

Rights and pandemics

THE FIGHT AGAINST HIV/AIDS: APPROACHES, KNOWLEDGE AND PRACTICES FOR MEETING PRESENT DAY CHALLENGES

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The French National AIDS & Viral Hepatitis Council (CNS) is an independent, consultative French agency comprising 26 members, chaired by Professor Patrick Yeni, that delivers opinions and recommendations on the issues facing society as a result of these epidemics. It is consulted about the health plans and programs drawn up by the public authorities.

Its papers are addressed to the French public authorities and to all those involved in or concerned by the epidemic. The CNS participates in the development of public policy, within a framework that promotes respect for fundamental ethical principles and human rights.

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PREAMBLE

As a witness and participant in the fight against HIV/AIDS for more than 30 years and being fully aware of the limitations of the comparison, the French National AIDS and Viral Hepatitis Council (CNS) is interested in asking, not just from a purely reflective perspective, what the fight against HIV/AIDS could bring to that against COVID-19 and future epidemics. Created in 1989, the National AIDS Council is one of the measures recommended by Prof. Claude Got in his report¹. It is therefore one of the tools regularly enlisted to advise public policies. Although HIV is now considered a chronic disease thanks to effective treatments and prevention policy, it would seem opportune to draw up a critical and dynamic review of the practical and methodological knowledge that researchers, civil society members, people living with HIV and/or campaigners have pioneered since the beginning of the 1980s in order to respond in a suitable and effective way to this pandemic.

This review is not exhaustive; it has been determined on the basis of our current situation, which is that of an unprecedented healthcare crisis. It is also a collective contribution, resulting from the individual experiences of council members (virologists, epidemiologists, associations, carers, researchers) and the CNS collective mentioned here. Likewise, this approach is not purely anecdotal; it is the result of work that has taken many different forms, based on external hearings, on the literature available and on a continuing debate; although it took the issue of risk reduction as its starting point for reflection, its work has shifted and the ethical dimension has become essential. It is not intended to be a lesson or a practical guide, but rather to relay a certain number of standards and values, resulting from the experience of the fight against HIV/AIDS. For the CNS, it is not about stating, but contemplating this situation, thus "providing advice" is "providing knowledge" in this exemplary fight. This knowledge can serve as a "weapon", in the words of the activists themselves², for today and for tomorrow.

¹ Got C. (1989), *Rapport sur le sida*, Paris, Flammarion.

² "Knowledge is a weapon" Act Up-New York, 1988.

INTRODUCTION

BACKGROUND TO THE CNS INVESTIGATION

At the end of the current mandate of its members (2015-2021) and after more than 30 years of activity, the Council wished to reflect on what has been achieved in the fight against HIV/AIDS and how this could potentially be useful in the current epidemic crisis and future epidemics; therefore, they have set up a commission for this purpose.

The CNS investigation is born out of a threefold observation made during the healthcare crisis: (i) the scant use of experience fighting against HIV/AIDS to respond to the questions asked, (ii) the lack of consultation by public authorities of its advisory boards, in particular the National Health Conference, (iii) concern about some of the responses given, with regard to health and civil liberties.

MISSION OBJECTIVE

The experience of the fight against HIV/AIDS, that is to say its knowledge, its debates and its mistakes, has made it possible to identify, on several different scales, a set of principles, front-line practices, actions and procedures. A critical and dynamic review of this experience has been carried out, with no intention to be exhaustive, in order to reflect on the knowledge likely to provide information, and perhaps answers, to stakeholders and help clarify public decision-making in the time of a new epidemic.

Using experiences from the fight against HIV/AIDS may not be an obvious course of action due to the unique characteristics of the epidemic, as evidenced by its means of infection and the groups affected, as well as the context of its emergence. The emergence of new epidemics raises questions today that were not asked in the 1980s in light of political, social, societal, cultural and technological developments, beginning with the globalisation of exchanges and movement. However, despite its unique characteristics, experience of the fight against AIDS/HIV could be implemented effectively for new epidemics, as has been the case in the fight against viral hepatitis.

METHODOLOGICAL APPROACH

Caution must be taken when reflecting on experiences in the fight against HIV/AIDS. This reflection must not sidestep the changing contexts that have defined this mobilisation and its various timeframes. Furthermore, it must be protected against any retrospective illusion so as not to attribute to the fight against HIV/AIDS a role that it has not had – or did not have alone – in a range of developments and not record it in linear time marked only by progress and success.

The revisiting of this experience has involved multiple sources. The commission was based on work by the Council, particularly its opinion and reports published since 1989, and on a literature review. This review has benefitted from the experiences of current members of the Council, some of whom come from the generation that faced the emergence of the epidemic and the development of the fight against HIV/AIDS. Four focus groups committed to issues of prevention, rights, collective mobilisation and research were incorporated within the commission in order to structure its work. To reflect on the experience fighting against HIV/AIDS in relation to other issues and epidemics, the commission has also undertaken an examination of a limited number of people whose field of expertise does not concern or exclusively concern that of HIV/AIDS.

OUTLINE OF THE OPINION

Experience in the fight against HIV/AIDS also forms part of a demanding ethical framework. Its knowledge and practices can set a precedent and have relevance in the face of emerging epidemics. In addition, the Council will direct recommendations to the public authorities at the end of the opinion.

1. EXPERIENCE IN THE FIGHT AGAINST HIV/AIDS: THREE LESSONS FROM AN ETHICAL APPROACH

Both in France and on a global scale, the fight against HIV/AIDS has borrowed or introduced various means of responding to the pandemic that were unique in many respects. In France, three lessons can be outlined here: an approach that respects human rights (1.1), a comprehensive approach of the subject, endowed with a body, a personality and knowledge (1.2) and a coordinated individual and collective commitment that does not avoid conflict (1.3).

These three lessons have as their common thread an ethical approach, which was being defined at the start of the pandemic. The commitments to medical ethics and management of therapeutic tests adopted by the international Declaration of Helsinki in 1964³ have been clarified in the Belmont report, which was published two years before the beginning of the HIV/AIDS epidemic⁴. It affirms the principles of respect for individuals, beneficence and justice, and outlines the implications relating to informed consent, evaluates the benefit-risk balance and the unbiased selection of subjects in research. These principles have guided the fight against HIV/AIDS, which has benefitted from them while it tried to respond to the challenges of the pandemic over forty years of mobilisation.

1.1. AN APPROACH THAT RESPECTS HUMAN RIGHTS

The ethical approach to the fight against HIV/AIDS has gradually resulted notably in the practical assertion of human rights, their recognition, including in positive law, and their implementation, which still remains insufficient.

From the first years of the epidemic, the fight against HIV/AIDS has stressed an ongoing and strong concern for the human rights of people exposed to or living with HIV, as well as a choice of prevention measures based on consent rather than on coercion. This approach, which recognises individual responsibility, broke away from the model of coercion⁵ based on checks, obligations and sanctions that was previously implemented in the fight against epidemics, at the same time as old processes of strict surveillance in order to contain spaces under control. This has been reflected, for example in the field of screening for infection, by collecting informed consent of individuals⁶, the insistence on respect for confidentiality, the principle of voluntarism and individual responsibility.

This liberal approach, which is defined as “exceptionalist”⁷, has become relevant particularly with respect to the characteristics of the epidemic. Indeed, outside of blood transfusion, the key behaviours of transmission were either accompanied by social stigma, with regard to homosexuality and prostitution, or prohibited by law and are still so with regard to drug use. The key populations of the epidemic, particularly prisoners, sex workers and migrants in a precarious administrative situation were, and still are, exposed to forms of administrative coercion. In addition, the model of coercion is ineffective in reaching people who, due to their situation, have limited trust in public institutions and adopt ways of escaping their control.

The attention to the rights of people is also reflected in the mobilisation against discrimination and stigmatisation suffered by people living with HIV (PLHIV) and the populations exposed to risk of infection. Campaigners in the fight against HIV struggled against, in particular, restrictions in access to care, employment and insurance, notably associations who from 1991 were able to exercise rights granted to the plaintiff for offences committed on grounds on health status⁸. The inequality of treatment in relation to access to insurance and loans for PLHIV in particular, led to protracted lobbying in the 1990s. The CNS thus opposed the too-expansive powers given to insurance

³ The Declaration of Helsinki – ethical principles relating to medical research involving human participants adopted by the 18th World Medical Association General Assembly in June 1964.

⁴ National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research (1979), *Ethical Principles and Guidelines for the Protection of Human Subjects of Research*, 18 April.

⁵ On the model of “secular constraint” see Dozon J-P. (2001), « Quatre modèles de prévention » in Dozon J-P., Fassin D. (ed.), *Critique de la santé publique : une approche anthropologique*, Paris, Balland, p. 23-46.

⁶ The CNS allowed one exemption in the case of an accidental exposure to blood where it was impossible for the person to respond to the proposed test due to their medical situation and combined its implementation with several mandatory conditions. See CNS (2000), *Screening in the hospital context following accidental exposure to blood (AEB) in situations where the patient is unable to respond to a proposal for a HIV screening*, 12 October; (2009) *Opinion regarding consent to screening following incidents of accidental exposure to blood involving protected adult patients*, 12 March.

⁷ Bayer R. (1991), “Public health policy and the AIDS epidemic. An end to HIV exceptionalism?” *N Engl J Med*, 324(21):1500-1504.

⁸ Act of 12 July 1990 relating to the protection of people against discrimination due to health or disability.

professionals in the context of the national convention in discussion, also emphasising the right to confidentiality⁹ and then proposing a new conventional framework¹⁰, which inspired the development of the current convention, AERAS¹¹. In another area of differential access to rights at the expense of PLHIV, the Council demanded a lifting of the ban on embalming for deceased persons infected with HIV¹², which has been in force since 2018. Despite progress in some areas, investigations highlight that discrimination still persists¹³, particularly at the expense of vulnerable people, justifying continuing action by campaigners in the fight against HIV.

Generally speaking, the fight against HIV/AIDS has contributed, thanks to the activism of associations, to the inclusion of some of these principles in positive law, notably with the Act of 4 March 2002 relating to patients' rights and the quality of the healthcare system. They also stressed respecting the dignity of the care receiver and their privacy, autonomy to make their own decisions, including refusal of care, right to information, free and informed consent during a personal interview with the doctor and their participation in the decision. By rebalancing the relationship between patients and the medical authority, who up until now held the monopoly on knowledge, the law treats the patient as an active, participating partner in decisions concerning their health.

Furthermore, a right to compensation has also been adopted in the context of the fight against HIV/AIDS. The recognition of no-fault liability in blood transfusion centres by case law led to the creation of compensation funds for transfusion recipients and haemophiliacs in 1991 in order to provide full and swift compensation for harm suffered by people infected with HIV. This recognition has contributed to the improvement of victim's compensation for medical accidents established by the National Office for Compensation for Medical Accidents caused by iatrogenic conditions and hospital-acquired infections (ONIAM) created by the Act of 4 March 2002.

The recognition of patient rights has been gradually acquired with great difficulty, particularly in the face of the medical establishment. In the early years of the epidemic, PLHIV reported having been confronted with aloofness from some doctors or a patronising, even moralistic, attitude, while some doctors conveyed a sense of powerlessness, fear or uneasiness¹⁴. With access to the first antiretroviral treatments, which were simultaneously not very effective, poorly tolerated and complicated to take, the compliance orders to prevent the emergence of resistance and treatment failure often defined the doctor-patient relationship. Then, little by little, including for the sake of effective care, the order and judgement diminished in favour of improved listening and patient participation in decisions. Support for patients by healthcare professionals and associations is based on counselling as part of a comprehensive approach¹⁵ focused on the experience of adverse effects of treatments. This has been implemented in therapeutic patient education (TPE) schemes since 2009.

The recognition of patient rights is also reflected in the individualisation of the care relationship and, to a different degree, in compassionate access to medication, obtained by associations fighting AIDS by derogation¹⁶. These approaches evidence the need to take into consideration the critical vulnerabilities of people in order to assist them, without systematic research for equality throughout society, in accordance with an ethos of care. Coined in the 1980s from the English-speaking world¹⁷, the care ethos, contemporary of the fight against HIV/AIDS, refers to both a feeling of concern and activity of care that calls for recognition¹⁸.

The gradual establishment of patient rights has been varied depending on the location of the professionals, in areas with either high or low incidence of HIV/AIDS, the patient situation, particularly their resources¹⁹ and their vulnerability, and the type of establishments concerned. On this point, the CNS has stressed ongoing concern

⁹ CNS (1991), *Assurances. Avis à propos de la convention Sida*, 23 September.

¹⁰ CNS (1999), *Assurances. Pour une assurabilité élargie des personnes et une confidentialité renforcée des données de santé. Rapport suivi d'un avis et de recommandations*, 20 September.

¹¹ S'Assurer et Emprunter avec un Risque Aggravé de Santé (Insuring and Borrowing with An Aggravated Health Risk).

¹² CNS (2009), *Note valant avis sur les opérations funéraires pour les personnes décédées infectées par le VIH*, 12 March.

¹³ Aides (2017), *VIH/ Hépatites. La face cachée des discriminations*; Les Séropotes (2020), *L'accès des personnes vivant avec le VIH à l'assurance et aux soins. Actes du Workshop du 20 janvier 2020*.

¹⁴ See for example Méchin N. (1999), *Médecin, Malade, SIDA: une rencontre*, Paris, L'Harmattan; Jaccopard, H. (2004), *Lire le sida: témoignages au féminin*, Bern, Peter Lang; Langlois E. (2006), *L'épreuve du sida: Pour une sociologie du sujet fragile*, Rennes, Presses universitaires de Rennes.

¹⁵ The counselling comprises the mobilisation of resources and people's ability to face potential difficulties as a result of establishing of a therapeutic relationship.

¹⁶ Barbot J. (1998), « Science, marché et compassion. L'intervention des associations de lutte contre le sida dans la circulation des nouvelles molécules », *Sciences sociales et santé*, vol. 16, n°3, p. 67-95.

¹⁷ Gilligan C. (1982), *In A Different Voice*, Cambridge, Mass., Harvard University Press; Gilligan C. (2008), *Une voix différente, Pour une éthique du care*, Traduction de Vanessa Nurock, Paris, Champs Flammarion.

¹⁸ For a summary, see for example: Worms F. (2021), *Le moment du soin. A quoi tenons-nous ?*, Paris, Presses universitaires de France.

¹⁹ Their social position, proximity to a community network, medical knowledge, ability to mobilise proceedings etc.

regarding people's rights in institutions or specific treatment measures, particularly (i) in prisons, before and after the Act of 18 January 1994 relating to public health and social protection, which entrusts the healthcare of prisoners to the public hospital service²⁰, (ii) in a medico-social establishment for people with specialised needs²¹, (iii) in support centres for drug users²² and (iv) in the context of arrangements relating to access to care for persons in an irregular situation²³. Attention must also be paid to access to support arrangements in homes and accommodation serving as therapeutic coordination apartments (ACT)²⁴ and for people in a dependent situation, the establishments providing care for the dependent elderly (EHPAD).

1.2. A COMPREHENSIVE APPROACH TO THE SUBJECT ENDOWED WITH A COMMUNITY, PERSONALITY AND KNOWLEDGE

The fight against HIV made a break with an approach of the anonymised individual that public policies had established up to this point, with consequences in particular for the place of the patient and the role of public authorities.

In the field of prevention, health policies have often been directed at rational individuals who are supposed to maximise their interests and minimise their risks, thus contributing to making them responsible people and "accountable for their health"²⁵. Other policies have viewed individuals as being moral or amoral, that is, either quick to comply with the recommendations of the law or healthcare professionals as a means of permanent self-control, or prepared to break away from this framework in a spirit of transgression²⁶.

Contrary to the approaches focused on the rational individual or the moral/amoral individual that can stigmatise "target" populations, the fight against HIV/AIDS considered, for ethical reasons and efficiency, each individual as a subject endowed with a community, personality and knowledge. It also took into account the socio-economic, family, marital, personal and temporal contexts of individuals and the role played by groups, and sociability and action networks. It also recognised the subject's ability to participate in public reforms and led to the voice of the individual patient being considered as a social reformer, that is to say, as an identifier of medical and social needs and issues, whereas until now only the doctor's voice had been associated with social reforms²⁷.

This approach has been led by various associations fighting AIDS – associations for those affected, associations for professionals bringing together doctors and PLHIV – created in the 1980s and 1990s such as "Vaincre le sida" (Stopping AIDS), Aides, Arcat, Act-Up Paris, etc. Their dynamic has strengthened support for PLHIV by producing knowledge and joint learning, and exerting an influence on public decision-making in keeping with the Denver Principles, which, as early as 1983, called for the questioning of medical authorities and the participation of the persons affected at all stages of decision-making²⁸. The associations created within the framework of mutual aid and socialisation networks have participated in this movement: gay doctors to improve awareness of gay health issues for health professionals since 1980²⁹, community associations and the French National Union of Gay

²⁰ CNS (1996), *Note valant avis à propos de la confidentialité en milieu pénitentiaire*, 8 July; (2005) *Rapport sur la politique publique de prévention de l'infection à VIH en France métropolitaine*, 17 November ; (2009) *Note valant avis sur l'expérimentation des programmes d'échange de seringues dans les établissements pénitentiaires*, 11 September ; (2020) *Avis et rapport sur la prévention, le dépistage et le traitement de l'hépatite C chez les personnes détenues*, 10 July.

²¹ CNS (2008), *Note valant avis sur le consentement au dépistage en cas d'accident d'exposition au sang impliquant un patient majeur protégé*, 12 March.

²² CNS (2001), *Note valant avis sur l'impact des politiques relatives aux drogues illicites sur la réduction des risques infectieux*, 20 January.

²³ See in particular CNS (2004), *Note valant avis sur le processus d'évaluation médicale des demandes de titres de séjour pour soins des étrangers*, 26 February ; (2014) *Avis sur la protection sociale des étrangers vivant avec le VIH en France et l'intérêt de son évolution vers le droit commun*, 18 April.

²⁴ Created in the 1980s by associations to allow isolated patients, sometimes without a home, to be housed, assisted and supported, the ACTs were established after an initial test phase in 1994.

²⁵ Moulin A-M. (2004), « Ordre et désordre dans le champ de la santé », in Schweyer F.X. et coll., *Normes et valeurs dans le champ de la santé*, Rennes, Editions ENSP.

²⁶ Massé R. (2007), « Le risque en santé publique : pistes pour un élargissement de la théorie sociale », *Sociologie et sociétés*, 39 (1), p. 13-27.

²⁷ Defert D. (1989), « Le malade réformateur », *Journal du sida*, June.

²⁸ The 1983 Denver Principles: <https://lebras.qc.ca/wp-content/uploads/2010/04/principes-de-denver.pdf>

²⁹ See Collet M. (2007), « L'Association des médecins gais. De la conquête de la parole aux difficultés de dire », *Le Journal du sida*, n°194, March.

Businesses (SNEG) to implement preventative measures in the gay scene³⁰ and self-support groups for drug users inspired by the American and Dutch efforts to promote risk reduction³¹.

The voice of PLHIV has been heard and listened to in hospitals and other health establishments, regional and national public policy steering committees and research bodies. The contribution of associations to the development of research and as participants of research has been particularly active within the TRT-5 inter-community group, which was established in 1992 by associations fighting AIDS. The experience of PLHIV proved relevant to providing guidance on the level of acceptability of a protocol, promoting the fair recruitment of participants to a trial and supporting or introducing an ethical consideration, particularly during the phase of assessment for research projects. The mediation undertaken by the associations has made it possible to provide the medical community and patients with information, particularly via specialist reviews³², on treatment trials and cohort studies, as well as the rights of individuals participating in the research.

The associations have made use of the knowledge and skills of the sociability networks to develop and establish prevention activities. The community-led associations, in connection with men who have sex with men (MSM), migrants, sex workers, as well as self-support associations for drug users and health associations like l'Arcat and Médecins du Monde (Doctors of the World) in France have also put in place programmes with vulnerable people exposed to HIV. Actions from peers and health mediators, who pursue projects of listening, support, prevention, screening proposal, etc., enable us to move towards and reach people in unfavourable environments through the intervention of public schemes.

These unique schemes focused on speaking and listening have also been established with all persons concerned to promote prevention. In addition, the helpline for AIDS information and guidance, Sida Info Service, created in 1990 in partnership with the association, Aides, has emerged as a valuable place for conversations concerning sexual health, risk-taking and fears of infection from callers and an important real-time intermediary for researchers and decision-makers for the development of questions, knowledge and practices from affected individuals.

This inclusion of the voice and experience of the subject has been unequal in the information and communication campaigns. It was recognised that the campaigns must avoid stereotypical messages and being out of touch with lived experiences by the target audiences and the messages addressed by the associations. The strategies that were only aimed at rational actors or, on the other hand, mobilised through fear, order or coercion towards individuals susceptible to being stigmatised as amoral could miss their targets. Likewise, unclear messaging that is insufficiently targeted at those who are most exposed and stand out in regard to acquired knowledge could expose inefficiencies. While several campaigns led by public entities have not avoided these pitfalls, prompting recurrent criticism from associations, other campaigns have been welcomed where they have involved the stakeholders at the designing stage and have mobilised their creative resources, such as the "3,000 Scenarios to Combat a Virus" campaign in 1994, which allowed input from young people on their experience and representation of HIV.

1.3. A DYNAMIC OF COMMITMENT AND COORDINATION THAT DOES NOT AVOID CONFLICT

The fight against HIV/AIDS created an individual commitment from stakeholders that was particularly pronounced. Collectively, this commitment has been coordinated, particularly in the field of research, thanks to the establishment of dedicated schemes on various scales. The strategies put in place have not been without delays, mistakes or conflicts in their conception and establishment.

National coordination

The development of research relied particularly on collaboration between multidisciplinary teams. At the start of the 1980s, the isolation and identification of the retrovirus responsible for the disease by a team of young researchers without institutional support gradually led to the development of ground-breaking programmes in different fields of life sciences – virology, immunology, diagnostics. This joint mobilisation made it possible to strengthen epidemiology, helping to identify the groups most at risk to the virus: MSM, drug users, haemophiliacs,

³⁰ Since its creation in 1990, the SNEG set up a department fighting AIDS, which became a stand-alone entity in 2013 called the French National Team for Intervention in Prevention and Health for Businesses (ENIPSE) and partners with several public institutions in the field of prevention and research.

³¹ Toufik A, Jauffret M. (1997), « Les groupes d'auto-support d'usagers de drogues », *Revue Toxibase*, n°4 - 4th quart.

³² Predominantly, *Journal du sida, Remaides, Protocoles and Info traitements*.

children born to HIV-positive mothers. Since 1985, social science has been mobilised³³, then coordinated, using investigations on knowledge, attitudes, behaviours and practices in the field of HIV and sexuality, to adapt strategies of prevention and combat discrimination³⁴. They have also contributed to studying the quality of life of PLHIV under treatment and its subsequent consideration in their treatment.

The decision to create a public establishment in 1988, the French National Agency for Research on AIDS (ANRS), in order to drive and finance research into HIV/AIDS, partly modelled on the American ACTG³⁵ for the therapeutic research section, has promoted multiple, and sometimes unprecedented, initiatives combining fundamental research, clinical and epidemiological research, in public health and in the human and social sciences. The emergence of a multidisciplinary response has proved constructive for (i) the evaluation of new medicines, by optimising the risk-benefit balance in developing evaluation protocols or the level of acceptability of individuals, (ii) the prevention of HIV transmission, for example by combining virology and socio-behavioural studies³⁶, (iii) the compliance of treatments and quality of life, (iv) the price evaluation of medicines.

Furthermore, the coordination has integrated associations, making it possible for them to contribute to the quality of therapeutic trials, which have been conducted from 1988 onwards³⁷, and to pilot community research in various fields such as screening, risk reduction risk within drug users and the later pre-exposure prophylaxis trials (PrEP). This coordination has been boosted by bodies of dedicated and long-term activity within the ANRS that were able to design and develop a research policy over time and organise working methods with the pharmaceutical industry and other partners. Gradually, a multidisciplinary HIV community was established, which has been regularly involved with the production of expert reports for the care of people suffering from HIV under the aegis of the ANRS and CNS since 2013.

Furthermore, the coordination of the ANRS was also pioneering by way of extending the scope of its actions to low-income countries, in coordination with researchers and doctors from these countries for therapeutic research – tuberculosis, prevention of mother-baby transmission and viral hepatitis – by involving human and social sciences in the areas of sexuality and key HIV populations.

This coordination problem has, on a regional level, resulted in the setting up of regional coordination committees to combat HIV (COREVIH) in 2005, instead of the Human Immunodeficiency Information and Care Centre (CISIH). The COREVIH, which has updated the CISIH projects, coordinates the actors in research, care, public health, social action and training and integrates associations for patients or healthcare system users. These regional structures are, in their composition and working, an example of “technical democracy”,³⁸ which promotes dialogue and coordination between researchers, healthcare professionals and representatives of associations. The CNS welcomed this organisation while stressing that their mission of coordination should be further strengthened and their skills further welcomed by regional healthcare agencies³⁹. One such example of strengthening skills and positioning has since been conducted in several regions.

International coordination

The coordination has been equally dynamic on an international scale, the results of joint actions by States, Non-Governmental Organizations (NGOs) and international organisations, as well as certain private organisations such as foundations.

Initiatives were set up in the 1990s promoting (i) the creation, in particular the initiative in France, of specific financial and technical instruments, such as the Global Funds for combatting AIDS, tuberculosis and malaria and Unitaid, (ii) the beginning of a managed international health governance, within the framework of the United

³³ Pollak M., Schiltz M.-A., Laurindo L. (1986), « Les homosexuels face à l'épidémie de sida », *Revue d'épidémiologie et de santé publique*, 34, 143-153.

³⁴ Spira A., Bajos N. et coll. (1993), *Les comportements sexuels en France. Rapport au ministre de la recherche et de l'espace*, La Documentation française ; Saboni L., Beltzer N. (2012), « Vingt ans d'évolution des connaissances, attitudes, croyances et comportements face au VIH/sida en France métropolitaine. Enquête KABP, ANRS-ORS-Inpes-IReSP-DGS », *Bulletin Épidémiologique Hebdomadaire*, n° 46-47, p. 525-9.

³⁵ *AIDS Clinical Trials Group* (ACTG), a public agency from the U.S. created in 1987 that replaced the unit for treatment and assessment of AIDS, which was created the preceding year by the National Institute of Health (NIH).

³⁶ For example, behavioural studies in viral pathophysiology study-oriented cohorts (ANRS-PRIMO, ANRS C02 Hemoco-Seroco, ANRS C015 ALT, etc.).

³⁷ Particularly, the ANRS SEROCO cohort of HIV-1 infected patients not treated with antiretrovirals at inclusion. The inclusion of patients began in 1988.

³⁸ Callon M., Lascoumes P. and Barthe Y. (2001), *Agir dans un monde incertain, essai sur la démocratie technique*, Paris, Seuil.

³⁹ CNS (2014), *Avis suivi de recommandations sur le bilan à mi-parcours du plan national de lutte contre le VIH/sida et les IST 2010-2014*, 16 January.

Nations system by the World Health Organisation (WHO) and UNAIDS (Joint United Nations Programme on HIV/AIDS) and (iii) the emergence of a model of international health democracy led by nonprofit networks. Coordination was also carried out within a bilateral framework, through hospital and community partnerships led between France and low-income countries, under the aegis of the public interest group, ESTHER, which was created in 2002 in order to improve treatment for HIV in these countries. Finally, coordination has relied heavily on dynamics of nonprofit coordination, particularly between French associations such as Solthis, Aides and Sidaction, but also international medical associations such as Médecins sans frontières (Doctors Without Borders) and Médecins du Monde (Doctors of the World) and associations from low-income countries to strengthen grassroots actions and promote sharing between these latter associations⁴⁰.

In the context of access to innovation, this international coordination has supported and promoted recognition of treatments as global public goods⁴¹ and the need for wider access in low-income countries. Not without difficulty due to the nature of the pharmaceutical industry, which is highly focused and anxious to protect its patents, with the support of certain States, progress has been made to drastically lower the prices of treatments as a group of countries. The two main initiatives have been (i) the Medicines Patent Pool (MPP), funded by Unitaid, which makes it possible, with the agreement of manufacturers, to make patents available as generics in order to make low-cost medication, (ii) the right recognised by the Doha Declaration (2001) within the framework of the World Trade Organization (WTO) for member countries to make use of exemptions provided for in the agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS), in particular compulsory licencing in emergency situations, even if these measures have unfortunately not confirmed their ambitions.

Delays, mistakes, conflicts

This collective and coordinated commitment has also been marked by delays, mistakes and conflicts responsible for negative consequences and more positive effects.

In France, while the fight against HIV has benefitted from an active response on the part of healthcare professionals and associations from 1982 onwards, the public authorities have been slow to implement a coordinated action. Indeed, the national government only set out a progressive policy for combatting HIV from 1986, drawing conclusions from the reports by Rapin (1986)⁴², Got (1988)⁴³ and Montagnier (1993)⁴⁴. Previously, public interventions had mostly supported progress originating from research⁴⁵ and highlighted the safety of blood transfusion. Furthermore, despite temporary measures, the public authorities did not put in place better adapted structural interventions, notably within the context of prevention, to fight the epidemic. In addition, associations, healthcare professionals and the CNS⁴⁶ warned public authorities about drug users being infected with HIV and the hepatitis C virus (HCV) for several years before succeeding in having a risk reduction policy implemented from 1994.

In addition to the delays and mistakes, some conflicts have impeded the implementation of effective coordination in the fight against HIV. In particular, there have been conflicts between associations and public authorities. Although the associations have been recognised, including in positive law⁴⁷, as having a role in the implementation of public action on the ground, they have previously contributed to the politicisation and publicising of HIV/AIDS, putting pressure on the public authorities through negotiation and confrontation and sometimes prompting the use of spectacular action⁴⁸.

Conflicts have also pitted the campaigners in the fight against HIV who are most affected by the epidemic against each other. This can be illustrated by the discussions which have surrounded the definition of risk with regard to HIV infection. The criticism of the idea of risk groups being rejected in favour of risk behaviours due to the fear

⁴⁰ For example, at the end of the 1980s, Aides developed the Réseau Afrique 2000 network in response to the demands of the association partnerships from the African continent. The network was then transformed with the creation of Coalition Plus to promote partnerships between associations from low-income countries.

⁴¹ The first work on global public goods was developed within the United Nations Development Programme: Kaul I, Grunberg I, Stern M. (1999), *Global Public Goods: International Cooperation in the 21st Century*, New York, Oxford University Press for UNDP.

⁴² Rapin (1986), *Investigation du working group sur le sida*.

⁴³ Got C. (1988), *Rapport sur le sida, op.cit.*

⁴⁴ Montagnier L. (1993), *Le SIDA et la société française. Rapport au Premier ministre*.

⁴⁵ Pinell P. (2002), *Une épidémie politique. La lutte contre le sida en France (1981-1996)*, Paris, Presses universitaires de France.

⁴⁶ CNS (1993), *Toxicomanie et sida. Rapport et avis relatifs à l'infection par le VIH parmi les usagers de drogues*, 8 July.

⁴⁷ Law of 9 August 2004 relating to public health policy.

⁴⁸ See for example Pinell P. (2002), *Une épidémie politique. La lutte contre le sida en France (1981-1996)*, *op.cit.*, Dodier N. (2003), *Leçons politiques de l'épidémie du sida*, Paris, Éditions de l'EHESS ; Broqua C. (2005), *Taking action For ne pas mourir ! Act Up, les homosexuels et le sida*, Paris, Presses de Sciences Po.

of stigmatisation and inability to include all individuals exposed, was followed by criticism of an approach targeted at individual behaviours and/or individual situations as it did not take into consideration some populations⁴⁹. With regard to these difficulties, the approach by key populations promised by UNAIDS made it possible to achieve an operational compromise, although this was not accepted by all stakeholders.

The debates between associations have been particularly intense due to diverging points of view, which have also fostered the production of common knowledge. Debates on the strategies for preventing the risk of sexual transmission, which have successively concerned the issue of serosorting⁵⁰, that of contamination with HIV from a person already infected by another type or subtype and that of the viral load with regards to the advice publication by Swiss experts⁵¹, have also contributed to the sharing and spread of knowledge on the challenges of HIV prevention and on the use and ways of implementing biomedical prevention.

Ultimately, the development of scientific knowledge has, in certain cases, made it possible to prevent conflict. The controversies linked to advice from Swiss experts, in particular, has been gradually overcome by the accumulation of knowledge and the arrival of powerful treatments, reinforcing the concept of non-transmission of HIV when the viral load is undetectable.

⁴⁹ Calvez M. (2004), *La prévention du sida. Les sciences sociales et la définition des risques*, Rennes, Presses universitaires de Rennes.

⁵⁰ Serosorting is the practice of using HIV status as a way of choosing a sexual partner who is of the same HIV serostatus as themselves.

⁵¹ Vernazza P. and coll. (2008), « Les personnes séropositives ne souffrant d'aucune autre MST et suivant un traitement antirétroviral efficace ne transmettent pas le VIH par voie sexuelle », *Bulletin des médecins suisses* 89(5):165-169.

2. DISCUSSION ON THE RELEVANCE OF THE FIGHT AGAINST HIV/AIDS TO OTHER PANDEMICS

The fight against HIV/AIDS has encouraged a set of principles and practices that have been proven through their implementation over 40 years. The measures put in place were determined by the context of the epidemic: type of transmission routes, the role of sexuality, drug use, the vulnerability of those at risk and, initially, by the regressive attitudes of public authorities, who largely left the task of innovations and intervention to NGOs. Despite these unique factors, the fight against HIV can serve as a model, taking into account the common challenges imposed by other epidemics and as shown by the campaign against hepatitis (2.1). Today's health crisis highlights the relevance of some of the responses used in the fight against HIV/AIDS to tackling emerging epidemics (2.2).

2.1. THE FIGHT AGAINST HIV/AIDS - AN EXPERIENCE TO BE LEARNED FROM

Confronted with HIV/AIDS, governments, along with all other stakeholders, have tackled challenges, particularly those posed by time, uncertainty and emotion, at both national and international levels, to which solutions have been found in other epidemics. The experience of the fight against HIV has fed into strategies and actions taken to combat hepatitis B and C, in particular.

The urgency that defined the fight against HIV/AIDS required an efficient and timely response to the epidemic by instigating research and prevention methods, and by prioritising unprecedented coordination, in the absence of treatment in the early stages, and of a vaccine. It also entailed allocating resources according to need, depending on the areas and populations most at risk, and responding to deficits in treatment availability by conceiving and implementing a "triage" system to prioritise patients' access to treatment on a temporary basis.

Insufficient or lacking scientific understanding of the epidemic, and therein the inability to control it, created uncertainty and demanded constant adaptation by stakeholders. This in turn may have been detrimental to the relationship of trust between those affected, the general public and the authorities. Conflicting communication, awareness and prevention decisions that were taken by different associations and institutions, along with policy decisions taken regarding care and research, at times caused confusion and engendered suspicion, even distrust. Such a challenge required enhanced dissemination of information, stakeholder consultation and participation by those directly affected in the decision-making process.

The challenge presented by the high level of emotion was particularly strong, given that it concerned the death of young people. It may also have reinforced stigmatisation and discrimination towards those affected and groups associated with the epidemic who were blamed for the spread of the virus. It has therefore required, with the help of social sciences, an enhancement of knowledge, beliefs and behaviours of individuals, constant adaptation of prevention messages, respect for the rights of individuals, in particular the right to consent and confidentiality.

At a national level, these challenges have resulted in a particularly ambitious public response going beyond the scope of health policies. Like other pandemics, the HIV pandemic is a syndemic, which required, on the one hand, an intersectoral response in order to mobilise all the sectors concerned – financial, medico-social, police, justice, transport, etc. On the other hand, it has required an intersectional approach in order to aim services at the most exposed people, who are generally at the intersection of several relationships of domination or fragility⁵².

Finally, the global dynamics of the epidemic and the difficulties faced by low-income countries required a coordinated, ethical and supportive international response. The demand for access to services, treatments and in particular innovation for low-income countries, voiced by NGOs, morally obliged pharmaceutical companies and public decision-makers to make use of uncommon means. The tools developed at this time by the fields of finance, technology and governance were innovative but not specific in their approach and can be used in other health campaigns. More generally, the internationalisation of the fight against HIV/AIDS supported by non-profit networks remains an unequalled model of health democracy for access to rights, prevention and care for the most vulnerable populations.

The responses to HIV/AIDS have already benefitted the fight against HBV and HCV. Therapeutic, virological and social science research was organised, within the framework of the ANRS, on the basis of an identical model of coordinating researchers, who, in a very short space of time, set up a "viral hepatitis" community involving associations of patients and service users of the health system. An expert report has provided a reference base

⁵² For further reading on the subject of intersectionality, consult: Singer M., Bulled N. (2012), « Interlocked infections: the health burdens of syndemics of neglected tropical diseases », *Annals of Anthropological Practice*, 36/2, p. 328-345.

for all issues of patient management and follow-up in a comprehensive approach. Moreover, the CNS itself has based its approach to the fight against hepatitis on the model of the fight against HIV/AIDS. At the international level, advocacy for access to direct-acting HCV treatment in low-income countries has followed the lead of advocacy for access to HIV treatment.

2.2. THE MEASURES TAKEN IN THE FIGHT AGAINST HIV/AIDS APPLIED IN THE CONTEXT OF EMERGING EPIDEMICS

Taking into account this history, experience of the fight against HIV/AIDS can help to shape the responses to other epidemics, in particular the SARS-CoV-2 pandemic and possibly other emerging epidemics in the future. The difficulties faced in providing a timely and appropriate response to the challenges of the current health crisis, in the main areas of public action, warrant an examination of past experiences, including that of the fight against HIV/AIDS. To some extent, many of the characteristic aspects of this struggle – rights, public health, coordinated research, international mobilisation, etc. – remain relevant and pertinent to shed light on the current situation.

The current health crisis has significantly challenged the entire health system. The workload of many hospital regulation services (SAMU-centre 15) and care services (emergency, medicine, resuscitation, follow-up care, palliative care, etc.) was profoundly affected by the demand for care from patients with Covid-19 and other patients. Despite difficulties related to administrative restrictions, lack of resources and lack of preparedness on the part of the public authorities, the hospital system has, overall, provided responsive and comprehensive care for patients. However, access to preventive services, access to care for other patients, mental health care and care for people with disabilities faced obstacles that were amplified during the health crisis. In addition, feelings of extreme isolation experienced by patients were reported by service user associations. The strained connection between patients and health professionals, who were then overwhelmed, highlighted the importance of more frequent use of mediation in hospitals in order to encourage time for dialogue and improve support for patients and their relatives. This function, promoted within the framework of the fight against HIV in communities, has had a reference guide since 2016⁵³.

The health crisis also highlighted the difficulties faced by health and social care institutions in fully guaranteeing the rights of individuals and effectively combatting the epidemic. Thus, an increase in violations of the rights and freedoms of EHPAD (care homes for the elderly) residents has been recorded since the beginning of the health crisis, with regard to the right to maintain family ties, freedom of movement and respect for prior consent to screening tests⁵⁴. EHPADs were particularly affected by the structural weaknesses in their operation that were exacerbated by the health crisis, especially the insufficiency of resources for health staff on many sites and an insufficient risk culture, with a large number of establishments not having a business continuity plan⁵⁵. In this context, the practice of mediation, which would require the creation of bodies not currently provided for in the medico-social sector, also appears justified.

More broadly, the health crisis has highlighted the vulnerabilities of certain populations, taking into account, in particular, social inequalities in exposure to the virus, geographical inequalities in access to healthcare and the social determinants of comorbidities that expose people to serious forms of Covid-19. These vulnerabilities, which have recently been highlighted⁵⁶, call for regular diagnosis and measures adapted to needs, both in terms of resource allocation and recommendations for care according to a holistic approach that takes into account medico-social, cultural, psychological, socio-economic and quality of life factors for people and their social circles. The development of the expert report on how the fight against HIV was managed, presented above, has made it possible to define, in addition to the most appropriate therapeutic solutions, a framework that facilitates holistic treatment and the safeguarding of patients' rights.

In terms of prevention, the health crisis has, despite improvements, highlighted the structural weakness of public health policies that are insufficiently supported, financed and coordinated between the advisory, expert and management organisations concerned⁵⁷. In 2020, the policies are focused more on adopting mandatory and

⁵³Law of 26 January 2016 on the modernisation of our health system.

⁵⁴ Défenseur des droits (2021), *Rapport sur les droits fondamentaux des personnes âgées accueillies en EHPAD*.

⁵⁵ Sénat (2020), *Santé publique : pour un nouveau départ - Leçons de l'épidémie de covid-19*. Rapport de Deroche C. (et coll.) fait au nom de la commission d'enquête Évaluation des politiques publiques face aux pandémies, 8 December.

⁵⁶ Bajos N. and coll. (2020), « Les inégalités sociales au temps du Covid-19 », *Questions de santé publique*, numéro 40 ; Papon S. et coll. (2020), « Une hausse des décès deux fois plus fortes pour les personnes nées à l'étranger que pour celles nées en France en mars-avril 2020 », *INSEE FOCUS*, issue 198.

⁵⁷ For more on the concept of coordination, see Bergeron H., Borraz O., Castel P., Dedieu F. (2020), *Covid-19 : une crise organisationnelle*, Paris, Presses de Sciences Po.

restrictive measures that have been insufficiently explained, rather than promoting similar interventions that are adapted to local and regional levels. Furthermore, prevention actions, often limited to top-down, poorly targeted, authoritarian communication based on fear or coercion and devised by advisory boards, have run counter to the principles of open social marketing that needs to be promoted, in terms of information and communication, taking into account life contexts, levels of health⁵⁸ and digital literacy. In these areas, the HIV/AIDS prevention model, designed and implemented with associations and those affected, based on the principles of health education and citizen empowerment, is still relevant.

The current crisis has also highlighted the limits of democracy in health. At national level, although the CCNE (French National Advisory Ethics Committee) was consulted at an early stage by the public authorities on the ethical issues involved in caring for patients⁵⁹ and in EHPADs⁶⁰, the reference body for health democracy, the CNS (National Health Conference), was consulted at a later stage, in December 2020, leading it to look into the matter directly⁶¹. Furthermore, the public authorities chose to create an ad hoc scientific council that did not include representatives of patient and health service user organisations⁶². Beyond the consultative bodies, the proposals for a liaison committee with citizens, notably those put forward by the CNS and the scientific council, have come to nothing. At the sub-national level, the regional (the Regional Health and Autonomy Conferences) and local (the Regional Health Councils) health democracy bodies had little or no consultation role during the health crisis, particularly during the vaccination implementation phase⁶³. More generally, "a collapse of the structures allowing the expression of collective rights" was noted by the representatives of the approved associations of health service users grouped within France Assos Santé (a health service user association)⁶⁴. This observation demonstrates the need to involve and consult the representatives of patients' and health system users' associations, as they were in the fight against HIV/AIDS, at regional level within the framework of the COREVIH and, at national level, with the steering committee of the national sexual health strategy.

In addition, the current crisis has shown the need for national and European leadership, coordination and funding capacity to meet the challenges in the field of research. In France, the REACTING consortium set up a scientific council in January 2020 to define research priorities, implement trials and cohorts in hospital and outpatient settings and strengthen national and European coordination. However, the absence of a proactive research policy in 2020 with substantial funding and directed by a dedicated operator modelled on the ANRS, has been a barrier to promoting ambitious research projects. On 1 January 2021, the creation of a new agency, ANRS | Emerging Infectious Diseases, based on the ANRS model, integrating the REACTING network on 1 January 2021, is now an opportunity to upgrade the leadership and coordination of research into new epidemics.

Finally, at the international level, the current crisis has highlighted the very inconsistent deployment of tools to fight the pandemic, particularly those inherited from the fight against HIV. While some countries, such as Thailand, Vietnam, Rwanda and Senegal, reacted early and mobilised community healthcare providers in an appropriate way, others, such as Tanzania and Brazil, did not do so, either sufficiently or at all. At the multilateral level, the WHO has been relatively quick to come up with HIV-inspired proposals for funding and technical assistance⁶⁵, though with limited success. The United Nations and multilateral organisations such as the G7, G20, IMF and World Bank have mobilised more slowly and in a very flawed way, focusing their efforts on access to vaccines rather than on support for countries, and with a view to international health security rather than solidarity. The use of TRIPS exemptions, implemented in the fight against HIV/AIDS, has not yet been implemented, despite requests from India and South Africa. For example, the temporary lifting of patents on vaccines remains a subject of debate and controversy between several high-income countries and the pharmaceutical industry.

⁵⁸ Health literacy is understood as the motivation and skills of individuals to access, understand, evaluate and use information to make decisions about their health. See Van den Broucke S. (2014), "Health literacy: a critical concept for public health", *Archives of Public Health*, 2014, vol. 72, no 1.

⁵⁹ CCNE (2020), *Contribution du CCNE à la lutte contre COVID-19 : Enjeux éthiques face à une pandémie*, 13 March.

⁶⁰ CCNE (2020), *Réponse à la saisine du ministère des solidarités et de la santé sur le renforcement des mesures de protection dans les EHPAD et les USLD*, 30 March.

⁶¹ Conférence nationale de santé (2020), *Avis de la CNS relatif à la crise sanitaire du Covid-19*, 2 April; *La démocratie en santé à l'épreuve de la crise sanitaire du COVID-19*, 15 April; *Avis relatif au projet de loi portant prorogation de l'état d'urgence et complétant ses dispositions*, 05 May.

⁶² A representative of ATD Fourth World, appointed by the President of the Senate, joined the Scientific Council a few weeks after its creation.

⁶³ Conférence nationale de santé (2021), *Avis relatif à la démocratie en santé en période de crise sanitaire*, 20 January.

⁶⁴ Sénat (2020), *Santé publique : pour un nouveau départ - Leçons de l'épidémie de covid-19. Rapport de Deroche C. (et coll.) fait au nom de la commission d'enquête Évaluation des politiques publiques face aux pandémies*, op. cit.

⁶⁵ The COVAX (COVID-19 Vaccines Global Access) initiative, the ACT accelerator partnership, a device to accelerate access to COVID-19 control tools.

RECOMMENDATIONS

At the end of this opinion, the CNS reflects that the response to emerging epidemics must be part of an ethical approach that pays particular attention to the principles of respect for the dignity and autonomy of individuals, and equity in access to rights and health, on a national and international scale. This approach, tried and tested over forty years of fighting HIV/AIDS, can be applied through three objectives and a set of actions that can contribute to the development of a timely and appropriate response to the challenges imposed by emerging pandemics.

The Council recommends:

→ *to consolidate an approach that respects the rights of individuals,*

- **uphold the objective of preserving the rights of individuals in the context of a pandemic,**
 - ensure respect for the fundamental rights of people, particularly the most vulnerable, as well as continuity of access to all rights, health, social, economic, etc.
 - ensure the dignity of victims of the pandemic and promote the support for relatives of the dying and deceased,
 - monitor the protection of people's rights and their access thereto, with the help of advisory bodies on ethical, social and human rights issues,
- **guarantee the rights of people in institutions, particularly health, social and medico-social institutions,**
 - create conditions that facilitate the preservation or expansion of individuals' rights, in particular respect for dignity and confidentiality, the right to information and the right to free and informed consent,
 - ensure that measures restricting liberty are necessary, proportionate to the health aim pursued and limited in time,
 - design and set up a mediation system in medico-social establishments and to support the development of mediation practices in all establishments in the near future,
- **reduce social and geographical health inequalities in access to rights, particularly rights to healthcare,**
 - rapidly adapt social protection systems for those affected and their dependants,
 - guarantee access to rights in all regions, taking into account the local resources of public services, geographical constraints, people's social situations, linguistic diversity and different uses of digital technology,

→ *to promote a global approach to the subject as part of an ambitious public health strategy, particularly through a community health approach,*

- **assert a strategy of universal access to diversified prevention,**
 - ensure safe, equitable access to prevention and risk reduction measures and tools, as well as to all essential products in every region, taking care to reach the most vulnerable populations and those who are furthest from the health system,
 - diversify prevention strategies in order to adapt them to the demographics concerned and the specificities of the regions,
 - ensure and promote the participation of those affected in the creation of prevention strategies,
- **promote information, prevention and health education in situations of emergency and uncertainty,**
 - ensure access to quality health information for the whole population, taking into account, in particular, the diversity of health⁶⁶ and digital literacy levels,
 - develop a culture of public health and comprehensive health, particularly in the context of education for young people, and with this purpose enhance guidance, information and prevention mechanisms and structures for the public,

⁶⁶ See note n° 58.

- set up information and communication campaigns adapted to the different life contexts of the populations and involve the people concerned in the design and implementation of these campaigns,
- **build on the knowledge of communities and associations**
 - promote the role of peers, health mediators and interpreters in communities,
 - support associations and structures that pursue outreach actions towards people and communities and that implement comprehensive approach to access to health and rights,

→ *to strengthen collective mobilisations,*

- **promote a responsive and involved health democracy,**
 - report the main proposed measures to the relevant health democracy associations at all levels, both national, regional and local,
 - coordinate between health democracy bodies and advisory bodies concerned with ethical, social and human rights issues,
 - support and involve patient and health service user representatives in health, social and medico-social institutions,
 - facilitate the pooling of experience and knowledge shared by local stakeholders, within the framework of health democracy associations, when this is in the interest of other regions or territories,
- **advocate a coordinated research policy,**
 - extend the model of HIV research based on the facilitation and coordination of multidisciplinary research from fundamental sciences to social sciences, and integrating community-based research into all emerging disease research structures,
 - guarantee sufficient and sustainable resources for research on emerging diseases within the framework of the new agency, ANRS | Emerging Infectious Diseases, which will also have to maintain the sustainability of research on HIV and viral hepatitis,
- **increase international initiatives based on solidarity,**
 - establish and develop models of participatory democracy and inclusive governance in the near future, taking into account the evolution and specificities of epidemics in different regions, contexts and vulnerabilities,
 - continue and expand the development of partnership tools for research, financing, technical assistance and procurement,
 - establish the principles and mechanisms of international health governance, for health emergencies, as well as for chronic diseases and the achievement of sustainable development goals in the field of health,
 - initiate an international discussion on the changing role of the intellectual property protection system for essential products, such as medicines and vaccines, with a view to their recognition as global public goods⁶⁷.

⁶⁷ See note n° 41.

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INDEX OF ACRONYMS AND ABBREVIATIONS

ANRS | MIE: National Agency for Research on AIDS and Viral Hepatitis | Emerging Infectious Diseases

CCNE: National Consultative Ethics Committee

CISIH: Human Immunodeficiency Information and Care Centre

CNS: French National AIDS & Viral Hepatitis Council

COREVIH: Regional Coordination Committee for the fight against HIV infection

EHPAD: Care home for the elderly

HBV: Hepatitis B virus

HCV: Hepatitis C virus

IMF: International Monetary Fund

MPP: Medicines Patent Pool

MSM: Men who have Sex with Men

NGO: Non-Governmental Organization

NHC: National Health Conference

ONIAM: National Office for Compensation for Medical Accidents, Iatrogenic Disorders and hospital-acquired Infections

PLHIV: People living with HIV

PrEP: Pre-Exposure Prophylaxis

TPE: Therapeutic Patient Education

WHO: World Health Organization

WTO: World Trade Organization

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