD recommended "complementarity" between the member states's and the Commission's actions through exchanges of information and experiences. CELAD and the member states envisaged the creation of a European Drug Monitoring Centre. At the summit meeting on 25 and 26 June 1990 in Dublin the heads of state and government of the Twelve asked the Commission to report on a regular basis to the Council of Ministers and ministers for health on the work done on drug demand reduction in the Twelve.<sup>84</sup>

On 31 December 1990 the European Community ratified the 1988 United Nations Convention against the illicit trade of drugs and psychotropic substances. With the exception of Spain, ratification is pending in eleven member states (See annex 1). The member-states differ in terms of legislation and judicial practices concerning acquisition, possession and use of drugs. It does not come as a surprise to find that the Twelve have some difficulties in reaching agreements on EC-action (Annex 2)

Executive dominance is present in the composition of the Council of Europe's select committee of experts to conduct a survey on the "Impact of AIDS on the National Health Services and Health Planning." The participants were the same national AIDS coordinators, representatives of national health authorities, one representative of the EC-Commission and a WHO-EURO and Canadian observer.<sup>29</sup> Most are regulars in EC-policymaking processes dealing with AIDS-related issues.

The Twelve have supported the 'Health for All Strategy' launched by WHO ten years ago both at the global level and the European regional level. From the beginning the 38 European targets included a specific target on AIDS (target 4). But many other targets are relevant to AIDS such as targets 13 through 17 (lifestyles and health), target 32 (research), 33-38 (health development), target 35 (health information system) and target 17 (illicit drugs).<sup>30</sup>

By way of summary, to distinguish genuine Community contributions to the fight against AIDS/HIV from those generated by international activities above is a complex task. It is easier to describe the European Community's current policy on AIDS below in general terms than to explain in depth how it came about, who pushed for it and how it is implemented.

"Interlocking" policymaking structures or networks, agenda, and outcomes

Multilevel and multiactor decision-making structures are by their very nature incapable of rapid action.<sup>31</sup> When such structures display a high level of formal and informal "interlocking" and "functional engrenage" across EC-institutions and between EC-institutions and national institutions, as they do in the case of European Community policymaking processes,<sup>32</sup> rapid and coordinated action is an unrealistic expectation. Such 'interlocking' and 'functional engrenage' has been a delaying factor in the AIDS/HIV policy field. The Commission, the Council and the European Parliament in the early and mid-1980s differed in which was more urgent, bio-medical research on AIDS or preventive strategies. The divergences have narrowed, but the Council and the ministers for health continue to keep tight control over health-and AIDS-related initiatives.

The emergence and the operation of policy networks which this research identified calls for a pragmatic understanding of policy networks which are more or less formal institutional arrangements in the European Community. They bring together a dominant cast of national policy actors and a new cast of policy actors who participate in policy development and may influence Community action on an AIDS policy, the conduct of research into AIDS, and activities in public health and education campaigns.<sup>33</sup>

The characteristics summarized in figure 2 below only partially conform with those identified as important in the policy-



literature. Some authors view policy networks as "corporatist networks". Others define policy networks as "inter-organizational networks of interest representation which stabilize collective action."<sup>34</sup> Still others have used a "power dependence and interorganizational relations approach."<sup>35</sup> More recently, the concept of policy networks is suggested as a variant of different "forms of governance."<sup>36</sup> "A policy network is described by its actors, their linkages and by its boundaries. It includes a relatively stable set of mainly public and private corporate actors. The linkages between the actors serve as communication channels and for the exchange of information, expertise, trust and other policy resources. The boundary of a given policy network is not primarily determined by formal institutions but results from a process of mutual recognition dependent on functional relevance and structural embeddedness."

The AIDS/HIV-related networks and their members are highly diverse. Traditional corporatist actors and interest group representation dominate in macropolicy development networks. They may qualify as approaching "forms of governance" because linkages and boundaries are evident, whereas those of research networks and community-based networks are not identifiable without further research. Community-based social services networks such as AIDS service organizations (ASOs), non-governmental community-based social services organizations (NGOs) and AIDS hotlines clearly go beyond "forms of governance." They are about caring for people

and patients. To label them service-networks, in contrast to policy networks, simply for methodological reasons appears too simple.

Figure 2 about here

Macropolicy development networks. Representatives from EC-organizational units within Directorates-General (DGs), designed as official Commission participants and senior national officials, AIDS coordinators, and others from the ministries of health, education, science and research interact with each other on a regular basis through fairly closed macropolicy development networks. Participation is restricted. Network participants have a formal institutional affiliation and their role is defined by his/her responsibility and position in the respective ministries. Networking is hardly the raison d'être of the activities of the members of macropolicy development networks.

Their agenda and the objectives for meeting on a regular basis seem to be determined in large part by both the international agenda and domestic concerns. Other objectives are fixed by the Resolutions, Conclusions and Recommendations of the Council of Ministers and the ministers for health. Occasionally ad hoc groups of senior officials and scientists, working parties, and/or select committees made up of governmental, intergovernmental and non-governmental members have recommended actions to the

Commission and the relevant Directorates-General (DGs). Other non-regular policy actors are included. Membership in these networks is fluid and temporary and seems terminated when specific tasks are completed. The institutional affiliation of the non-regular cast can vary widely.

Transeuropean research networks and community-based service networks and AIDS service organizations. Research networks and community-based social networks differ in three important ways from macropolicy development networks. Although the participation of representatives of the Commission and the member states remains the same, a broader and more heterogeneous set of representatives are network members. They come from laboratories, universities, ACP projects (under the Lomé Convention), non-governmental social service organizations (NGOs), AIDS service organizations (ASOs), AIDS hotlines, healthy schools, agencies participating in local projects on drug reduction, public health and educational institutions. Their institutional affiliation can be in the public or the private sector. Finally, networking is a primary raison d'être of network members. Although one could say that the reason for their involvement in EC-or WHO-sponsored activities is to make a contribution to the development of an AIDS strategy at the Community or the WHO-level, rather than to network, it is difficult to draw boundaries for any of these individuals because they can be simultaneously involved in both activities.

Voluntary non-governmental organizations have been considered central to any strategy on AIDS, whether it is of the "identify-and-isolate the carrier" variety or the "safer-sex-and-harm-reduction" variety.<sup>37</sup> Yet international and intergovernmental bodies and most countries have been slow to invite them to participate in AIDS-related activities, and the European Community is the last supranational institution to lend them political legitimacy.

As one participant in an October 1991 meeting enthusiastically wrote: "Apart from the fact that EuroCASO and ISC+ (International Steering Committee for People with HIV) were invited"...for the first time..."the most sensational outcome was that it was decided that EuroCASO should be included in future co-operation meetings between the intergovernmental agencies: EC, Council of Europe and WHO."<sup>38</sup>

The European Council of AIDS Service Organizations network (EuroCASO) was founded "as a forum of co-operation for European ASOs, with the aim of working on the specific problems of the pandemic that affect our region."<sup>39</sup> It is part of a global network under the umbrella of the International Council of AIDS Service Organizations (ICASO)<sup>40</sup> and has 359 AIDS Service Organizations from 30 European countries on its mailing list considered members of EuroCASO.

Member organizations are of four types serving different clienteles: AIDS service organizations, gay and lesbian organizations, organizations for people with AIDS and organizations for drug users. Seventy-one ASOs have signed a Charter outlining the goals of EuroCASO reflecting the International Council of AIDS Service Organizations (ICASO).

Mobility and AIDS are of concern to European Community policy actors and experts, the World Health Organization and the Council of Europe.<sup>41</sup> The findings on tourism and sex tours to exotic countries, prostitution, migration and traffic in women and forced prostitution are no more encouraging for the societies in the European Community than they are for other continents.<sup>42</sup> To keep abreast of problems raised by migration and tourism in the European Community, a First European AIDS Hotline Conference (co-sponsored by the Commission) took place in April 1989 in Amsterdam.<sup>43</sup> A survey prepared prior to the conference found a "striking variety." ... "The information available about optimal prevention measures is torpedoed by dominant political groups in some countries." Information is "contradictory", "incomplete" and serious doubts exist that the data are "correct." "Drug users and others do not use the telephone lines."<sup>44</sup>

Serious doubts have been expressed about the effectiveness and the feasibility of achieving a unified European-wide informa-

tion and education campaign.<sup>45</sup> Coordinating the content of health education campaigns will doubtless be an uphill battle in a Community where the diversity of political cultures and traditions has prevented the European Community from playing any significant role. Equally difficult is the work and the acceptance of NGOs and ASOs as primary pillars of a national AIDS policy.

#### European Community policy on AIDS

The European Community has pursued three broad policy lines supporting activities in the area of prevention and control of HIV-transmission, health care, and the social and ethical implications of AIDS. Additional policy lines have been added over the years. By complementing national and local activities, these measures are expected to generate added value and quality at the Community level through the exchange of information, experience and activities in the following areas: information and health education; treatment and counselling; epidemiological surveys; manpower training and development; medical, clinical, biological and, above all, viro-immunological research. Biomedical ethics is emerging as a new field in the Community.<sup>46</sup>

These activities are embedded in four official components based on a budget line in the Community budget: (1) measures in public health, prevention and information, including 'Europe against AIDS' managed by the Directorate-General V (DG V-E-1);

(2) the AIDS research program as part of Medical and Health Research (previously MHR, since 1991 BIOMED1) administered through Directorate-General XII (DG XII-F-6); (3) the sub-programme Tropical Medicine as part of Science and Technology for Development administered through Directorate-General XII (DG XII-G-4); and, finally, (4) cooperation with the ACP countries under the Lomé Convention implemented by Directorate-General VIII (DG VIII). The discussion below is limited to a descriptive analysis of the first two areas.

'Europe against AIDS'. Ten years after the outbreak of the epidemic, the EC-Council of Ministers and the ministers for health finally on 4 June 1991 adopted a plan of action for 1991-1993 'Europe against AIDS' "without prejudice to the responsibilities of the Member States in this area" and in close cooperation with the competent authorities...."<sup>7</sup> It is restricted to action by the Commission. The Directorate-General V Health and Safety is in charge, and is assisted by an advisory committee composed of the senior officials from the relevant national authorities. The ministerial members are drawn from a variety of areas in health, health education, health promotion and information.

The Decision of the Council which launched 'Europe against AIDS' carries more weight than a Conclusion, Resolution or a Recommendation but less than a Directive.<sup>8</sup> Since 1986 the Coun-

cil at intervals of six months has adopted numerous non-binding instruments which 'widened' and 'deepened' over time. The Council has drawn attention to AIDS and attempts to halt the spread of HIV, stop discrimination, protect individual rights, provide care and the necessary means of prevention to the public, the young and special high risk groups. As new insights have been gained, these have become part of the official positions of the Council,<sup>49</sup> reflecting the preoccupations of the international leaders, the national senior AIDS coordinators and their governments. However, they have selectively chosen only that international expertise on AIDS/HIV which serves to justify their own political preferences.

A brief comparison of the Commission's proposal and the final version adopted by the Council yields a few differences in form but none in substance. The Council Decision, establishing a new budget line, provided very modest funding of 6 million ECU for 1991-1992, less than half the amount allocated under the Medical and Health Research Program (MHR4, since 1991 BIOMED1).

The language of the Decision is fairly similar to previous declarations adopted between 1986 and 1991 and international documents. It places high priority on the exchange of information, experience with AIDS prevention strategies and the need to launch education campaigns addressed to health workers, the public at large and population groups at risk. As a matter of



routine, emphasis is placed on medical research and research on the social and economic consequences.

A few new elements seem to reflect the resolve of the national representatives to do something about AIDS beyond the symbolic positions taken earlier. First, a new standard for participation and representation was set. Parallel to the recognition of non-governmental groups within the UN system, the gate was opened to community-based social service organizations, AIDS services organizations (ASOs) and others. They were already legitimate participants in WHO-EURO-sponsored activities. The monopoly of the social partners (i.e., trade union and employers' representatives through the EC-Social and Economic Committee was ended. However, the extent to which ASOs wish and can influence Community AIDS efforts, independent of the official representatives of the member states, is unclear, as is their ability to influence the judgements of the Commission representatives. Second, the Commission was asked to coordinate the activities carried out by its own various organizational units under several Directorates-General with national AIDS coordinators, other external organizations and social networks. Third, procedures have been strengthened. It has been unusual to find voting procedures, working arrangements and time limits mentioned in previous Resolutions, Conclusions or Recommendations. Even this Decision leaves the last say to the national committee members.

'Europe against AIDS' of 1991 outlined a specific workplan and timetable for the Commission building on the accumulated expertise and experience of public and private programs and voluntary and professional activities in the Community and worldwide. The primary goal is to boost the effectiveness of national programs through the exchange of information, experiences and activities. The plan is to be implemented in close coordination with the responsible national authorities and in cooperation with international organizations active in this field such as the World Health Organization and the Council of Europe.

The Resolution of the Council and the ministers for health of 11 November 1991 concerning fundamental health-policy choices preceded the inclusion of a new Title X Public Health in the new draft Treaty on European Union in Maastricht on 12 December 1992.<sup>50</sup> The foundation was laid for more broad-ranging changes to come in the European Community and Europe as a whole in the field of health and public health.<sup>51</sup> 'Europe against Cancer' had been a first major strategy.<sup>52</sup> However, it was understood then that many details needed to be worked out way into the 1990s, under the Portuguese (1992), the British (1992) and the Danish (1993), the Belgium (1993) and subsequent Presidencies.

The draft treaty now requires ratification in each member state through referendum or parliamentary ratification. If Denmark and the United Kingdom in the course of 1993 can embrace the

new draft treaty on European union, decisions on public health matters could theoretically be taken in the future by a qualified majority vote.<sup>53</sup> But as in many other policy fields, it is doubtful that the Council would impose decisions on AIDS and HIV on any unwilling member state.

The Medical and Health Research (MHR1) Program. A consensus among the Twelve on the need to support basic, clinical, and epidemiological research on AIDS and a minimum of social science research on AIDS emerged only in 1987 and 1989 when the ministers for health adopted non-binding Conclusions strengthening the research initiatives of the Commission and its Directorate-General XII which had started in 1983 and were extended in November 1987. "Research was there from the beginning, and was the first field of EC-cooperation", writes one national insider to the process; "all others-policy, public health administration, etc.-followed years later."<sup>54</sup>

The political rationale for supporting research, while delaying the launching of an action program for information and education campaigns, demonstrates a science and research bias of the Commission and national governments working through the Council of Ministers and the European Parliament with Leon Schwarzenberg, a known French medical researcher, serving as an effective spokesperson for national interests and the scientific research community.<sup>55</sup> The European Parliament voted for numerous amend-

ments to the Commission's text.<sup>56</sup> The Commission accepted and rejected many of them on the grounds of no EC-competence.<sup>57</sup>

Several amendments deserve attention. First, "the approach must cover scientific, medical, cultural and social aspects." Second, the 'Science and Technology for Development' Programme and the fight against drugs--decided on the year before--must include a section on AIDS." Third, Parliament proposed a draft European code on AIDS modelled after the European code on Cancer. According to an informed source, there is only a slim chance that the ministers for health will adopt a code on AIDS. There simply are too many differences among them, their governments, the corporatist actors of employers and trade unions, professionals, and AIDS-specific groups and last not least peoples in the European Community.<sup>58</sup>

In 1978 Medical and Health Research (MHR1) became part of Community R&D policy for the first time after the Treaty of Rome through the Single European Act of 1987 was revised adding a new Title VI on research and technology (Articles 130-130g). A Council Decision laid the foundation for AIDS research for the period of 1978-1981 and institutionalized research on cancer (six priority areas), AIDS (3 priority areas), age-related health problems (3 priority areas), environment, health and lifestyle (4 priority areas) and health resources (7 priority areas). To manage these concerted action programs, Comités d'Actions Con-

certées in Health Services Research (COMAC-HSRs) were created in 1980.<sup>59</sup>

The initial pilot research program was extended by a second program (1980-1983 MHR2) and a third (1982-1986 MHR3). The number of concerted actions increased from 2 in the first period to 34 in the third program (MHR3, 1982-1986), and the number of cooperating research teams rose from 100 to 1460 by 1985. The fourth program (1987-1991 MHR4) added more AIDS-specific research projects to the program and predicted the creation of about 2000 to 3000 research teams. In 1992, over 3,500 research teams were cooperating in the medical and health fields in EC and non-EC or COST countries.<sup>60</sup>

National political and scientific interests are represented in Community policy development networks on R&D at three levels: (1) the Framework Programs where the Community's R&D policy is developed, influenced and decided, (2) the Medical and Health Research programs (MHR until 1991, now BIOMED1) and (3) the concerted action projects, including those on AIDS (See Appendix 3).

Many delegates from a variety of backgrounds attend the Framework Program meetings from each member country, whereas the size and composition of delegations attending the meetings at the program level is more variable. Two national representatives usually attend meetings at the concerted action project level; a

senior government official and a government-appointed scientist. However, the pattern of representation differs according to the country and the circumstances. Members of the management groups (CGC-MHR) come from EC and COST countries.<sup>61</sup>

The EC Research Program on AIDS The EC Research Program on AIDS<sup>62</sup> has been part of the Community's overall R&D policy since 1978 and the Biomedical and Health Research Program (MHR) initiated the same year.<sup>63</sup> 14 million ECU were allocated to AIDS research under the Community's Medical and Health Research Program (MHR4) out of a total budget of 60 million ECU for medical and health research.<sup>64</sup> Funding for AIDS research exceeds funding for "Europe against AIDS" (6 million ECU).

A Working Party on AIDS Research, made up of physicians from the basic and clinical sciences, was approved in 1987. It was strengthened by a Council Decision of 17 November 1987 following the adoption of the Single European Act the same year. The heads of state and government on 8 June 1987 at the summit meeting in Venice had specifically requested that "further cooperation should be promoted for basic and clinical studies on prevention, treatment and the exchange of information."<sup>65</sup> The Conclusions of 16 May 1989 and 22 December 1989 outlined specific research areas.

The research program on AIDS is a concerted action program. The Community funds the costs for the meetings of the research

teams from cooperating centers throughout the Community and COST countries, while national funds pay for the actual research. European scientific cooperation in research into AIDS must, as research cooperation in the Community in general, be "complementary to national efforts." European collaborating networks must yield "Community-added value."<sup>66</sup> Research is expected to produce results which could not be obtained through national efforts alone. Research teams enjoy a high degree of autonomy and independence in carrying out the research in national laboratories, research centers and universities.

By standards of the Commission, another indicator of added Community value is the registration of patents with the European Patent Office. Teams cooperating on AIDS research in the EC countries have a good record, but it should be noted that "most of these international cooperations are not EC-internal ones, but joint research with other countries and first of all with the United States."<sup>67</sup>

Until 1991, the AIDS research program had four main components: control and prevention of disease; viro-immunological research; clinical research; and European Vaccine against AIDS (EVA). BIOMED1 (1991-1994) has added two new foci: behavioral, socio-economic and health services research and the development of antiviral drugs<sup>68</sup>... "to exploit the differences in health care systems and to identify the most effective methods of

health care delivery, particularly in view of demographic changes expected after 1992." Epidemiological studies will shed light on "the multicultural, multi-ethnic community of Europe, e.g. studies on the interactions of genetic and environmental factors on health."

The Community-wide management of research on AIDS is in the hands of a Management and Coordination Advisory Committee on Medical and Health Research (CGC-MHR). The membership in CGC-MHR is closed and consists of four groups: representatives from national authorities (AIDS coordinators); the Commission; scientists representing the six priority areas of the Biomedical and Health Research Programme (COMAC and WP chairmen); and governmental and scientific representatives from COST countries. Decisions are said to be reached by consensus. Frequently, these national representatives are the same who also participate in WHO/EURO-sponsored networks.<sup>69</sup>

In 1991 the EC Programme on AIDS Research included about 7 centralised facilities which served global objectives and supported the work of scientists, research organizations and industry worldwide. It had about 25 concerted actions (CAs), involving researchers from a total of 530 participating laboratories/institutions in the European Community (630, if both EC and COST countries are included).<sup>70</sup> This is a considerable increase since 1985, when only 92 laboratories in the EC and two in COST countries collaborated at the European level.<sup>71</sup>



Of the 530 laboratories located in EC countries, 215 work on disease control & prevention, 154 engage in clinical research, and 148 are involved in viro-immunological research. 13 laboratories work on a vaccine.

Table 2 about here

In Western Europe, 253 of the 630 laboratories were involved in research on disease control and prevention; 175 were engaged in viro-immunological research; and 169 in clinical research. A surprisingly small number of laboratories participated in the program European Vaccine against AIDS (EVA) (13 are from EC and 2 from COST countries).

The epidemiological monitoring of AIDS is carried out by the European Centre for the Epidemiological Monitoring of AIDS created in 1984 in St. Maurice near Paris.<sup>7\*</sup> It is funded roughly half by the French Government and half by the European Community. It is also a WHO-EC Collaborating Centre serving the WHO-sponsored research networks (under the GPA-EURO program), the member states and the European Community as a whole as well as the Centers of Disease Control (CDC) in Atlanta, Georgia, U.S.A.

Another centralised facility with a global objective is 'The EC Concerted Action on Mathematical Modelling of HIV Infection.'

In 1991, it included about 30 research institutes from Europe, Canada and the United States of America focusing on "public health strategy development"<sup>73</sup>

Research teams from a few countries played a dominant role in AIDS-related research. These included teams from Belgium, Germany, France, Italy and the United Kingdom, Spain and Italy. However, each EC member state has research teams involved in the EC program, and this is another explicit objective of the Community's R&D policy. Teams not yet operating at the level of the 'best research practices' should be enabled to improve their standards and performance through cooperation.

#### Table 3

In vaccine research the leading countries are Germany and the United Kingdom (3 laboratories each) followed by France (2), and Belgium, Spain, Greece, Italy and The Netherlands (each with one laboratory). Four countries (Denmark, Ireland, Luxembourg and Portugal) are not participating in research on EVA.

Policy outcomes. The authors of The Research Networks Built Up under the MHR4 Programme try to capture the consequences of EC-sponsored research in terms of building cooperative links among researchers across national boundaries.<sup>74</sup> The information is valuable for this paper.

434 research teams (rather than laboratories) are involved in AIDS research organized into 25 concerted actions (CAs) with an average membership of 17 researchers. Research teams from Belgium, Denmark, France, Italy and the Netherlands are leading. Of 13 teams about whom more information was available, the authors found that two teams were "academic teams" involved fulltime in research. The remaining teams were identified as those with an "academic orientation" (i.e. treating patients and pursuing an interest in research). Two were labelled as having a "mixed orientation" (i.e., between basic and applied research and caring for patients; two others had only a "clinical orientation", that is, they were primarily interested in patient care. Three teams had researchers from private companies among their members. The participants in 13 research networks or teams on AIDS came from different backgrounds. Most (57) came from academic institutions, 24 are from university hospitals, 15 from service institutions and 4 from industry. Predictably, researchers from academic institutions are the leaders in AIDS research networks.

Access to research networks appears closed. Network members include senior, sometimes junior, government officials, nationally appointed researchers, members of the Working Party on AIDS and 'EC-liaison officers' appointed by WHO-EURO. The overlap of membership in a concerted action, a higher level Program Management Group and the Working Party on AIDS Research can be

significant. The participation of a more diverse group in research networks tends to be discouraged for reasons which range from a deliberate decision and choice of network members to poor information and communication.

It is not unusual for the same individual to participate in several EC- or transeuropean networks, ad hoc working groups and select committees. For example, a member of a WHO-sponsored activity may be a member of an EC-sponsored working group and at the same time be a member of a select committee sponsored by the Council of Europe. Activities relating to CELAD fit this description.

How did network members communicate with each other and what did they do was one research interest which the Laredo et al. team pursued. This team points to the significance of meetings and the exchanges of literature, data and information in all concerted actions, including AIDS (p.24, file 1). Visits, the exchange of papers, data, protocols, samples, reference materials and reagents and software are other ways of communication. (p. 8)

The main achievements of AIDS-specific research networks are described as "more than academic science." (p. 19). Table 4 lists new scientific knowledge, methods and instruments for research, methods and instruments for prevention, diagnosis and therapy, and commercial applications among the expected results. Members

of research network expected two different outputs. "First, building a new basis for research through the production of protocols, standards, reference materials, databases and experimental facilities."... "Second, economic and social impacts are focused on clinical aspects."

Table 4 about here

The results and value of transeuropean research were assessed by two teams of evaluators.<sup>75</sup> By focusing on different analytical foci and using different methodologies they reach widely different conclusions about the 'added value,' performance, quality and effectiveness of EC-sponsored bio-medical and health research. While any assessment of these evaluations lies outside the scope of this paper, it should be stressed that their results say as much about the evaluators and the criteria which they chose for the evaluation, as they do about the nature of transeuropean research.

The observations by the Larédo team, which focused on the processes of communication among and the interaction of researchers rather than the products of research itself, are pertinent. They write: "while we can characterize global effects, it is difficult, even impossible, to understand how they are produced." By the same token, this paper could only describe the general effects of EC-sponsored research and the specific Community

action programs which culminated in 'Europe against AIDS' of 1991. To go beyond this survey would require systematic research into the activities of networks behind the scenes.

These networks were created as a direct result of decisions made by the Commission and the Council of Ministers, as well as senior officials from national ministries for health and science. The networks and the particular membership of players from different institutional settings, backgrounds and sectors would not have come about without these decisions. Over this ten-year period the formulation of new elements of Community action, as reflected in the many Recommendations, Resolutions and Conclusions, resulted both from new insights gained into research on AIDS/HIV and the work of these networks. The inclusion of members of WHO-EURO, international and Council-of-Europe-sponsored networks in networks promoted by the EC-Commission seems to suggest that European-Community-based networks do not make a contribution to the search for a solution to AIDS/HIV beyond that produced by other transeuropean networks.

### Conclusion

The research reported here has been as much about AIDS as an intrinsically international issue as about international and European cooperation and transnational problem-solving and governance in the changing world of the 1990s. AIDS-related

networks operate across EC and national policymaking levels, borders and policy sectors, and they link governmental, professional and voluntary groups in ways that can be considered new forms of political and institutional adaptations to changing global and Community environments. Their emergence is significant beyond the issue of AIDS.

The diffusion of knowledge about and policy responses to AIDS/HIV and the exchange of experiences with AIDS/HIV worldwide over a ten-year time span makes it almost impossible to identify with accuracy the most effective elements in Community policymaking with any more precision than was possible in this paper. An array of policy actors will claim recognition for designing a 'master' policy on AIDS/HIV. The difficulty in ascribing responsibility for policy development and agenda-setting to any group is a serious one. In any case, national considerations and AIDS control programs remain dominant, and hopes for a gradual erosion of national control over AIDS prevention programs are ill-founded.

Goals and objectives in the fields of AIDS/HIV were set internationally and Europe-wide, but the methods used to achieve and finance them were administrative routines and standard operating procedures (SOPs) both of the EC and the member states, as well as routines and SOPs for debate and communication among international actors. The convergence of goals and priorities in

national, Community-wide and international programs is striking but not unexpected. It was in the interest of national governmental representatives from Foreign Affairs, Justice, Health, Education, Science and other policy sectors to lend political support to international and European policy declarations, consensus documents, norms and standards, models of good practices, protocols, guidelines and the like which justified political action.

The Commission led in research sponsorship and concerted actions in Europe, but in other public-health and AIDS-related areas the Commission of the European Community was a late comer. In many other areas it simply duplicated the content, the priorities and the targets which the international, transnational policy actors and the member states had set, without adding any new initiatives. EC-research networks have been vital in EC-responses to AIDs/HIV.

Because the member states retained full control over public health and medical care, and because policy content seldom starts de novo, responses to AIDS and HIV evolved at every policymaking level--national and Community--and in every policy domain, mixing preexisting policy components of, for example, measures to respond to a threat to public health, the delivery of medical care, with new AIDS-specific elements. This happened at the international, the EC- and the national level. Their snowballing



and cross-fertilizing effects should not be underrated neither should their feedbacks at the Community level.

The 1991-1993 plan 'Europe against AIDS' built on previous EC-decisions and did not change much. It reiterated the principles and activities recommended for Community action since 1986 and stressed the need for continued international and Community-wide collaboration.

Agenda setting has become an international process while at the same time remaining very local. Structural and alternative forces are actively participating in it.

In the past, the European Community, the Council of Europe and the World Health organization made a distinct contribution to the international community. Europeanization of health issues may pose a new threat. As the Single European Act extended EC competences in health matters (and the draft Treaty on European Union of 12 December 1991 intends to further strengthen them), the four goals set out for the integrated European market--the free movement of goods, services, people and capital--across Europe and beyond will require coordination of a great number of policy areas that lie beyond economic and trade matters at home and in the Community at large. In all likelihood, based on the insights gained from this research, this coordination will be done within the existing policy making structures of both the EC-

institutions and the political-administrative systems of the member states.

The inclusion of Title X Public Health in the Draft Treaty on European Union in Maastricht on 12 December 1991 seems to reflect a strengthening of pro-health forces in Europe interested in a visible and health conscious European Community. Although the Treaty may never be ratified, the draft Title X can be interpreted to have added political legitimacy and credibility to, and acceptability of, on-going and new activities in the field both of AIDS and public health at the Community level.

Given the complex institutional arrangements for European Community policymaking and the particular problem structure of AIDS/HIV, it was no surprise to find evidence of many constraints which affected policy choices and their consequences. Among the more significant constraints were those which emanated from the multiple layers of decision making and the heterogenous actor constellations. With such a high degree of 'interlinking' and 'functional representation' or 'engrenage', it is difficult to be more specific about who controls policy processes. But one observation stands out: members of the executive branch in each member state retained the ultimate authority and control over AIDS/HIV issues.

<sup>1</sup>Throughout this text the terms AIDS and HIV are used interchangeably.

<sup>2</sup>Commission of the European Communities. Directorate-General Employment, Industrial Relations and Social Affairs Health and Safety Directorate. AIDS and Human Rights in the European Community. Report prepared by Pia Carle, Aart Hendriks and Dieneke Zeegers, 1991, p. 28. Doc. CEC/V/E/1/Lux/52/91.

<sup>3</sup>Harold D. Laswell, "The Policy Orientation," in Daniel Lerner and Harold D. Laswell, eds. The Policy Sciences. Stanford: California. Stanford University Press, 1950: 9-15. Harold D. Laswell, "Policy Sciences," International Encyclopedia of the Social Sciences, vol. 12. New York: Macmillan and Free Press, 1968: 119-189.

<sup>4</sup>Yehezkel Dror, Public Policymaking Reexamined. San Francisco: Chandler, 1968; and Design for Policy Sciences. New York: American Elsevier, 1971.

<sup>5</sup>The body of literature in each subfield is extensive and cannot be included here. The separation of political science into highly specialized subfields has unfortunately delayed fruitful communication between researchers in various subfields. Even the literature on European integration has not integrated a policy-perspective until very recently. Foreign and defense policy, economic and monetary policy and, obviously, agricultural policy have been of interest, but the emphasis has not been on the strategies and content of policy per se.

<sup>6</sup>Fritz W. Scharpf, "Decision Rules, Decision Styles and Policy Choices." Journal of Theoretical Politics. Vol. 1 (2), 1989: 148-176.

<sup>7</sup>See contributions in Douglas E. Ashford (ed.), History and Context in Comparative Public Policy. Pittsburgh: Pittsburgh University Press, 1988.

<sup>8</sup>The acronym ACR stands for AIDS-Related Complex.

<sup>9</sup>Christa Altenstetter, "Health Policy Regimes and the Single European Market." Journal of Health Politics, Policy and Law. Winter 1992: 105-125.

<sup>10</sup>Peter Lange, "The Politics of the Social Dimension," in Alberta M. Sbragia, ed., Euro-Politics. Institutions and Policymaking in the "New" European Community. Washington, D.C.: The Brookings Institution, 1992: 225-256, here 229.

<sup>11</sup>The Commission's proposal of 11 December 1990 gave a figure of 20,000 ECU as the average yearly cost for medication, hospitalization, home care and psycho-social support for AIDS

patients. Overall 3 billion ECU were required in 1992.

<sup>12</sup>Commission of the European Communities. Report on drug demand reduction in the European Communities, 1992 (incomplete reference).

<sup>13</sup>WHO-Regional Office for Europe. Aids and Mobility. The impact of international mobility on the spread of HIV and the need and possibility for AIDS/HIV prevention programmes by Aart Hendriks, 1991, p. 91. EUR/HFA Target 4. EUR/ICP/GPA 023.

<sup>14</sup>For a multidisciplinary discussion of AIDS, see "A Disease of Society Cultural Responses to AIDS (Part 1 and Part 2) edited by Dorothy Nelkin, David P. Willis, and Scott V. Parris in The Milbank Quarterly, Volume 1968, Supplement 1, 1990, pp. 1-174, Supplement 2, 1990, pp.179-319; also for opposite views on the same topic by members of the research community see, Carole Levine and Nancy Neveloff Dubler, "Uncertain Risks and Bitter Realities: The Reproductive Choices of HIV-infected Women," The Milbank Quarterly, Vol. 68, No. 3, 1990, pp. 321-352 and Jan D. Arras, "AIDS and Reproductive Decisions: Having Children in Fear and Trembling," The Milbank Quarterly, Vol. 68, No. 3, 1990, pp. 353-382. For an international history and cross-cultural analysis of a 'new' disease and the ways the scientific community has been trying to come to grips with it, see Mirko D. Grmemek. History of Aids. Emergence and Origin of a Modern Pandemic. Princeton, N.J. Princeton University Press, 1990.

<sup>15</sup>For a first inventory of national responses, see S. Wayling, National AIDS Study WHO-EURO, 2 March 1989 and update 29 March 1989 (internal document). For an update through 1991 which is controversial, see Pia Carle, Aart Hendricks and Dieneke Zeegers, AIDS and Human Rights in the European Community April 1991. Commission of the European Communities Directorate-General Employment, Industrial Relations and Social Affairs Health and Safety Directorate. Doc. CEC/V/E/1/Lux/52/91.

<sup>16</sup>See contributions in Günther Teubner, editor, Dilemmas of Law in the Welfare State. Berlin: De Gruyter, 1988.

<sup>17</sup>Commission of the European Communities. Directorate-General Employment, Industrial Relations and Social Affairs. Health and Safety Directorate. AIDS and Human Rights in the European Community. Report prepared by P. Carle, A. Hendricks, Dineke Zeegers. April 1991. Doc. CEC/V/E/1/Lux/52/91.

<sup>18</sup>B. Guy Peters, "Bureaucratic Politics and the Institutions of the European Community." In Sbragia, ed., Euro-politics. Institutions and Policymaking in the "New" European Community. Washington, D.C.: The Brookings Institution, 1992: 75-122.

<sup>19</sup>George Tsebelis, Nested Games: Rational Choice in Comparative Politics. Berkeley, University of California Press, 1990.

<sup>20</sup> Alberta M. Sbragia, "Thinking about the Future: The Use of Comparison." in Alberta M. Sbragia, ed., Euro-politics. Institutions and Policymaking in the "New" European Community. Washington, D.C.: The Brookings Institution, 1992: 257-291, here 271-272.

<sup>21</sup> Commission of the European Communities. Doc. CEC/V/E/1/LUX/52/91. AIDS and Human Rights in the European Community. Report prepared by Pia Carle, Aart Hendriks, Dineke Zeegers, Luxembourg: April 1991, pp.24-25.

<sup>22</sup> 1. Surveillance 1. Notification and reporting systems; 2. Confidentiality; 3. Registration; 4. Measures against wilful transmission of HIV; 5. Screening and testing of human products; 6. Testing in connection with transborder movement; 6. HIV-positivity or AIDS as a ground for expulsion from a state; 7. Isolation or segregation of HIV infected persons; 8. Other legislation or regulation. 2. Health Care; 3. Social and ethical implications: work, access to health care. In: Commission of the European Communities. Directorate-General Employment, Industrial Relations and Social Affairs Health and Safety Directorate. AIDS and Human Rights in the European Community. Report prepared by Pia Carle, Aart Hendriks and Dineke Zeegers, 1991, p. 28 Doc.CEC/V/E/1/Lux/52/91.

<sup>23</sup> As an intergovernmental body the Council of Europe pursues three ambitious aims: to protect and strengthen pluralist democracies and human rights; to seek solutions to the problems facing society; to promote the emergence of a genuine European cultural identity.

<sup>24</sup> Council of Europe, Report on the Activities of the Council of Europe 1989. Strasbourg 1991, pp.139-150, Report on the Activities of the Council of Europe. Strasbourg 1991, p.27, 57-58, pp.61-71. On social and socio-economic problems, see pp.75-88, 114-124..

<sup>25</sup> These are Arese (Italy), Bremen (Germany), Dun Laoghaire (Ireland), Athens (Greece), Durango (Spain, Ledeberg, Liège (Belgium), Rennes (France), South Glamorgan, South Tyneside (United Kingdom), Turku (Finland).

<sup>26</sup> Council of Europe. Health. Activities and Publications. Strasbourg, 1991. pp. 5-15 (internal document).

<sup>27</sup> The Commission has co-financed a number of joint EC-WHO seminars, for example in April 1990 on AIDS, June 1990 in Madrid on AIDS, Juli 1990 Southampton on drugs and health, September 1990 in Strasbourg on drugs and education.

<sup>28</sup> Commission of the European Communities. Directorate-General Employment, Industrial Relations and Social Affairs, Health and Safety Directorate. Report on National Programmes for Drug Demand

Reduction in the European Community. Brussels, 8 November 1990, COM(90) 527 final. The report's conclusions are summarized as follows: "The approaches to drug demand reduction are continually and often rapidly evolving in Member States; furthermore a large variety of approaches is being explored. Member States consider it important to introduce and improve evaluation programmes. They emphasize the importance of a broader framework of prevention measures in which various cultural, health and social problems are addressed and for a comprehensive approach to drug abuse problems."

A follow-up to the first report is Regionally Based Drugs and AIDS Study. A Report on Coordinated Drugs and AIDS Projects Based in Barcelona, Berlin, Dublin, Glasgow, Lille and Turin. Prepared by F.E. Edwards. Doc. CEC/LUX/VE/E/1/26/91.

<sup>29</sup> Résultat d'une enquête auprès des Administrations Sanitaires Nationales, Administrations Sanitaires Pénitentiaires, services Hospitaliers, Associations bénévoles. Council of Europe. Restricted CDPS (91) 24 Def. 3. Comité Européen de la Santé (CDPS), 29ème réunion, Strasbourg, 18-20 Juin 1991. Comité restreint d'experts sur l'impact de l'épidémie du SIDA sur les services de santé et leur planification (SP-R-AIDS/O) 3ème réunion, Strasbourg, 23-26 avril 1991. This committee made specific recommendations on the financing for AIDS; access and delivery of care; education and training; coordination of services; organizations of health services for special risk groups including women, children, UDI, blood recipients and blood products, sexual and bi-sexual men, prison inmates; ethnic groups; quality and evaluation of care.

<sup>30</sup> The process of revising the 38 European regional targets came to a close in late 1991. Some targets were substantially changed, while others were changed slightly or were expanded such as women's health issues. Health and ethics of concern to the international community of health experts is a new target.

<sup>31</sup> For systematic research on the obstacles arising from vertical bargaining structures across two levels of government, see Fritz W. Scharpf, "The Joint-Decision Trap: Lessons from German Federalism and European Integration." Discussion Papers IIM/LMP 85-1. Berlin: Wissenschaftszentrum. Kenneth Hanf and Fritz W. Scharpf, eds., Interorganizational Policy Making. London and Beverly Hills: Sage, 1978. Even horizontal bargaining structures display some of the same difficulties, as Arthur Benz, Fritz W. Scharpf and Reinhard Zindl discuss in the new book elaborating on the 'theory of Politikverflechtung', Horizontale Politikverflechtung. Zur Theorie von Verhandlungssystemen. Frankfurt a.M.: Campus, 1992.

<sup>32</sup> B. Guy Peters, "Bureaucratic Politics and the Institutions of the European Community," in A. Sbragia, Euro-Politics. Institutions and Policymaking in the "New" European Community. Washing-

ton, D.C. The Brookings Institution, 1992: 75-122.

<sup>33</sup>For a discussion of the literature on policy networks and policy analysis, see Bernd Marin and Renate Mayntz, Introduction: Studying Policy Networks, in Bernd Marin and Renate Mayntz (Eds.) Policy Networks. Empirical Evidence and Theoretical Considerations. Frankfurt: Campus Verlag and Boulder, Colorado: Westview Press, 1991: 11-22; see also the issue devoted to policy network research of the European Journal of Political Research. Vol. 1, 1992.

<sup>34</sup>Gerhard Lehmruch, Concertation and the Structure of Corporatist Networks. In John H. Goldthorpe (ed.). Order and Conflict in Contemporary Capitalism, Oxford: Clarendon Press, 1984, pp. 60-80.

<sup>35</sup>H. Aldrich, Resource dependence and interorganizational relations. Administration and Society. 7 (4), 1976, pp.419-454; Kenneth Hanf and Fritz W. Scharpf, Interorganizational policy-making. Limits to Central Control. London: Sage Publications, 1978; David L. Rogers and David Wetten, Interorganizational Coordination. Ames: Iowa State University Press, 1982; Basil J.F. Mott, The Anatomy of a Coordinating Council. Implications for Planning. Pittsburgh: University of Pittsburgh Press, 1968; Morris Schaefer, Intersectoral Coordination and Health in Environmental Management. An Examination of National Experience. Geneva: WHO 1981. Jerry L. Weaver, Conflict and Control in Health Care Administration. Beverly Hills: Sage Publications, 1975.

<sup>36</sup>Patrick Kenis and Volker Schneider, "Policy Networks and Policy Analysis: Scrutinizing a New Analytical Toolbox," in Bernd Marin and Renate Mayntz, eds., Policy Networks. Empirical Evidence and Theoretical Considerations. Frankfurt a.M.: Campus. Boulder, Co. Westview Press, 1991: 25-59, here p. 41

<sup>37</sup>Global Program on AIDS. WHO Regional Office for Europe. Taking up the challenge in the '90s. p.7.

<sup>38</sup>WHO Regional Office for Europe. Global Programme on AIDS, AIDS Services Organizations into the 1990s: People's needs and the best response. Report on a WHO Workshop. 1991. EUR/ICP/GPA 095; and österreichische AIDS Hilfe, First Regional Workshop for AIDS Service Organizations in Europe on Collaboration and Networking Activities. 12-15 October 1989, Vienna.

<sup>39</sup>EuroCASO Newsletter, No. 4, November 1991, p. 3 and p. 10.

<sup>40</sup>RB/ICASO/Update.A91. p. 1.

<sup>41</sup>WHO Regional Office for Europe. AIDS and Mobility. The impact of international mobility on the spread of HIV and the need and possibility for AIDS/HIV prevention programmes by Aart Hendriks. National Committee on AIDS Control of the Netherlands. Global Program on AIDS. 1991 EUR/HFA Target 4. EUR/ICP/GPA 023.

<sup>42</sup> Council of Europe. European Committee for Equity between Women and Men. "Tourism-Prostitution and AIDS." Memorandum by Mechthild Maurer. Strasbourg 1991. p. 1; and Survey on Prostitution, Migration and Traffic in Women: History and Current Situation by Licia Brussa. Strasbourg 1991.

<sup>43</sup> Commission of the European Communities and Nationale Commissie AIDS-Bestrijding. First European Hotline Conference. Conference Report. n.d., n.publisher.

<sup>44</sup> According to the former representative of the Commission of the European Communities, Dr. A. Berlin, 1.5 million calls to AIDS hotlines in the member states were counted per year (representing 0.5 million man-hours) in 1989.

<sup>45</sup> See in particular Mr. Hans Moerkerk from the National AIDS Control Commission in the Netherlands, The European AIDS Policy: AIDS as the spearhead? A survey and critical analysis. First European AIDS Hotline Conference, Conference Report, pp.59-71.

<sup>46</sup> Report of the Committee on the Environment, Public Health and Consumer Protection on the proposal from the Commission to the Council for a decision of the Council and the Ministers for Health of the Member States meeting within the Council adopting a plan of action in the framework of the 1991-1993 'Europe against AIDS' programme (COM(90) 0601 final - C3-0028/91) Rapporteur: Mr. Léon Schwartzenberg. European Communities. European Parliament Session Documents, 29 April 1991, A3-0108/91, pp.19-20.

<sup>47</sup> (91/C 107/03) Official Journal of the European Communities No. C 170/3-5, 29 June 1991.

<sup>48</sup> Article 189 of the Treaty of Rome is pertinent here. "A Directive shall be binding, as to the result to be achieved, upon each Member State to which it is addressed, but shall leave to the national authorities the choice of form and methods. A decision shall be binding in its entirety upon those to whom it is addressed. Recommendations and opinions shall have no binding force."

<sup>49</sup> The details of these documents are chronicled in chapter 4 of Christa Altenstetter, European Community-wide Efforts to Address AIDS. Discussion Paper Series. Mannheim Centre for European Social Research, 1992.

<sup>50</sup> Resolution of the Council and the Ministers for Health, meeting within the Council, of 11 November 1991 concerning fundamental health-policy choices (91 C (304/05) Official Journal of the European Communities No. C 304/5-6, 23 November 1991.

Regional Committee. Forty First Session, Lisbon, 10-14 September 1991. Report. World Health Organization. Regional Office for Europe. EUR/RC41/R7.

<sup>51</sup> Belmont European Policy Centre. The New Treaty on European



Union. Volume I: A Practical Guide. 19 December 1991.

<sup>52</sup> Michel Riconnier, "How the European Community went into public health. In Liam Fahey (ed.) Winning in the New Europe. New York: Prentice Hall (forthcoming).

<sup>53</sup> Belmont European Policy Centre, The New Treaty on European Union. Volume 1: A Practical Guide. 19 December 1991.

<sup>54</sup> Hans Stein, "Future Research Policies," in D. Schwefel, R. Leidl, J. Rovira, M.F. Drummond (Eds.), Economic Aspects of AIDS and HIV Infection. Springer Verlag: Berlin..., 1990, p. 344.

<sup>55</sup> Debates of the European Parliament, No. 3, 405/30-34, 13.5.1991. And Debates of the European Parliament No. 2-378/246-252, 25.5.1989. European Parliament Session Documents. 29 April 1991. A3-0108/91, p.3 and p. 18. The code on AIDS is printed as appendix to 'Europe against AIDS' in DOC. EN/RR/108855-PE 148.262/fin.

<sup>56</sup> Speaking on behalf of the Commission Madame Papandreou said: "The Commission can accept Amendments Nos. 1,3,4,9,10 and 12 in part, 21 and 29 in part, 32 and 36 in part, and 38,23, 26, 27 and 24 and 25 in part." Debates of the European Parliament. No. 3, 405/31, 13.5.91.

<sup>57</sup> Debates of the European Parliament No. 3-405/31, 13.5.91.

<sup>58</sup> As evidence the reader is referred to the Eurobarometer surveys on AIDS and the value of medical and health research. EUROBAROMETER Vol. I: Report No. 32. December 1989 and later issues.

<sup>59</sup> A total of 65 million ECU were allocated, spread over three years (1978-1981). 18 million ECU (27.5 % of the total) went to cancer research), 14.0 million ECU (21.5 %) for AIDS research. 9 million ECU (14 %) was allocated to age-related health problems and 5.5 million ECU (or 8.5 %) for research on the environment, health and lifestyles. Another 11.5 million ECU (17.5 %) was allocated to the development of medical technology and 7 million ECU (11 %) for health services research.

<sup>60</sup> COST is the acronym for the French equivalent of European Cooperation in the Field of Scientific and Technical Research. For an early history, see Jean-Luc Roland with a preface by Pierre Aigrain. A review of COST cooperation since its beginning. Commission of the European Communities. Luxembourg: 1989. EUR 11640, pp. 119-121.

<sup>61</sup> Agreements on cooperation with Sweden, Switzerland and Canada were formally established. Informal cooperation was at first practised with Austria, Finland, Norway, Portugal and Spain (prior to their entry to the Community) Yugoslavia, the United

States. Cooperation with Japan was intended. Formal agreements between the Community and these countries were signed in 1989.

A first initiative on "criteria for the choice and definition of volunteers for phase I and II in drug development" in January 1984 at the suggestion of France. A proposal for "quality assurance in nuclear medicine software" was submitted by Finland in May 1985. Denmark, France, Finland and Norway signed a Memorandum of Understanding on 24 February 1986, but it took another few years before these projects began to operate.

<sup>62</sup> AIDS Research within the Biomedical and Health Research Programme. Commission of the European Communities. Directorate-General Science, Research and Development, Directorate Biology - Medical Research Division. Published on the occasion of the VIIth International Conference on AIDS, Firenze, 16-21 June 1991. Reference: CEC-XII/F/6-AEB-MC-AIDS-1991.

<sup>63</sup> In September 1983, the Commission (DG XII) set up a group of experts to explore the AIDS problem, and in 1984-1986, it co-sponsored four seminars, in Copenhagen (immunology), in Paris (virology), in Bilthoven (epidemiology) and in Brussels (clinical research) in collaboration with WHO Regional Office for Europe and national institutions. In each scientific area stock-taking both of on-going research and major concerns in the member states was a first activity.

<sup>64</sup> P. Laredo, B. Kahane, J-B Meyer and D. Vinck The Research Networks Built UP Under the MHR4 Programme. Centre de Sociologie de l'Innovation de l'Ecole des Mines de Paris. XII/224/91-EN Suite 1. June 1991. Summary Report What do Concerted Action Projects Build and Produce?; File 1: Quantitative Approach. Results from the Mailed Questionnaire to all Participating Teams; File 2: Characterizing Concerted Action Projects and Their Dynamics. Results from the Interviews of 100 Project Leaders; File 3: The Managerial Dimensions of Concerted Action Projects. Problems Posed to MHR (Medical Health Research) Organization and Practices; File 4: The Dissemination of the Results of Concerted Action Projects. An Experimental Approach.

<sup>65</sup> 10/06/87 Ref.: Doc/87/1, p.2.

<sup>66</sup> Italics in original.

<sup>67</sup> Commission of the European Communities. Patents as Indicators of the Utility of European Community R&D Programmes. Fraunhofer Institute for Systems and Innovation Research (ISI) U. Schmoch, H. Grupp, U. Kuntze in cooperation with N.Kirsch and E. Strauss and Karatzas (Monitor/Spear coordinator). Luxembourg: June 1991, p. 29. Directorate-General Telecommunications, Information Industries and Innovation. Research evaluation EUR 13611.

<sup>68</sup> Commission of the European Communities Directorate-General XII for Science, Research and Development. Biomedical and Health

Research (BIOMED1) 1991-1994. Information package.

<sup>69</sup>Four Programme Management Groups (PMGs) exist. Each PMG is responsible for one of the four priority areas. Under the new BIOMED1 umbrella some restructuring has been implemented.

<sup>70</sup>MC/09.04.1990. (internal fact sheet) 1.2 AIDS.

<sup>71</sup>Document d'Information sur le Quatrième Programme de Recherche Médicale et Sanitaire 1987-1991 (MHR4). Décembre 1985. Koordinierung der Medizinischen und Gesundheitsforschung. Hier: Anzahl der beteiligten Forschungsteams: Dezember 1985.

<sup>72</sup>Commission of the European Communities. AIDS Research within the Biomedical and Health Research Programme, n.d., p.5.

<sup>73</sup>Ibid., p.8.

<sup>74</sup>See endnote 64.

<sup>75</sup>Commission of the European Communities. Evaluation of the Fourth Medical and Health Research Programme (1987-1991). Research Evaluation Report No. 44. Authros: A. Maynard, D. Frederickson, S. Garattini, H. Mäkela and M. Papadimitriou. July 1990 The second team was the Larédo, Kahane, Meyer and Vinck Team. For reference, see endnote 64.

**Table 1 Total number of reported AIDS cases for the EC countries**

	B Belgium	DK Denmark	D Germany	E Spain	F France	GR Greece
10/83	38	13	42	6	94	-
10/84	65	31	110	18	221	2
10/85	118	57	295	63	466	10
10/86	180	107	675	201	1.050	25
10/87	280	202	1.400	624	2.523	78
10/88	408	319	2.488	1.858	4.874	151
10/89	563	470	3.872	3.965	8.025	249
10/90	924	718	5.612	7.489	13.145	412
3/91	852	805	6.303	8.199	14.449	457
	IRL Ireland	I Italy	L Luxembourg	NL The Nether- lands	P Portugal	UK United Kingdom
10/83	-	3	-	12	-	24
10/84	-	10	-	26	-	88
10/85	-	92	-	83	-	225
10/86	-	367	5	180	40	512
10/87	25	1.104	8	370	81	1.067
10/88	64	2.556	13	605	173	1.794
10/89	108	4.663	20	983	306	2.649
10/90	179	8.227	33	1.531	573	4.098
3/91	193	9.053	37	1.683	663	4.454

Source: European Centre for the Epidemiological Monitoring of AIDS (WHO-EC Collaborating Centre in Paris) as reported in: Commission of the European Communities. AIDS RESEARCH Within the Biomedical and Health Research Programme. Published on the occasion of the VIIth International Conference on AIDS. Firenze, 16-21 June 1991. CEC-XII/F/6-AEB-MC-AIDS-1991. Figures for 1991 from WHO-BGA, as reprinted in Mannheimer Morgen 16./17/ November 1991, Nr. 266, S. 26.

Table 2 Distribution of Participating Laboratories,  
by country

Country	Disease Control & Prevention	Viro-Immunolog. research	Clinical research	EVA	Total
B	22	11	6	1	40
DK	15	11	2	-	28
D	25	24	4	3	56
E	21	4	49	1	75
F	20	30	22	2	74
GR	13	5	8	1	27
IRL	7	1	5	-	13
I	19	18	25	1	63
L	6	2	5	-	13
NL	26	13	8	1	48
P	15	6	14	-	35
UK	26	23	6	3	58
Total EC	215	148	154	13	530

Source: MC/09.04.1990 (internal document-fact sheet attached to Commission of the European Communities. AIDS research within the Biomedical and Health Research Programme Directorate General XII)

file:tablex

Table 3 Research teams on AIDS in 1985

	B	DK	D	E	F	GR	IRL	I	L	NL	P	UK
Aids	11	9	14	2	13	7	2	10	2	12	1	2

Source: Document d'Information sur le Quatrième Programme de Recherche Médicale et Sanitaire 1987-1991 (MHR4). Bruxelles, Novembre 1987. Basé sur le document COM(86)549 final/2, et incluant La Decision du Conseil du 17 Novembre 1987, p. 18.

Two teams from COST countries participated in Community research programs.

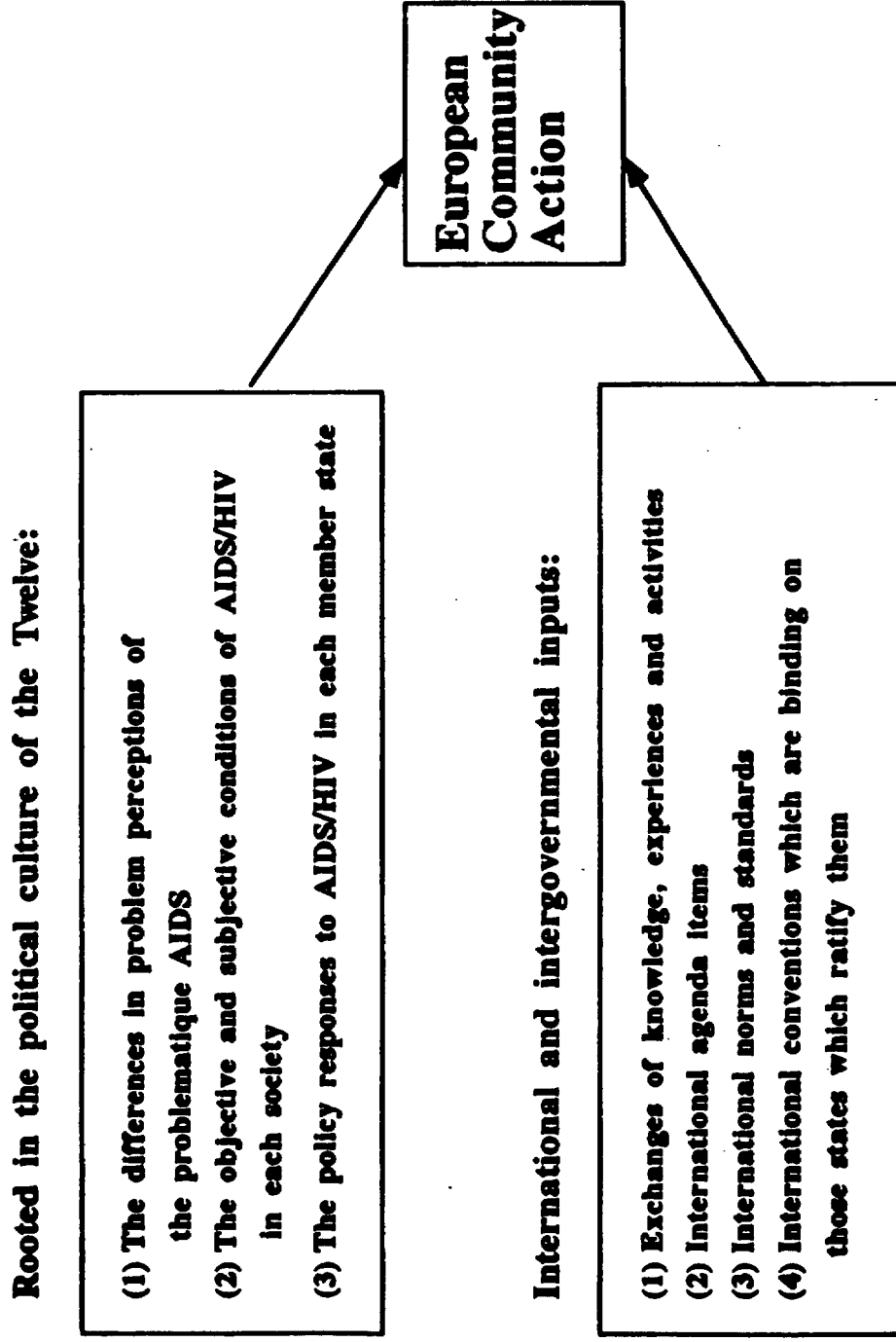
file:xxxx

Expected results	Answers by AIDS research teams		
	Percent of Mentions		
	Total	AIDS	% of 1st Priority
New scientific knowledge	24	28	52
New methods for research	40	42	20
Methods for prevention			
Diagnosis and therapy	24	20	23
Commercial results	12	10	5

Source: Larédo et al., 1991, p. 20.

Figure 1

# The Determinants of the European-Community-wide debate





file:figure2

Figure: 2 Trans-European and European Community-wide networks			
Characteristics	Macropolicy development networks	Research networks	Mixed governmental community-based networks
Members	One governmental representatives, one appointed scientist	EC staff, one senior health official, one appointed scientist	EC staff, national representatives, community-based representatives, Observers: WHO, Council of Europe, Others
Membership	Stable	Stable	Changeable
Number of members	Restricted	Restricted	Unrestricted
Meetings	Regular	Regular+irregular	Irregular
Composition	Homogenous	Homogeneous	Heterogeneous
Role definition	Task-defined	Task-defined	Task-defined for office-holders; interest-defined for community-based groups
Institutional affiliation	Formal	(a) Formal (official) (b) Disciplinary scientist)	Formal and informal but largely problem-oriented
Networks	Permanent	Permanent	Non-permanent
Networking	No task description but possible	No task description but possible	Strong likelihood
Objectives	Defined by the international agenda and by bargaining and negotiation between EC officials and national representatives	Defined by theory and scientific methods	Defined by AIDS-specific problems and issues

file:annex1

Annex 1		<u>List of ratifications</u>					ILO, No.111
State/ treaty	ICCPR	ICESC	ECHR	ECHR P4	ESC		
Belgium	x	x	x	x		x	
Denmark	x	x	x	x	x	x	
France	x	x	x	x	x	x	
Germany (old FRG)	x	x	x	x	x	x	
Greece		x	x		x	x	
Ireland			x	x	x		
Italy	x	x	x	x	x	x	
Luxembourg	x	x	x	x	x	x	
The Netherlands	x	x	x	x	x	x	
Portugal	x	x	x	x		x	
Spain	x	x	x		x	x	
United Kingdom	x	x	x		x		

The data is based on the following sources:

International Labour Conference, List of Ratifications of Conventions (as at 31 December 1989), Report III (part 5), Geneva 1990;

Human Rights. Status of International Instruments, as at 1 September 1989, (ST/HR/5), United Nations, Geneva, 1989;

Chart of Signatures and Ratifications, Council of Europe with regard to ESC as at 4 January 1990 and with regard to ECHR and ECHR P4 as at 14 November 1989.

For further information with regard to signatures and reservations consult these above mentioned documents.

Source: Commission of the European Communities. AIDS and Human Rights, 1991, p. 70.

<u>Ratifications of United Nations Convention</u>			
	1961 Convention	1971 Convention	1988 Convention
Germany	03-12-1973	02-12-1977	Ratification pending
Belgium	17-10-1969	Not ratified	Ratification pending
Denmark	15-09-1964	18-04-1976	Ratification pending
Spain	01-03-1966	20-07-1973	13-06-1990
France	16-02-1969	28-01-1976	Ratification pending
Greece	06-06-1972	10-02-1977	Ratification pending
Ireland	16-12-1980	Not ratified	Ratification pending
Italy	15-04-1975	27-11-1961	Ratification pending
Luxembourg	27-10-1972	Not ratified	Ratification pending
The Netherlands	16-07-1965	Not ratified	Ratification pending
Portugal	30-12-1971	20-04-1979	Ratification pending
United Kingdom	02-09-1964	24-03-1966	Ratification pending

Source: B. Leroy, The Community of Twelve and drug demand. Medicine and Health. Commission of the European Communities. Directorate-General Employment, Industrial Relations and Social Affairs. Final Report. 1991, p. 57. EUR 13447.

file:annex2

---

Annex2	<u>Legislation on drug use</u>
Germany	Drug use not a criminal offence
Belgium	Only collective use a criminal offence
Denmark	Drug use not a criminal offence
Spain	Drug use not a criminal offence
France	Penalties for use (flexibly applied in practice)
Greece	No direct repression of use
Ireland	Drug use not a criminal offence (except opium)
Italy	Use prohibited but not penalised as such
Luxembourg	Penalties for use
Netherlands	Drugs use not a criminal offence
Portugal	Drug use not a criminal offence
United Kingdom	Drug use not a criminal offence (except opium)

---

Source: B. Leroy, The Community of Twelve and drug demand. Medicine and Health Commission of the European Communities. Directorate-General Employment, Industrial Relations and Social Affairs. Final Report. 1991, p.(?) EUR 13447.

---

	<u>Comparison of legislation on acquisition, possession, and use</u>		
	Acquisition	Possession	Use
Germany	as for trafficking	specific offence	not an offence
Belgium	as for trafficking	as for trafficking	punishable offence (1)
Denmark	as for trafficking	as for trafficking	not an offence
Spain	not an offence	not an offence (2)	not an offence
France	as for trafficking	as for trafficking	punishable offence
Greece (3)	specific offence	as for trafficking	not an offence
Ireland	not an offence	specific offence	not an offence (7)
Italy (4)	specific offence	specific offence	not an offence
Luxembourg	specific offence	specific offence	punishable offence
The Netherlands (5)	not an offence	specific offence	not an offence
Portugal	specific offence	specific offence	not an offence
United Kingdom (6)	not an offence	specific offence	not an offence (7)

---

(1) Collective only.

(2) Permissible quantity at the discretion of the magistrate.

(3) Except where the user is an addict.

(4) Up to the maximum quantity corresponding to daily dose.

(5) In theory only.

(6) According to product category.

(7) Except opium (theoretically a punishable offence).

Source: ibid.

