Institutionalising New Policies in the Health Sector.
The Challenge of the AIDS Epidemic

Monika Steffen

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Steffen: Institutionalising New Policies in the Health Sector. The Challenge of the AIDS Epidemic

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This Working Paper has been written in the context of the 1998-1999 European Forum programme on Recasting the European Welfare State: Options, Constraints, Actors, directed by Professors Maurizio Ferrera (Universities of Pavia and Bocconi, Milano) and Martin Rhodes (Robert Schuman Centre).

Adopting a broad, long-term and comparative perspective, the Forum will aim to:

- · scrutinize the complex web of social, economic and political challenges to contemporary European welfare states;
- identify the various options for, and constraints on institutional reform;
- · discuss the role of the various actors in promoting or hindering this reform at the national, sub-national and supra-national level;
- · and, more generally, outline the broad trajectories and scenarios of change.

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### Abstract\*

Welfare state policies in the health sector centred on medical care and cost containment. The AIDS epidemic challenged the central position of the medical model and introduced new public policies at the periphery of the welfare state, in the field of prevention and public health management.

The article compares the evolution of national policy responses in several European countries. Each of them combined the general principles of the fight against the epidemic, conceived in international forums and based on educational strategies aiming at behavoural changes, with path dependencies at various levels, especially the institutional structures of health systems and the public/private borderline. Both determine the potential field for public health policies and condition the capacity of implementation in each national context. The importance of "private life" issues in the epidemic introduced cultural phenomena into official health policies, and provided an occasion to observe the interaction of cultural and institutional factors in health management. The general principals of AIDS policies were revised as implementation progressed, shifting from an initial focus on the protection of anonymity and privacy towards the improvement of public health management and the reinforcement of its institutional support.

The epidemic posed a threefold challenge for European health systems: co-ordination across different policy fields, the extension of educational strategies to socially marginalised groups, and beneficiary participation which introduced non medical dimensions as well as pressure for the legal protection of patients and the control of research developments. All called into question the corporatist mode of health management, the institutional fragmentation of health policy networks and the dominant influence of the medical profession over health issues. In all these respects, AIDS policies have contributed to the general reform trends in European health systems. Future perspectives indicate that the responsibility of public authorities will not diminuish but grow with therapeutic progress.

<sup>\*</sup> This text is a revised version of a paper presented at the European Forum Conference on "Beyond the Health Care State: Institutional Innovations and New Priorities in Access, Coverage and Provision of Health Services", 26-27 February 1999, at the European University Institute. The conference was organised by Maurizio Ferrera (University of Pavia), Ana Guillen (University of Oviedo) and August Oesterle (Vienna University of Economics and Business Administration) in collaboration with DG V.

Policy studies in the health sector have generally centred on the relationships between the medical profession, the financing institutions and the state authorities. International comparison developed as growing health expenditure met with limited economic growth and as European welfare states were confronted with the common problem of cost containment. The cost problem provided the main intellectual framework for comparative studies of health systems and policies. This article focuses on the dynamics of change at the periphery of the medical systems, in the field of public health and risk management. It analyses how European health systems reacted to the unexpected challenges of the AIDS epidemic which constituted one of the most important public health issues of this century.

The case is interesting in many respects and significant for future developments in European health systems. It calls into question the central role of the medical model and economic factors. Globalisation trends in this case are due to international dimensions in risk transmission and to international movements of solidarity. Control and management of the epidemic call for reinforced public intervention and state responsibility. New financial ressources are needed for research, care, social support, prevention and public health administration. The growing number of people living with HIV-infection calls for comprehensive coverage linking acute medical care and service provision for the chronically ill and physically handicapped. The connection of the risk with sexuality, marginal behaviour and blood donation links public health policies with social and cultural phenomena, and thus introduces cultural dimensions into health policy analysis. The AIDS case facilitates the observation of how different health systems respond to a similar problem, and wether and how they learn to adapt their institutional organisation to new norms, constraints and priorities. The comparative analysis contributes to the understanding of health management in Europe.

This article first analyses the challenges of the epidemic to European health systems and their responses to the new problem. It then examines the two central difficulties health policy makers had to face, the public-private borderline on the one hand, and the introduction of public health dimensions into previous policies on the other. The last chapter shows how AIDS born innovations are linked with the general reform tendencies in European health systems, and how the public health policies connect with cost containment strategies.

### THE CHALLENGE OF AIDS

The unexpected arrival of a new public health risk confronted health systems with an emergency, in a context where no expert group existed which could

have spoken on the subject with the required legitimacy. The way risk-alarm was channelled through the different health systems provides an insight into their functioning and priorities. It indicates the specific responses to public health issues.

The first European AIDS case was discovered in Paris in June 1981, by a hospital doctor who diagnosed the symptoms in a patient just after he had read the very first article published by the US Center for Disease Control. He set up an informal group of doctors and researchers, in order to find more patients, initiate research and ascertain whether the first patients were isolated cases or the indicator of an epidemic. The initial expert group remained informal, without institutional support apart from a modest link with the General Department of Health, the weakest part of the Health Ministry. In Germany, a nurse warned the gay organisations and the Health Department of the City of Berlin, to obtain social and psychological support for the first patients. The City's health authorities informed the federal authorities who invited age delegation from the United States in order to receive first hand information. Once convinced of the risk, they initiated a consultation structure between the health authorities, medical specialists and representatives of the gay organisations, with the aim of establishing a diagnosis on the German situation and launch prevention strategies among homosexual men. In Britain, a similar bottom-up process channelled the information from London urinary clinics receiving the first patients up to the top level of the National Health Service (NHS), whose executives informed the Government and the medical authorities. After a visit to the United States, the Secretary of State for Health confirmed the need for rapid action.

In Britain, Germany, Switzerland and the Northern European countries, institutional channels favoured a relatively rapid awareness of the public health risk and the governement took up the problem (Day and Klein, 1989; Kirp and Bayer, 1992; Steffen, 1996). In France, scientific interests prevailed over risk awareness. Although the virus was isolated in March 1983 by researchers from the Institute Pasteur in Paris, medical authorities and the Government only reacted when the same discovery was announced by an American team (Seytre, 1993). AIDS entered the political agenda in France when national interests in the fields of science and industry were threatened. In Southern Europe, especially in Spain, Portugal and Greece, AIDS received no notable public attention until the early nineties, when the many deaths of drug addicts could no longer be ignored.

The AIDS challenge developed simultaneously in three directions: research, care and prevention. Scientific investment aimed at a vaccine and curative treatment. In the main disciplines concerned with AIDS, notably immunology, fundamental research was reoriented towards HIV-relevant

questions. Previously neglected fields were developed, notably retro-virology. Infectiology became a noble discipline again. Two particularly under-developed fields were scientifically structured: public health research in the field of sexuality, and social science research in the field of coping with illness. Clinical research reinforced collaboration between hospitals, public research agencies and the private pharmaceutical industry, on national as well as international levels. The AIDS challenge introduced multi-disciplinary co-ordination into health related research. In France, all public AIDS research was placed under the authority of the ANRS (Agence Française de Recherche sur le Sida), created in 1988. Recently, the agency's activities have been widened to cover other transmittable diseases with priority for hepatitis C. The extension of the AIDS model to infectious and sexually transmittable disease has became an international world wide trend.

For the provision of medical care, AIDS patients and doctors were backed by the welfare state. In European health systems, access to adequate care was granted by the compulsory health insurance. The major difficulty was to coordinate hospital care, ambulatory care and social services. Elsewhere, AIDS represents an acute problem of care provision which depends either on exceptional procedures, like the mobilisation of the AIDS organisations in the United States, or on international assistance and funding, as illustrated by the Eastern European countries (Steffen, 1999b) and the Brazilian anti-AIDS plan which was carried out under the auspices of the World Bank.

### **Beyond the Scope of Medical Treatment**

In European welfare states, AIDS management differed mainly in the ways prevention policies were conceived and implemented. The key problem was indeed the absence of a curative treatment. After the thirty glorious years of antibiotic use, a transmittable disease with fatal consequences was spreading without any medication being available to stop it. The limits of medical art had to be made up for by preventive measures based on social intervention strategies, aiming at long term behavioural changes. This in turn led to political controversy. Public policies were introduced into the field of sexuality and health goals into drug policies. Information systems had to be set up to monitor the epidemic, for epidemiological purposes and hospital planning. The weakness of expert capacity in public health became evident as did the necessity to construct efficient statistical tools. Controversy arose over the type of declaration systems needed and over the guarantees of confidentiality. The AIDS case revealed the potential extent of controversy over health intervention when based on non-medical tools, in sharp contrast to the consensus on the extension of medical services.

The second problem concerned the capacity of co-ordination, at governmental as well as professional levels. Care and prevention strategies had to be co-ordinated over a wide range of policy sectors with no previous links: the prevention of sexually transmittable diseases (STD), health oriented sexual education, care for drug addicts and prisoners, specific counselling and medical monitoring for HIV-infected mothers, the reinforcement of safety standards in hospitals, blood and organ donation systems and parts of the pharmaceutical industry. Only a strong commitment to public health and a well organised health administration could guide such comprehensive policies which contrasted with the individual treatment patterns of medical art and the fragmented structure of services and policy networks in most countries.

The third strategic problem concerned public health management. No reforms had modernised this field, which had been neglected during the extensive development of medical services. Belief in victory over transmittable disease had driven public health away from medical and political attention. The traditional intervention models were based on legislation on infectious and sexually transmittable disease, including case reporting, compulsory treatments contact tracing, and in certain cases isolation of disease carriers. These methods appeared unsuitable for AIDS where the active collaboration of the people as risk was needed. When the antibody test became available (1985), public health specialists as well as gay militants argued that the application of traditional procedures would lead to breaches of civil rights and private life. It was argued that AIDS sufferers would avoid attending medical services to escape social risks, especially as no effective treatment could be offered to them. These arguments subordinating preventive approaches to their curative interest were particularly evident in France. The central question concerned the interest and dangers of systematic screening in particular risk groups. The "exceptional AIDS coalition" between public health experts, clinicians and gay activists gave the answer to that question (Bayer, 1991). It ensured that AIDS was taken out of the field of public health regulations and replaced by a policy of voluntary testing, voluntary partner information and medical confidentiality. Lack of therapeutic benefits pleaded for subtle intervention strategies based on education and participation.

### The Twofold Epidemic

The epidemic went through two distinct phases. Initially, it was perceived as an interesting medical and social issue. AIDS appeared as an illness afflicting an international elite of eccentric people. The respect for the individual, privacy and human rights occupied the front line of AIDS mobilisation. The picture changed as the epidemic spread in underprivileged social classes, drug addicts and ethnic minorities less used to the respect of their individual rights. AIDS became a traditional public health issue linked with poverty, social exclusion,

migration, prostitution and sex tourism. By the end of the eighties, the epidemic had turned out to be an extremely serious public health problem.

Health authorities were faced with the challenge of providing comprehensive care and prevention strategies to marginalised populations. The principles of AIDS management which were elaborated during the "exceptionalist" period and conceived for middle class gay communities, had to be implemented in social environments where conditions were very different. The new clients did not have an equal capacity of collaborating with public authorities and promoting education. The professionals were confronted with the challenge of bridging the social gap and generalising the new public health approach. New modes of intervention had to be developed, based on proximity strategies, long term follow-up and free provision of services and equipment such as medicine, condoms, syringes and sterilising equipment. The practical means of prevention and care were in fact more similar to social work than to the medical model.

The presence of AIDS activists, especially the ACT-UP groups, contributed to maintaining political pressure. Their impact, however, proved more efficient in obtaining medical care than in the field of prevention. This was illustrated when the new multi-therapies appeared in the mid-nineties and allowed mortality rates to be curbed for the first time. In several countries, health authorities intended to limit access during the first year, arguing that a period of observation was needed in respect to long term consequences. These arguments were swept away by a storm of protest and, finally, free access was granted for all HIV carriers who could support the new treatment. Cost considerations were thrust aside with the argument that the new medication economised in hospital expenditure.

The issue reappeared at international level as a North/South problem. In 1997, controversy arose between the international agencies responsible for economic and social development. They were divided over the use of international funding either for medical care or primary prevention and economic development. A project of "international therapeutic solidarity", initiated by European activists and the French government with support from the European Union aimed at free provision of the new medication to the AIDS patients in the Third World<sup>2</sup>. The project remained of limited impact, since it depended on the negotiations over price policies with the international pharmaceutical industry, funding policies with the international development agencies and scientific tests to evaluate the most efficient strategies for targeting specific populations. The AIDS epidemic confronted national as well as international health policy systems with the challenge of evaluating the respective impact of curative and preventive intervention.

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### NATIONAL POLICY RESPONSES

European health systems faced the new challenges with different inputs and outcomes. Two decades after the outbreak of the epidemic, HIV occurrence is up to six times higher in France than in Great Britain. France, which had the greatest number of cases in the European Union for many years, was finally overtaken by the Southern European countries struck with massive HIV transmission related to intravenous drug use (IDU). The latter had greater difficulty in responding to the challenge for several reasons inside and outside the health systems. One specific reason was related to the mismatch between the dominant prevention model, catering for homosexual males, and the IDU-profile of the Mediterranean epidemic. The following tables show the striking differences in policy outcomes, between countries which have a comparable level of economic and social development.

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Table 1. National profiles. Origins of virus transmission Registered AIDS cases, adults, totalled at 31.12.1998

	Homo and Bi- sexual	IDU	Homo. and IDU	Hetero- sexual	Blood transf. and products	Other or unknown
France	45.1	23.6	1.3	19.9	4.7	5.4
Italy	13.9	61.8	2.0	12.3	1.6	8.4
Germany	65.5	14.2	0.9	8.5	4.5	6.4
Great-Britain	68.4	6.5	1.8	17.4	4.8	1.1
Spain	14.1	65.1	1.6	12.4	2.0	4.8

Source: WHO-EC Collaborating Centre on AIDS, Paris.

Table 2. Extension of the epidemic

	Spain	France	Italy	Germany	G.B.
Reported AIDS cases, totalled at 31.12.1998 and adjusted for declaration delays	52,216	48,676	42,760	17,836	15,675
Estimation of HIV-infected persons, alive, 31.12.1995* - total number - per million inhabitants	not known	120,000 2,030	95,000 1,650	42-52,000 520-640	20,000 330

Source: WHO-EC Collaborating Centre on AIDS, Paris.

Table 3 . Incidence rates of declared AIDS cases per million inhabitants, by year of diagnosis, adjusted for reporting delays

3 May 1	1992	1995	1998
Sweden	14.7	21.9	6.2
Germany	22.5	20.8	10.6
Great Britain	27.2	29.9	13,6
France	88.2	88.2	30.0
Italy .	74.6	99.0	40.9
Spain	125.5	173.2	93.3

Source: WHO-EC Collaborating Centre on AIDS, Paris.

<sup>\*</sup>Figures have deliberately not been actualised. Until 1995, the epidemiological data reflected the history of the epidemic and the policy responses to it. Since then, the new multi-therapies introduced a new factor determined by access to the new treatment and its strict observation by the beneficiaries.

Unequal success or failure in fighting the epidemic raises general questions concerning the way national health systems respond to identical issues, and the effectiveness of international policy solutions when implemented in different national contexts. What common features in Sweden, Great-Britain and Germany explain why they have been more successful in fighting the epidemic and what in Spain, Italy and France explains their failure? Why was the French scientific advance not translated into corresponding policy achievements, with the help of the well developed French public administration and strong executive? The factors and classifications usually referred to in welfare state literature and health policy analysis proved of little relevance to the question. The public or private status of management structures and care delivery, which bring together France and Germany for their public-private mix on the one hand, Italy, Great-Britain and Sweden for their public systems on the other, had no influence. Similar degrees of centralisation or decentralisation even produced opposite effects. In Great Britain, the institutional structures of the National Health Service (NHS) provided favourable conditions for rapid public intervention and co-ordination. In France, on the contrary, the high level of centralisation made necessary changes extremely difficult due to lack of consensus between the national policy makers. In 1987, AIDS policies were placed under the exclusive control of the central state government, as the policies concerning drug addiction had been in 1970. The legally prescribed centralisation hindered local innovation. In Germany, the regionalisation of health policies and the decentralisation of implementation structures favoured innovation and experimentation at the level of the Länder and municipalities. This in turn helped to overcome resistance from vested interests at the national level. In Italy on the contrary, a comparative degree of decentralisation led to lack of co-ordination, unequal implementation and conflict between the different levels of health administration.

A major difference between the countries was the attitude of the medical profession towards the public health risk. Everywhere, doctors played an important part in health policy. Their most central position in France, however, is exceptional in the international comparison (Jobert and Steffen, 1994). The lack of interest of the French medical elite for the public health problem had crucial consequences. It legitimised politicians and intellectuals in their strategy of risk minimisation and enabled them to politicise the issue.

In Italy, on the contrary, a group of medical professors, specialists in infectious disease, lobbied the government and obtained the creation of the National AIDS Commission which conceived the Italian public policy and the national anti-AIDS plan, voted as a law in 1990. The case illustrated the important role university professors play in the modernisation of Italian public policies (Regonini and Giuliani, 1994). Implementation however proved conflict laden and remained weak. The health policy agencies opposed the

alliance at the central level between the administration, the government and the interested clinicians. The regions brought the issue before the constitutional law court. Private organisations, which played an important role in caring for drug addicts, contested the resource allocation, up to 85% reserved for public hospitals, and the little attention given to the private sector and the psychosocial services it operated. In 1993, most of the public funding had not reached its destination (Calvaruso, 1993). It had been diverted to other uses, especially to pharmaceutical consumption. Such "redistribution", including clientelist politics and corruption<sup>3</sup>, form part of the still "immature welfare states of Southern Europe" (Ferrera, 1996). The Italian case showed how established policy networks resisted AIDS exceptionalism and urgency.

In Great-Britain, public health specialists pushed the reluctant Thatcher Government into action, with the threat that the epidemic would absorb the entire health budget if it was not stopped in time (Street and Weale, 1992). In the British system, the institutional structure of the NHS and the political level of decision making are linked by the position of the "Chief Medical Officer", an independent person whose role is to advise the Minister of Health. During the early AIDS years, the position was held by an epidemiologist, whilst practical measures were elaborated under the leadership of a clinical specialist in sexually transmittable disease. The combined approach of institutional and medical management of public health resulted in an efficient model for AIDS prevention. Great Britain succeeded in confining the disease within the initial risk population.

In Germany, politicians made the strategic choices. Like all regional ministries in the Federal Republic, the health ministers have the "Permanent Conference of Health Ministers" as a standing working structure. It brings together the ministers and their close collaborators from all Länder, from the right as well as from the left wing parties according to the majorities in regional parliaments. This forum enables them to discuss priorities and co-ordinate policies. The health ministers declared AIDS a public health problem requiring the means of a national public policy. They drew up the compromises on controversial subjects and mobilised the public health agencies under their authority. Reluctant local or regional administrations were officially encouraged to implement the new prevention policies.

The institutionalisation of AIDS policies clearly followed national patterns. The high level of initiative of the British Department of Health and the NHS officials corresponded to previous reforms in Britain (Hayward and Klein, 1994). The capacity of the German politicians to reform health policies and the importance of the regional level in this process have been documented in historical analyses as well as in cost containment (Jobert and Steffen, 1994). Public health was the poor relation of the health sector in all countries. In

Germany and Great-Britain, however, institutional resources and processes compensated for the internal medical hierarchy. France and Italy lacked such adequate institutional support. Furthermore, in Britain and Germany, AIDS policies benefited from an explicit political consensus. The new public health policies were legitimised by Parliament, they were evaluated and re-examined by parliamentary commissions, from 1986 to 1990. In Italy, the role of parliament was limited to voting a law, which was poorly implemented, and the French parliament was deliberately excluded from the issue.

### PUBLIC HEALTH AND UNCERTAIN BORDERLINES

AIDS prevention confronted health systems with conflict resolution involving a larger polity than the traditional partners of the medical care system. The use of the antibody test, the public promotion of condoms, the provision of clean injection equipment and methadone for IDU addicts, blood donor screening and protection of health workers from the risk of infection, all called into question existing legislation, ethical beliefs and professional paradigms. Unlike cost control policies which confronted identified parties defending precise interests, the public health strategies provoked conflicts with moving affinities and multiple environments.

The Antibody Test

Two types of arguments initiated demands of systematic screening, in specific situations: medico-professional arguments populations or epidemiological surveillance and protecting health professionals and patients from the risk of contamination during hospitalisation on the one hand and, on the other, socio-political arguments aimed at avoiding contact with infected people in normal life situations like school attendance, sports activities or sexual relationships, and in particular circumstances such as accidents and physical aggression involving drug addicts or prison inmates. The screening issue was central because of interests outside the health sphere. Test results could be used by insurance companies, employers or housing owners. The potential social risks excluded compulsory screening from the range of policy tools. The professional risk was therefore met by educational strategies based on the respect of the general rules of hygiene, the reinforcement of security norms and controls and the provision of specific training programmes as well as single-use equipment.

The international principal of voluntary testing was adopted by all European countries, although not always strictly observed. Sweden made an exception by updating its traditional methods of public health surveillance and applying them to AIDS. In fact, the controversy over screening led to a compromise. HIV-antibody tests were "systematically proposed" in a growing number of situations such as pregnancy, pre-marriage medical examinations, artificial inseminations, drug abuse and medical consultations. This policy combined the protection of marginal groups from compulsory screening with the possibility of testing growing parts of the population.

The screening controversy illustrated the sensitivity of the respective health systems to general political debates and their ability to impose public health references. In Great Britain, the screening debate remained limited to epidemiologists, divided over the usefulness of systematic testing as a scientific means to monitor the epidemic. In Italy, AIDS intervention started with the systematic screening of hospital patients, drug addicts and prison inmates. The internationally proscribed method provided the Italian authorities with a precise picture of the domestic epidemic related to IDU, and very little to homosexuality. When the National AIDS Commission was operational, its medical experts took up the screening issue and set up a policy of voluntary testing for the health professionals and the Ministry of Justice, which was responsible for prison administration. Outside the commission, the issue raised little public debate. Social and political bases for AIDS mobilisation were lacking in Italian society (Moss, 1990). Even the controversy around the haemophiliac issue remained limited.

In Germany, open conflict arose inside the conservative alliance in power at federal government level. The Bavarian branch of the Christian Democrats (Christliche Soziale Union, CSU) demonstrated its independence by taking advantage of the regional authority over health policies. Bavaria applied the existing regulations on epidemics and transmittable disease to AIDS, although the option had been overruled by the Federal Health Minister and the Health Ministers' Conference. Candidates for public appointment, foreigners wanting to settle in Bavaria and prostitutes were HIV-tested. Homosexual men however were not concerned since the legal rules did not include such a category. The issue entailed passionate debates between specialists on constitutional and administrative law as well as court procedures to clarify the institutional authority. The conflict subsided after the 1986 general election which renewed the conservative alliance in the Federal Parliament. The newly elected parliament engaged in an active AIDS policy with a four-year emergency programme (1986-90) voted by all parties including the CSU, based on the educational approach in collaboration with the AIDS organisations.

In France also, the epidemic served electoral politics. The AIDS years coincided with the unprecedented "cohabitation" between a President of the Republic and a parliamentary majority from opposed parties. Electoral competition between the Right and the Left intensified and focused on the potential voters of the extreme right wing National Front. Decisions concerning

AIDS prevention were systematically delayed before each new election. The laws forbidding condom publicity and the sale of syringes were only revised in 1987 and 1988. When the National Front started an anti-AIDS crusade in 1986-87 demanding systematic screening of large parts of the population and quarantine for HIV carriers, protest arose from all political parties, the intellectuals and the press. The common political response was "the defence of freedom" and "the fight against discrimination". the National Front finally withdrew from the unfruitful subject but the arguments shaped the subsequent public AIDS campaigns. When the French Agency for AIDS Prevention was finally set up in 1989, messages focused on "solidarity" with the victims of the epidemic and on a common risk concerning "everyone". The public health risk was subordinated to political values. The AIDS case provided the ground on which the Republican principle of egalitarian treatment which excluded references to specific groups was demonstrated.

### **Private Life and Public Policy**

The initial AIDS policy promoters stressed individual behaviour as a risk factor and the fact that the disease was not infectious like tuberculosis. The behavioural model, which normally refers to pathologies linked with smoking and alcohol consumption, was forwarded in support of the educational approach to exclude AIDS from the application of existing public health laws. In fact, AIDS corresponds with the model of sexually transmittable disease (STD). Sexuality belongs to private life but it has public consequences (Bayer, 1989). This private-public junction is common to most public health issues.

The STD model allows the main conditions of successful public health management to be isolated. Prevention depends on the capacity to develop public policies in an intermediate sphere across this public/private junction. In countries where the political culture imposes a clear borderline between what is considered as private and public, as in France, prevention policies are likely to meet with political resistance. Implementation is favoured in a context where sexuality is no longer regarded as a moral or societal issue, but as a responsibility for all educational authorities. Available institutional and professional authority can then be mobilised and oriented towards the new problem. Health oriented sex education in schools illustrates the case. Previous policies in the field of sexuality and contraception shape the range of policy choices and their social acceptability. Finally, since beneficiary participation constitutes a major element in AIDS prevention, the degree of organisation and the attitudes of gay communities towards health issues condition the policy impact.

In Italy, state intervention in the field of sexuality was delayed because the Catholic Church considered the subject to be part of the Christian marriage and family, a subject considered to belong under its normative authority. Condom promotion became a public policy only after the health minister changed from a Christian Democrat to a member of the Liberal Party in 1989, and under the pressure of the medical experts from the National AIDS Commission. However, public promotion of condom use and sex education in schools had to compromise with moral views if they were to be politically and socially acceptable. Public campaigns therefore insisted on "normal family life" (Cattacin and Panchaud, 1997).

France had a long tradition of legal prohibition on condom production, sale and in some periods even on use (Vidal, 1991). From the mid 1960s onwards, several laws were passed favouring sexual liberty. Legislation passed "from a post-Vichy regime to a post-68 regime", towards a model of "sexuality without norms" (Mossuz-Lavau, 1991). Contraception was introduced after a battle with left wing women's organisations which imposed general access to oral contraception and abortion, free of charge (Veil Act, 1975). As a result of the political compromise with the conservatives, publicity for all contraceptive means, including condoms, was legally forbidden. The final stage in the sexual liberation process was the abolition of laws on homosexuality in the early eighties, coinciding with the outbreak of AIDS. The still badly organised gay community considered the risk alarm to be propaganda against their recent freedom. As a consequence, the first AIDS organisation, operational since 1985, was accepted only reluctantly among French gays. The post-1968 inheritance, combined with the weak position of public health experts provided uncertain grounds for AIDS prevention.

Britain and Germany did not need to overcome such historical handicaps. Britain could even rely on historical achievements. The campaigns against venereal disease at the end of War II provided a precedent of public condom promotion (Porter, 1988). Furthermore, the gay communities in the two countries were already well organised and even accustomed to negotiations with public health agencies, because of earlier initiatives aiming at improving care and prevention of STD (hepatitis B).

The private/public challenge resulted in different policy styles. In Great Britain and Germany advertisements for condom use referred directly to AIDS, precise risk situations and the personal responsibility of the partners. This was illustrated by the British slogans aiming at encouraging people to "keep to one partner or at least to use a condom" (Street and Weale, 1992, p. 204) and "You know the risk, the decision is yours", and in the German slogans: "Responsibility is part of it", "Our fidelity protects the two of us" and "AIDS does not fall on you, you catch it yourself". French public campaigns, on the contrary, spelled out little as to the practical behaviour in concrete situations and carefully separated AIDS from sexuality. Condom campaigns were only

launched on a large scale from 1989 onwards, by the French Agency for AIDS Prevention. Messages promoted a joyful image of free sex with condoms. These, it was advertised, "preserve(d) from all, even from being ridiculous", and "wish(ed) everyone a happy holiday". The link with AIDS, illness and the fatal risk was deliberately not referred to, in order not to frighten the public and drive infected people into isolation. AIDS and HIV were only addressed in connection with solidarity and love, illustrated by advertisements from 1991 where young smiling girls and boys asked in a quiet, assured manner "If I am HIV-positive, would you dance with me?".

The Agency was criticised for inefficiency in the Montagnier report (1993), and closed down in 1995. Its short and conflict laden existence illustrated the difficulties in the French context, of promoting prevention strategies across the public/private borderline. The Agency had seven directors in six years and suffered from continuous conflict with the private AIDS associations, over authority and control issues and over the content of prevention messages and their destination, to the general public or targeted groups. When AIDS prevention was transferred to the General Department of Health, the conflict over the models of STD prevention continued inside the gay associations, which were divided over their relation with the state and their position in society. Finally, in 1998, fifteen years after the epidemic was identified, the specific AIDS unit in the General Department of Health was transformed into a new larger division in charge of all transmittable disease. This transition illustrates the shift from ideological controversy to technical risk management. Adequate institutional support is now being provided by the new public health agencies and surveilling structures which were recently set up at the national level<sup>5</sup>.

### **Beneficiary Participation**

The most exceptional element in AIDS management, compared to cost containment and other health policy issues, was the active implication of the beneficiaries. The wide range of initiatives, goals and country specific situations have in common the introduction of non-medical dimensions.

Participation was initiated by gay groups in order to meet the urgency and new needs in their own ranks. Experiments centred on group specific prevention campaigns aiming at new patterns of sexual behaviour (safer sex), psychological and social support for the ill and dying, and interest representation. The latter covered a wide spectrum of goals ranging from fund raising and improvement of medical care to ensuring access to lodgings, insurance coverage, employment and the provision of legal services to defend victims of discrimination. Haemophiliac associations focused on financial compensation for those infected by medically transmitted HIV. Attempts to extend compensation to all those infected during transfusion, notably hepatitis B and C which concerned not only haemophiliacs but many former patients, were rejected because of the financial burden. Instead, safety standards in the blood and plasma industry as well as in hospitals became the centre of interest.

The distinct channels of interest representation converged towards common goals. Pressure for resource allocation to AIDS research, care, prevention and compensation schemes constituted the traditional part of it. The innovative parts were the right to "normal life" for the chronically ill, comprehensive medical and social services and the legal protection of patients. The "normal life" issue was the main raison for the refusal of traditional public health methods. It also explained why haemophiliacs and their doctors had refused to renounce the prophylactic treatment with potentially dangerous clotting concentrates. The normal life argument was put forward to press for coordinated care structures allowing AIDS patients to stay at home and if possible continue to work. In the field of psychological and social support, the associations acted simultaneously as voluntary structures fostering self-help and as private providers for public services. Private-public collaboration corresponded to more general reform agendas in the health sector, especially in the British NHS (Berridge, 1996), aiming at reducing the role of the public sector in the provision of services. Concerning legal protection, gay activists aimed at non-medical issues whilst haemophiliacs focused directly on the safety of medical treatment. Arguments that public authorities were responsible for risk management, that doctors were responsible for their prescriptions and that patients had to be clearly informed about potential risks were the bases for compensation claims. In France, where the responsibility regime for patients receiving blood or other elements of human origin was unclear and weak, the legal procedures around the "contaminated blood scandal" redefined and reinforced the medical and public responsibility for patients.

The long term strategies of haemophiliacs and pressure groups concerned with AIDS are now moving in a common direction aiming at scientific developments and control over relevant parts of the pharmaceutical industry. Medical experts, themselves belonging to the gay or haemophiliac communities, play an important role in mediation and the transmission of knowledge. AIDS pressure groups watch therapeutic progress closely. They have obtained rapid access to new therapies, so reducing the delays for clinical trials, placebo methods and marketing authorisations. They lobbied governments to negotiate research and development, price setting and commercial strategies with the pharmaceutical firms. Haemophiliacs followed genetic research and the production of medicines to replace human blood donation by risk-free technology closely. They lobbied for a strategy aiming at a "zero risk" level in the blood banks and the plasma industry. New tests were introduced to screen out extremely rare risks, at huge financial expense. Cost-benefit approaches have limited impact on European AIDS management.

Gay and haemophiliac associations succeeded in imposing their views after they had shaken off medical dependency and turned towards political pressure and legal support. The need orientation of AIDS policies was often explained by the impact of gay lobbying. European comparison however suggests that it is more likely to be explained by institutional characteristics. Germany provides the best example of sustainable participation, developed in line with the model of co-management in the health sector and implemented as part of the official principle of subsidiarity. In this model, common policy goals were limited to health protection, excluding gay identity issues (Buchow, 1997; Rosenbrock, 1994). In the British NHS context, voluntary organisations became a policy relay to ensure the implementation of the public policies in gay or IDU communities (Berridge, 1996), whilst Italian gay groups, although they promoted rather efficient prevention campaigns in their own ranks, obtained only limited access to local policy networks in northern towns. In France, open conflict with beneficiaries, gay activists as well as with haemophiliacs and blood transfusion victims, illustrated and challenged the corporatist model of governance in the health sector which was particularly resistant to beneficiary participation (Steffen, 1997). The AIDS epidemic opened a breach in medical leadership. Participation extended well beyond the traditional limits of patients' associations dominated by doctors, because it addressed non-medical issues and general problems of health management.

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### INTRODUCING HEALTH DIMENSIONS IN PUBLIC POLICIES

Introducing a public health approach into drug policies and the blood banks was a major challenge for AIDS prevention. Whilst safer sex could be viewed as a matter of individual choice and education, prevention in these two fields depended on public and professional intervention. Policy priorities had to be revised and institutional changes introduced. Previously, drug policies had been considered from a public security perspective, with path dependency reaching back to the ways youth and urban problems were dealt with. Blood collection was viewed as part of the medical system serving individual patients, with an emphasis on sufficient supply and voluntary donation. In these fields of drug abuse and the therapeutic use of blood products, problem framing had to shift from social philosophies towards the management of the public health risks.

### Risk reduction for drug addicts

The evidence which had accumulated since 1982-83, showed that disease transmission spread among drug users through needle sharing. The educational approach of prevention could only be effective if clean injection equipment was provided on a large scale, through free sale in chemist's shops and vending machines, free distribution in medical or social services, and through needle exchange programmes. These consisted in the provision of disinfecting kits or the exchange of a clean syringe for a used one, and were particularly relevant because this method fostered regular contact with the addicts which provided a framework for educational intervention. Also, medical care had to be offered to addicts because, à part from the medical benefits, relief from suffering constituted a powerful incentive for socially marginalised people to frequent the services and develop health awareness. Repressive policies which penalised drug consumption and drove addicts underground, had to be revised if the new strategies were to be implemented. AIDS policy makers and pressure groups, therefore, focused on law as the central prevention factor.

However, comparison showed that public health strategies depended less on law than on the institutional capacities of co-ordination between medical and social services. Britain and Italy shared a liberal legislation towards drug consumption whilst Germany and France had a similar legal context of prohibition. Yet, in 1998<sup>6</sup>, AIDS prevalence due to intravenous drug injection was still much higher in Italy than in Great Britain, although it was estimated that prevention messages were more widely diffused among Italian addicts<sup>7</sup>, and higher in France than in Germany although addiction was estimated much "stronger" in Germany<sup>8</sup>. The law remained unchanged, but practical changes took place in Germany much earlier and on a broader scale than in France. Path dependency in its twofold sense of previous policies and institutional channels

shaping problem framing and decision making determined the national capacities to respond to the new public health challenge.

Before AIDS was known, "harm reduction strategies" had already emerged in Britain, in local initiatives which had brought together voluntary organisations and social services (Berridge, 1993). They aimed at reducing the social consequences of addiction, such as marginalisation and delinquency. With AIDS, these networks reoriented their activity toward "health risk reduction". Needle exchange programmes and comprehensive primary care for addicts had been launched, by in the mid-eighties, under the responsibility of the local NHS units and with national support. The autonomy of Scottish health authorities, which had hesitated to implement the new strategies, brought about considerable local differences in policy content and results. Whilst nearly half of the IDUs in Edinburgh were HIV-infected, transmission remained an exceptional accident in Manchester and Liverpool<sup>9</sup>.

In Italy, favourable general conditions, including easy access to low cost syringes and intervention strategies maintaining the social integration of addicts, did not compensate for the lack of co-ordination between separate policy networks, at national and local levels. The surveillance and management of addiction was partly given over to private associations, which run many of the famous therapeutic communities. The care institutions linked with local governments and the political Left promoted the new risk reduction strategies, including needle provision and methadone treatment. Those linked with Catholic organisations tried to maintain their traditional commitment to abstinence goals, in the fields of addiction as well as sexuality. The gap resulted in unclear and even contradictory messages being delivered to people at risk, a factor found to be highly counterproductive for behavioural changes in recent AIDS research (Campenhoudt et al., 1997). Coherent prevention strategies depended on isolated local circumstances, found in Bologna and Modena (Cattacin, Lucas and Vetter, 1996).

In Germany, health risk reduction was implemented under pressure from professionals in the drug as well as the public health field. They were supported by the health ministers but, in the case of treatment of addicts with methadone, they encountered strong opposition from the national medical commission responsible for clinical classifications of medicines. This resistance was overcome by reform dynamics originating from the regions. Left governed regions and large cities launched methadone programmes under their own authority, as part of their general anti-AIDS programme. When opponents turned to the courts, jurisprudence established that legal restriction did not apply to public health goals. Subsequently, the sickness funds supported the programmes financially, because they estimated that methadone provision to addicts would be less expensive than long term care for new AIDS and hepatitis

cases. The various components of IDU/AIDS prevention were adapted to local needs, with an emphasis on street work, under the authority of the public health offices (*Gesundheitsämter*), each of them staffed, for at least five years (1988-93), with a co-ordinator for AIDS prevention.

In France, risk reduction met with twofold political and professional opposition which was not compensated for by the weak public health experts or by organised social demands. Although the sale of syringes was allowed from 1987 onwards, the police continued to arrest addicts, especially near chemist shops. Syringe possession continued to be officially considered as an "indicator of illegal consumption". The professionals caring for drug addicts, affiliated to a single national association, were committed to the psychoanalytical paradigm using abstinence as a sign of personality change (Bergeron, 1998). Until the early nineties, professionals refused to accept the AIDS risk, in order to prevent the "re-medicalisation of their sector (interview)" and escape from medical authority. When growing numbers of addicts arrived in hospital services and the staff were confronted with behavioural problems, the General Department of Health organised joint training sessions, from 1988 onwards, for medical staff and professionals from the drug sector in order to foster mutual understanding. Risk reduction strategies were first launched by a humanitarian medical association which operated the first mobile street unit, with a modest funding from the ministry. Greater awareness for necessary changes grew only in the aftermath of the contaminated blood trial, towards the mid-nineties. The Henrion Commission (1995) introduced, for the first time, experts from fields outside the narrow corporatist network. Tension then arose between general practitioners, hospitals and the drug caring services over the question of who should be authorised to prescribe substitutive medication. However, pragmatic changes slowly followed. At the end of 1996, some 300 places for methadone treatment were operational, compared to 15-17,000 in Germany, Britain and Italy.

AIDS prevention for drug addicts also entailed national inquiries into health conditions and disease transmission in prisons. In most European countries, efforts have been made to improve health protection and medical care for inmates, in order to prevent disease transmission when they return to normal life. A European network is now operating, funded by the European Commission and specialising in sexually transmittable and infectious diseases linked with imprisonment <sup>10</sup>. AIDS prevention in prisons illustrates the broader issue of public health management in marginalised populations, developing outside the traditional sphere of the welfare state, in connection with the programmes of the European Union.

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### Risk management in the blood transfusion sector

Public health decisions had to be made in uncertain circumstances. Experts were divided over risk evaluation. Despite growing evidence of the fatal issue which was confirmed in 1984, many experts maintained the hypothesis that a positive antibody test indicated immunity against the virus. It was thought that only 10% of HIV-infected people would develop AIDS. Furthermore, it was not always clear who was responsible for blood security. In France, governance problems extended to a point when fifteen years after the facts, in early 1999, three former ministers were tried for their inappropriate action at the time, and a further criminal trial of thirty medical specialists and government advisers is still to take place. All this followed the conviction of four top executives of the transfusion and plasma system in 1991-92.

The overall challenge was to introduce a serious selection of blood donors (to be extended to all organ, sperm and cell donation), systematic screening of the blood samples and virus inactivated medicine for haemophiliacs. Crisis management proved more or less difficult in the national transfusion systems, according to their cultural inheritance and co-ordination capacities. Donor selection depended on professional paradigms and practice; the systematic screening of blood samples on provision of finance; access to purified clotting concentrates on the information and the effective freedom of prescription of the clinicians; reduction of blood transfusions in hospitals and clotting concentrates in haemophilia treatment on individual medical decisions and the collective attitude of the haemophilia establishment.

In most countries, haemophiliacs refused to go back to former treatment and pushed for access to the new virus-inactivated medication which was available on the international market from the end of the seventies. The higher costs had to be negotiated with the health insurance funds. In France however, an unwritten rule of national self-sufficiency opposed importation. National production of clotting concentrates started in 1981 and was fully operating in 1984, coinciding with the spread of the epidemic. Technological choices had far reaching consequences. The new production units were set up without an inactivation process and technical difficulties arose when inactivation techniques had to be integrated into French production methods. This was finally achieved in the autumn 1985. The unwritten rule of protectionism originated from two sources; an ethical conviction which had prevailed since the early fifties, according to which blood security was based on voluntary donation in line with the Titmuss model (1970), and economic priorities adopted in the early eighties, according to which the biomedical industry was to be developed both for employment and export. With the approach of the free European market for pharmaceutical products, was approaching, in the mideighties, economic interest prevailed in the public service sector for blood.

Although the screening of all blood samples was adopted relatively early in France (1st August 1985), legal investigation established that the official decision should have been taken earlier, and that it had been delayed for at least three months, in order to preserve the domestic market from international competition with the American Abbott test. Cost containment aims in health insurance also added to the delays. Initially, no provision was made for free access to HIV-testing apart from blood donation. People at risk used the blood banks to obtain information on their serological status. Tests prescribed by doctors were only reimbursed from February 1986 and anonymous centres for free testing were only set up in late 1987.

Donor selection started in most countries with an official request addressed to identified risk groups to abstain from blood donation. Furthermore, a questionnaire had to be answered by each donor on his individual behaviour and risk factors (Feldman and Bayer, 1999). The French authorities followed opposition from the gay representatives, the intellectuals and the media against the designation of risk "groups", which it was thought, would lead to stigmatisation. At the same time, blood donor associations and the blood centres refused to question donors about their "private life", considering it a moral offence. When the General Department of Health released an official directive in June 1983, ordering the blood centres to reinforce donor selection, it was simply ignored. Furthermore, the need for blood had grown rapidly as the national production of clotting concentrates had developed. To meet the demand, collections were organised in streets of red light districts and in prisons. In early 1985, the department of prison administration called for more blood collection in prisons, which was considered as part of the social reinsertion of prisoners. This risky collection represented less than half a percent of the total volume of donated blood but caused 30% of contaminations (IGASS/IGSJ, 1992).

Public health management in France was confronted with a specific combination of symbolic values and economic interests (Steffen, 1999a). The over-valuation of blood donors which made donor selection very difficult was linked with a World War II and Liberation born ideology assimilating blood donation to a heroic act of national solidarity and independence (Hermitte, 1996). Social beliefs contributed to the "sinistre exception française" (Morelle, 1996, 24-27), totaling 60 % of all HIV-infection transmitted by blood transfusion in the twelve countries of the European Union. In Britain, where the blood transfusion system operated within the NHS, donor selection was reinforced immediately when the new risk was known. In Germany, the Red Cross in collaboration with the medical experts of the public health institutions led the way. In Italy, the blood banks took local initiatives, more or less coordinated by the regional health authorities. Following regional initiatives, the

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Health ministry finally established a list of groups to be excluded from blood donation, with the risk of legal pursuit if it was not respected.

The contamination of haemophiliacs was similar in countries where access to the new clotting factors was granted. The French public system did not manage to protect its patients any better than the international private companies which where operating on the European market.

Table 4. Blood transfusion and haemophilia treatment

10300	France	Italy	Germany	GB
Recorded AIDS cases,	**	16		
31 Dec. 1998 :		-	1	
- haemophiliacs	582	332	542	640
- transfusion recipients	1,734	384	266	133
Total HIV cases (estimates)	> 4,000	<1,200	<1,100	<800
Contamination rate among haemophiliacs	45 %	23 %	46 %	48 %
HIV-positive donations per 100,000 :				
1986	40.6	27.6	4.2	2.0
1991	7.9	6.0	2.3	0.9
1997	2.2	2.7	1.2	1.1

Sources: The European Epidemiological Surveillance Center for AIDS, EU-WHO, Paris (*Quarterly Reports*). Koch E.R. (1992), Heine, W.G. (1993).

The institutional characteristics of the French system rendered policy and decision making very difficult. The industrial plasma sector developed as part of traditional blood transfusion activities, without an institutional reform to ensure adequate control procedures (Setbon, 1993). The central health administration depended on national expert commissions for information and advice but had no effective control over the sector. The blood banks were largely autonomous since they were placed under the authority of a medical director entitled like all doctors to professional autonomy. This led to confusion in the perception of legal responsibility (Hermitte, 1996) which was seen as belonging to the regimes of medical and public service responsibility. These were both under obligation to provide equal access to services but were not subject to product liability<sup>11</sup>. Furthermore, little connection existed between the blood banks and the hospitals. Transfusion transmitted disease, therefore, went largely unnoticed (IGASS/IGSJ, 1992). It was only in the aftermath of the HIVcontamination that systematic follow-up systems was established enabling each single batch of blood to be traced and long-term records of donor origin and patient destination to be kept. The 1993 reform restructured the entire blood and plasma sector which is now effectively controlled by the health authorities, advised by independent commissions. Blood products integrated the status and the surveillance procedures for pharmaceutical products, which were also reformed and reinforced.

AIDS management favoured the rationalisation of professional pratice and public intervention in both sectors, in the field of drug policies and the blood transfusion industries. It led to the harmonisation of safety standards, the reinforcement of public and medical responsibility for potential risks and the recognition of the rights of patients, regardless of specific medical "errors". The changes were naturally most important in France where incremental change proved most difficult because of corporatist policy patterns.

## PUBLIC HEALTH DYNAMICS, MEDICAL PROGRESS AND CHRONIC DISEASE

Finally, what was so new about AIDS? Most of the innovations developed to meet the challenge already existed. Therapeutic apartments had been set up as part of psychological care. Self-support and self-help organisations had operated in various fields in Germany, Holland and elsewhere. Social and psychological support had already been developed to cope with alcoholism, drug abuse and chronic disease. Patients' associations already existed for cancer and other chronic pathologies. As with donor selection, harm reduction of drug abuse and the public promotion of condoms, all these elements had been experimented with before. Their simultaneous application in a unique case however was new. Under the threat of an international public health catastrophe, these elements formed a coherent dynamic in which public health moved from the periphery of the medical system to the centre of political attention. This is easily illustrated by the example of sexual health. Public intervention in the field of sexuality became legitimate when oriented towards the protection of public health. Although to varying degrees, health oriented sexual education was introduced in normal school programmes. In Germany "sexual pedagogy" became a new university discipline, based on knowledge and theories largely drawn from the experience acquired with AIDS (Sielert, 1995).

The public health dynamic was amplified at the European level. Initially, as in most health issues, European implication was limited, to some coordination between loose networks of a medical and scientific nature on the one hand and activist initiatives on the other (Altenstetter, 1994). Closer integration was achieved through the European anti-AIDS programmes which structured research and introduced a comparative evaluation of different intervention strategies. Specific European policies arose with the creation of epidemiological

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surveillance systems and expertise capacity, focusing on the harmonisation of statistical data and, as a second step, in policy tools and goals. This development is well illustrated by the European Agency for anti-drug policies. The blood transfusion issue contributed to the harmonisation of security standards and the marketing authorisation for plasma products, now placed under the newly created European Agency for pharmaceuticals. The AIDS programme extended to cover all transmittable disease, with a focus on transnational problems. AIDS helped to initiate European public health policies, compensating for the lack of authority over the organisation and financing of medical care systems which have remained under national control.

The common direction between AIDS fostered innovations and general reforms in the health sector was also new. AIDS management favoured the restructuring and rationalisation of services, in line with cost containment. Three specific aspects are to be mentioned here. Firstly, the rapid progress in therapy, combined with the pressure for access from mobilised patients, led to standardised treatment protocols and the strict surveillance of medicine delivery. In AIDS treatment, the doctors' freedom of prescription was severely limited, which contributes to the general trend towards the evaluation of medical activity. Secondly, medical care for AIDS patients fostered comprehensive service structures combining hospital and home care, a particularly difficult issue in many European health systems. Until very recently, the pathology has evolved with alternate phases of acute life threatening illness and remissions allowing home care. Cost containment and the patients' demand for "normal life" created a common pressure for closer service co-ordination. Thirdly, the contamination of blood banks, the discovery of growing risk of disease transmission in hospitals and the development of antibiotic-resistant pathogens made hospital hygiene a new priority and new task for hospital management. Reinforced control over medical activities and the legal protection of patients, have contributed to breaking the monopoly of the medical profession.

Future developments and perspectives are dominated by the new therapeutic progress. The recently introduced multi-therapies reduce the viral charge in the infected body. Patients now rarely die, they recover to nearly normal health. The heavy treatment is most efficient when started in the early stage of infection. People at risk now have a direct therapeutic interest in being HIV-tested after each risk exposure. Consequently, a growing number of people are under medical treatment and surveillance for life. The new treatment moves AIDS into the category of chronic disease. Yet there are important differences compared to other chronic diseases. The patients are young, of working age, and they remain infectious. The main motivation for individual behavioural changes, however, faded with the perspective of possible survival and recovery. Furthermore, the medical victory is already showing its limits. Important

secondary consequences have appeared, individual resistance to the treatment is growing and, most of all, multi-resistant viruses have already developed within less than two years, a phenomenon observed with antibiotics which took thirty years. This gives a view over the lasting scientific, medical and social challenge.

The recent developments signify, in addition to growing budget allocation, the necessity to organise long term medical monitoring of growing numbers of patients and, simultaneously, to maintain and reinforce prevention strategies. Unlike previous transmittable diseases but similar to chronic disease and age related pathology, the responsibility of public health authorities in the case of AIDS is not diminishing but growing with therapeutic success.

### CONCLUSION

Management of the AIDS epidemic has offered an occasion to observe health systems in a transversal perspective. It has revealed their capacity to respond to new issues and their interaction with broader policy networks and social demands. The health systems examined here have faced a multi-fold challenge: the introduction of non medical intervention strategies, co-ordination of several policy sectors, beneficiary participation and public health management, the latter extending over the control of infectious disease and health protection in underprivileged populations. All finally adopted similar policies, but by different ways and with different timing, according to their institutional capacities and models of change.

The policy responses to the public health challenge indicated Northern and Southern models, which may suggest different hypotheses. To what extent is public health management related to cultural influences? How is it related to the organisational features of the welfare states? The comparative results suggest the following conclusions:

In the public health field, cultural values act via risk perception, the social attitude towards sexuality and marginal behaviour, and the public/private borderline. They condition the content of what is considered to be a personal or state responsibility in health protection.

Welfare states focused on the development of the medical care system. Public health remained a weakly structured field where cultural references and political attitudes maintained influence over public choices and professional practice. When policies have to be developed in this marginal field, then intergrated health systems such as the British and Scandinavian models tend to be more efficient. Integrated systems can be defined by public control over the

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development of activities, an organisation which favours links between care and prevention, and a joint responsability over hospital and primary care structures.

Public health policies are not cost saving. The global cost of efficient AIDS management, including the budgets for research, prevention, care, and the provision for "normal life" conditions represent a heavy charge inside and outside the health systems. The generalising trends of AIDS management are essentially linked with breaking the medical power over health issues. Law courts have played a role in the protection of patients, and doctors have accepted limitations in their freedom of prescription and medical decision making which they had refused in both other medical fields and cost containment.

The combined pressure of cost containment and public health management fosters a new model of health protection within European welfare states, aiming at greater global efficiency. The European level constitutes a strategic lever in this reorientation. Whether the tendency will help to narrow the gap between Northern and Southern European health systems remains an open question.

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The Author(s).

### References

Altenstetter, C., (1994) "European Union responses to AIDS/HIV and policy networks in the pre-Maastricht era", *Journal of European Public Policy*, 13, 3, 414-40.

Bayer R., (1989) Private Acts, Social Consequences: AIDS and the Politics of Public Health, Rutgers University Press, New Brunswick (reprint with a new Afterword).

Bayer, R., (1991) Public Health Policy and the AIDS Epidemic. An End to HIV exceptionalism?', New England Journal of Medecine, 324, 1550-04 (May 23).

Feldman, E. and Bayer, R., (Eds.) (1999) Blood Feuds. AIDS, Blood and the Politics of Medical Disaster, Oxford University Press, Oxford, New York.

Bergeron, H., (1998) Soigner ou prendre soin des toxicomanes: anatomie d'une croyance collective - analyse historique du champ de la toxicomanie en France de 1970 à 1995 ou l'histoire de la domination d'un paradigme, Thèse de doctorat, Institut d'Études Politiques de Paris, janvier.

Berridge, V., (1993) 'AIDS and British drug policy: continuity or change', in Berridge, V. and Strong, P., (Eds.) AIDS and contemporary history, Cambridge University Press, Cambridge, 135-56.

Berridge, V. (1996) AIDS in the UK. The making of Policy, 1981-1994, Oxford University Press, New York.

Bochow, M., (1997) 'Hat AIDS die soziale Situation schwuler Mäner verändert ?' in Grumbach, D., (ed. by.) Was heisst hier schwul? Politik und Identitäten im Wandel, Männerschwarm Skript Verlag, Hamburg.

BKA (Annual reports) Rauschgift Jahresberichte, Bundesrepublik Deutschland, Wiesbaden (Germany).

Calvaruso, C. (1993) Gli interventi sull'AIDS in Italia dal 1982 al 1993, report, LABOS/CERAT, Rome, Grenoble.

Campenhoudt, L., Cohen, M., Guizzardi, G., Hausser, D., (1997) Sexual Interactions and HIV Risks - New Conceptual Perspectives in European Research, Taylor & Francis, London.

The Author(s).

Cattacin, S., Panchaud, C. (coll. Tattini V.), (1997) Les Politiques de Lutte contre le VIH/SIDA en Europe de l'Ouest. Du risk à la normalisation. L'Harmattan, Paris, 1997.

Cattacin, S., Lucas, B. and Vetter, S., (1996) Modèle des politiques en matières de drogue, une comparison de six réalités européennes, L'Harmattan, Paris.

Day, P. and Klein, R., (1989) Interpreting the unexpected: the case of AIDS policy making in Britain', Journal of of Public Policy, 9 (3), 337-53.

Ferrera, M., (1996) The partitocracy of health. Towards new welfare politics in Italy ?', RES PUBLICA Belgian Journal of Political Science, n° 2, 447-59.

Guillaume, P., (1986) Du désespoir au salut: les tuberculeux aux 19è et 20è siècles. Aubier, Paris.

Hayward, J. and Klein R. (1994) 'Grande-Bretagne: De la gestion publique à la gestion privée du déclin économique' in B. Jobert (ed.) Le tournant Néo-libéral en Europe, L'Harmattan, Paris, 87-121.

Heine, W.G. van, (1993) La collecte et l'utilisation de sang et de plasma humains en Europe, Report for the Council of Europe and the Commission of European Communities, Strasbourg.

Henrion, R., (1995) Rapport de la Commission de réflexion sur la drogue et la toxicomanie (at the demand of the Minister of Social Affairs, Health and Urban problems), La Documentation Française, Paris.

Hermitte, M.A. (1996) Le sang et le droit. Essai sur la transfusion sanguine. Seuil, Paris.

IGASS/IGSJ (joint report), (1992) Rapport d'enquête sur les collectes de sang en milieu pénitentiaire. Observations et Annexes. (Report IGASS n° SA 07 92 119; n° IGSJ RMT 12 92), Ministry of Health, Ministry of Justice, Paris.

Jobert, B. and Steffen, M. (eds) (1994), Les Politiques de Santé en France et en Allemagne, Observatoire Européen des Politiques Sociales, Espace Social Européen, Paris.

Kirp, D.L. and R. Bayer (ed.) (1992) AIDS in the Industrialised Democracies: Passions, Politics and Policies, Rutgers University Press, New Brunswick.

Koch, E.R. (1992) Sang rouge, sang noir, Chronique d'un scandale médical, Édition Frison-Roche, Paris.

European University Institute.

The Author(s).

Montagnier Report (1993) Ministry of Health, France, Annexe 5.1.2.

Morelle, A. (1996) La défaite de la santé publique, Flammarion, Paris.

Moss, D. (1990) 'AIDS in Italy: Emergency in slow motion' in Misztal B.A. and Moss, D. (ed.) Action on Aids, National Policies in Comparative Perspective, Westport, 1990, 136-60.

Mossuz-Lavau, J. (1991) Les lois de l'amour. Les politiques de la sexualité en France (1950-1990), Payot, Paris.

Murard, L. and Zylberman, P. (1996) L'hygiène dans la République. La santé publique en France, ou l'utopie contrarié. 1870-1918, Fayard, Paris.

Porter, E. and R. (1988) The enforcement of Health: The British Debate' in Fee, E. and Fox, D. (eds) AIDS, The Burden of History, University of California Press, 97-120.

Quétel, C. (1986) Le mal de Naples. Histoire de la syphilis, Seghers, Paris.

Regonini, G. and Giuliani, M. (1994) 'Italie: Au-dela d'une démocratie consensuelle?' in B. Jobert (ed.) *Le tournant néo-liberal en Europe*, L'Harmattan, Paris, 123-99.

Rosenbrock, R. (1994) 'Die Normalisierung von Aids - teils nach vorne, teils zurück' in the German edition of D. Kirp, R. Bayer (eds) Strategien gegen Aids. Ein internationaler Politikvergleich, Sigma Ed., Berlin, 1994, 480-501.

Setbon, M. (1993) Pouvoirs contre Sida. De la transfusion sanguine au dépistage: décisions et pratiques en France, Grande-Bretagne et Suède, Seuil, Paris.

Seytre, B. (1993) Sida: les secrets d'une polémique, Presses Universitaires de France, Paris.

Sielert, U. (1995) 'Prävention: Erfahrung, Mythen und Möglichkeiten', Dokumentation der Fachtagung vom 13-15 Juni 1994, Landesinstitut für Schule und Weiterbildung, Soest, Allemagne.

Steffen, M. (1996) The Fight against AIDS. An international public policy comparison between four European countries: France, Great Britain, Germany, Italy, Presses Universitaires de Grenoble, Grenoble.

The Author(s). European University Institute.

Steffen, M., (1997) 'La santé: les bénéficiaires en dehors des réformes' in Warin, P. (ed.) Quelle modernisation des services publics? Les usagers au coeur des réformes, La Découverte, Paris, 201-20.

Steffen, M. (1999a) 'The Nation's blood: Medecin, Justice and the State in France' in Bayer, R. and Feldman, E. (eds) *Blood Feuds. Aids, Blood and the Politics of Medical Disaster*, Oxford University Press, New York, Oxford.

Steffen, M. (1999b) "Protection sociale et management de la santé publique en Europe de l'Ouest et de l'Est", Matériaux pour l'histoire de notre temps, Revue de la Bibliothèque de documentation internationale contemporaine, forthcoming,, 2nd trim. 1999.

Street, J. and Weale, A., (1992) Britain: Policy-making in a Hermetically Sealed System' in Kirp, D.L. and Bayer, R. (eds) AIDS in the Industrialised Countries, Rutgers University Press, New Brunswick, 185-220.

Titmuss, R.M. (1970) The gift relationship, Allen & Unwin, London.

Vidal V. (1991) La petite histoire du préservatif, Paris, Syros.

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## **Endnotes**

- Morbidity and Mortality Weekly Report (MMWR), 5th June 1981.
- <sup>2</sup> The French-European project was presented publicly at the Second International Conference on AIDS and Sexually Transmittable Disease, in Abidjan, Côte d'Ivoire, 7 11 December 1997. Journal du Sida, n° 102, Jan-Feb. 1998.
- <sup>3</sup> The former health minister at the time, under whose authority Italian public AIDS policy was launched, became one of the most severely condemned officials in the *mani polite* trials, harged with of corruption on a large scale.
- <sup>4</sup> The very first French TV campaign, in 1987, showed a well dressed elegant woman stating "AIDS will not pass through me", followed by a telephone number to call for more information.
- <sup>5</sup> According to historical studies, public health intervention in France was to a large extent in the hands of local élites and dominated by the approaches of private medecine: Murard and Zylberman, 1996; Guillaume, 1986; Quétel, 1986.
- The number of recorded AIDS cases due to IDU, by 31st December1998, amounted to 1,024 in Great-Britain, 26,400 in Italy, 2,532 in Germany and 11,499 in France. New cases diagnosed in 1998 were less than one per million inhabitants in GB and Germany, five in France and nineteen in Italy: Source: WHO-EC Collaborating Centre on AIDS, Paris, Quaterly Report, no 60, 4/1999.
- According to a European Community Enquiry, 75% of Italian IDU addicts were in contact with AIDS prevention, as against 40% in Britain, quoted by Montagnier (1993).
- In 1991, 2,125 deaths from overdose were recorded in Germany; compared to a hundred cases recorded in France and 465 in 1995 (Sources: BKA Report 1992, n° 3 for Germany; OCTRIS Office Central pour la Repression du Traffic illicite des Stupefiants for France, quoted by Le Monde 22nd September, 1996).

- <sup>o</sup> Journal du Sida, n° 38-39, April-March 1992. In the early nineties, 40% of the addicts were HIV-positive in Edinburgh, compared to 1% in Manchester and 0,2% in Liverpool.
- The European network functions regularly since 1996. It is co-ordinated by the Observatoire Régional de la Santé Publique Provence-Alpes-Côtes d'Azur, in Marseille/France and the Institut der Ärzte Deutschlands (WIAD)/Germany. The aim is to organise comparative scientific discussion on epidemiological data and prevention strategies, to initiate comparative data systems and develop an interdisciplinary approach of public health linked with emprisonment, addressing epidemiologists, care and prevention professionals, legal experts and prison administrations.
- This is the distinction in French law between the 'obligation des moyens' and the 'obligation de résultat' (obligation to provide all technical and scientifically available means, as opposed to producing the expected results).
- A new policy sector is at present being organised in France: "Sécurité sanitaire" (health security). The legal foundations, theories of global risk management and institutional structures for an effective management of the "sécurité sanitaire" were the main subjects in the 1997-98 programme of the prestigious élite school, l'ENA (École Nationale d'Administration) which selects and trains the future top excecutives of public administration and the top political staff.



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