

HIV OUTCOMES ITALIA  
2022  
GOOD PRACTICES

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# GOOD PRACTICES IN ITALY

## RECOMMENDATION 1 - ADOPT AN INTEGRATED, OUTCOMES-FOCUSED AND PATIENT-CENTRED APPROACH TO LONG-TERM HIV CARE

a) *Put comorbidity prevention, treatment and management at the centre of long-term HIV care*

### DEDICATED VACCINATION PROGRAMMES FOR PWH

(We suggest to keep this practice, that is already present, with some integrations)

#### CONTEXT

Due to their compromised immune system, people with HIV (PWH) face a higher risk of developing infections. In addition, risky behaviours might result in greater risk of acquiring certain infections. This means that certain infections pose a greater risk to PWH than they would to the general population. Vaccination is a fundamental tool for preventing a number of communicable diseases. However, because of their immunodeficiency, there are specific warnings: first, PWH with low Cd4 count cannot be given vaccines composed by alive, attenuated viruses. For example, the measles vaccine should not be administered to seriously immunocompromised people – including PWH – because it increases their risk of developing the infection. Second, also in less compromised PWH the response to vaccines might be weaker or short lasting as compared with general population, thus making them still at risk.

It is crucial that vaccinations for PWH should comply with the treatment guidelines for people with HIV already adopted both at the European and at the national level.

The Covid-19 vaccination program in Italy has considered persons with AIDS or with <200 CD4+ as a priority category, to be vaccinated before the general population. And all PWH have been considered for vaccination before the general population.

#### INTRODUCTION

In Italy, vaccination programmes targeted at PWH are regulated by two plans:

1. National Vaccine Prevention Plan (Piano Nazionale di Prevenzione Vaccinale – PNPV)
2. National HIV/AIDS Plan (Piano Nazionale di Interventi contro HIV e AIDS – PNAIDS)

Both plans were drafted by the Ministry of Health and agreed upon in the State-Regions Conference. This means that they are shared by the two levels of Government responsible for managing the NHS. Both plans have a section dedicated to vaccinations for PWH.

#### AIMS

The goal of the National Vaccine Prevention Plan is to harmonise vaccination programmes across the country. This should ensure that everyone has access to the benefits of vaccination, thus improving individual and collective health. In addition, the plan aims to provide target sub-populations – including PWH – and actively offer them vaccines.

Those vaccines listed in the plan are classified as the basic levels of assistance and thus are offered free to those belonging to the relevant target sub-populations.

In the HIV/AIDS plan, vaccines are viewed as a method of preventing infections in PWH. It includes specific actions designed to address the needs of PWH relating to immunodeficiency. The plan sets the following objectives:

- Implement the National Vaccine Prevention Plan and the guidelines adopted by the scientific community (in particular by the Italian Society of Infectious and Tropical Diseases – SIMIT)
- Conduct a survey in a number of infectious disease units to determine the genuine vaccination rate in PWH and any flaws or shortcomings in the provision of vaccines
- Promote personalised vaccination programmes targeted at PWH
- Harmonise vaccines on offer across the country.

As a consequence of the Covid-19 pandemic Italy introduced a vaccination program identifying priority groups in reason of the augmented risk of infection and worse outcomes. Persons with AIDS or with <200 CD4+ have been considered as Priority 1 – to be vaccinated as early as possible-, while PWH have been considered as Category 4, to be vaccinated before the general population.

## METHOD

Both plans have set the goal of increasing immunisation coverage for people with HIV (PWH). However, achieving this goal has been frequently hampered by the limited funding available.

A more sustainable way of promoting immunisation is to put in place dedicated programmes for providing specific sub-populations of PWH (e.g. aging people) with access to vaccines.

A number of infectious disease units across the country have already implemented dedicated vaccination programmes targeting the needs of specific categories of PWH. More specifically, the units offer the following vaccines:

- Meningococcal
- Pneumococcal
- Herpes Zoster
- Hepatitis A and B
- Human Papillomavirus Infection (HPV).
- To be added the anti-SARS CoV-2 vaccination and, in risky groups, the monkeypox vaccine

A number of the units have a dedicated vaccination schedule in place.

In addition, in units where patient registries have been digitalised, selected vaccines are actively offered to specific sub-groups of people at risk.

Where digitalised and integrated systems are available, the personalised vaccination programmes also include serologic follow-up after vaccine administration as well as automatic alerts (e.g. for recalls) to minimise the risks potentially harming the retention in care.

## RESULTS

Data on the outcomes of vaccination programmes in PWH is not yet available, as both plans are still in the course of being implemented. However, the HIV/AIDS Plan has established performance indicators, giving a

clear sign that policymakers aim to assess the outcome and performance of the PWH vaccination programmes with a view to updating the Plan.

Yet even before any outcome assessment, it is clear that adopting dedicated vaccination programmes for PWH in infectious disease units has been a major success. It marks a major advance, from planning vaccination strategies at the national level to actually implementing them locally. Although the vaccines offered to PWH vary considerably between regions and even within individual regions, vaccines are now successfully actively offered to PWH in a number of units across the country.

## RECOMMENDATIONS

- Set PWH vaccination programmes for all infectious disease units across the country
- Digitalise all vaccination registries
- Wherever dedicated vaccine programmes are in place, systematically collect data on number and types of vaccines offered to PWH to help estimate the number of infections avoided
- Create a dedicated registry for adverse events following vaccinations in PWH.

In addition, the pandemic experience suggests that whenever a new virus is found, it should always:

1. be verified the impact of the new virus on the specific target compared to the general population;
2. be verified the possible risk of vaccine infection in relation to the immunodeficiencies of PVHIV;
3. be expressed the opinion on vaccination priority for the target.

## AGING CLINICS

(We suggest to keep this practice, that is already present, with some integrations)

## CONTEXT

The most recent therapeutic solutions, particularly the introduction of anti-retroviral therapies (ART), have transformed HIV/AIDS from a fatal viral disease to a manageable chronic condition. Life expectancy in people with HIV (PWH) now has the potential to match that of the general population. Moreover, diagnosis of HIV infection in adults has increased over the years.

However, HIV can accelerate the aging process, due to HIV-related chronic inflammations and the cumulative effects of pharmacological treatments.

Healthcare professionals involved in HIV care should adopt an approach that takes account of the associated frailty and disability as well as the increased risk of developing comorbidities. This approach should focus on the Health-related quality of life (HRQoL) of Older Adults with HIV (OALWH).

## INTRODUCTION

In Italy, as in other European countries, Aging Clinics have been established in a number of healthcare facilities to target the specific needs of OALWH. These clinics provide a multi-disciplinary health service with a mission of addressing comorbidities and complications associated with HIV/AIDS and/or antiretroviral therapy (ART) use in OALWH.

## AIMS

From an HIV/AIDS perspective, the aim of Aging Clinics is to ensure that OALWH receive integrated and holistic treatment. A multidisciplinary staff of infectious disease specialists, cardiologists, diabetologists, nephrologists, orthopaedists, oncologists, neuropsychologists, nutritionists and occupational therapists evaluate patients' anthropometric, immune-metabolic and physical functions as well as any cognitive impairment combining clinical practice with educational interventions on lifestyle (i.e. exercise and nutrition) with the aim of ensuring healthy ageing in PWH.

## METHOD

The patient is at the centre and all services are coordinated to offer a multidisciplinary assessment in a single access. In the Modena Metabolic Clinic, the most relevant experience of this kind at this concern in Italy, all patients, over 50, are subjected to a "comprehensive Geriatric assessment (CGA)" which allows to evaluate not only HIV and related co-morbidities, but also the problems related to age and frailty and the vulnerability of individuals and the risk of developing disabilities. The CGA is feasible thanks to a strong integration between support services and research and the presence of dedicated professionals such as occupational therapists, neuropsychologists, dieticians and a "health coach" that is a nurse specialised in promoting lifestyles. The path deals not only with the disease, but above all with the health of PWH, measuring the evolution to aging through health indicators based on the WHO model.

Patient-reported outcome measures (PROMs) are administered to patients through online questionnaires before the scheduled date of the visit, allowing the clinicians a better understanding of the health status of the patient identifying areas for further discussion and investigation during consultations.

Access to Aging Clinics is free for all PWH; patients do not need a NHS prescription from their general practitioner. This service is organised by infectious disease units, with each patient managed by a multi-disciplinary team of clinicians focusing on the health status of OALWH.

In addition to the routine blood test, OALWH attending Aging Clinics undergo a number of additional tests (e.g. DXA, abdominal and thoracic CT, IMT). This information is then used by the infectious disease specialists to help personalise lifestyle interventions, optimise treatment for non-infectious comorbidities, manage polypharmacy and, perhaps most importantly, optimise anti-retroviral treatment.

## RESULTS

Experience with OALWH has shown that access to Aging Clinics improves quality of life and makes an important contribution in mitigating the harm and side effects of both HIV and/or aging.

In particular:

- Screening programmes have allowed serious diseases (particularly cancers) in PWH to be detected earlier
- Where a patient is the subject of multiple treatment regimens for different diseases, comprehensive information on the patient's current state of health allows healthcare professionals to evaluate potential changes to medicines to avoid the risk of any drug/drug interaction and manage potential inappropriate prescriptions

- Aging Clinics have improved the relationship between patients and their healthcare professionals, particularly where OALWH had not previously visited infectious disease units on a regular basis.

The Modena Metabolic Clinic has been active since 2003 and since then 5,500 patients have been evaluated, 2,500 of whom have been treated. The results observed from the point of view of quality of life and social inclusion are important, and they were presented in 2022 to the European Parliament in Brussels as part of the HIV Outcomes initiatives.

The prospective description of the prevalence and incidence of specific health conditions of elderly people with HIV traces the patient's biological aging trajectory by providing individual clinical information, but also general epidemiological information on care needs of patients with HIV disease.

The metabolic clinic is currently carrying out a study aimed at validating a “virtual metabolic clinic” to offer specific support services to infectious disease clinics in Italy.

## RECOMMENDATIONS

Aging Clinics are not uniformly spread across the country. An important short-term goal should be to replicate this practice by establishing new metabolic care networks in those infectious diseases units that do not currently offer them. The work of Aging Clinics should be undertaken in close coordination with the clinics where patients receive their ART, beginning with the introduction of CGA for OALWH having HIV for a long time and with the implementation of multidisciplinary staff.

## WORKING GROUP ON AGING

### CONTEXT

The aging of the Italian population is among the fastest in the world and this has suggested the need to reflect on the problem of the quality of life of elderly people, and on the process of chronicization in HIV for people of geriatric age. Even if data show that the life expectancy of PWHs is similar to that of the general population, but they face a greater risk of developing comorbidities, in Italy there was no awareness of the problems inherent in the aging of PWHs.

### INTRODUCTION

The management of a chronic condition implies to tackle several factors that have to do with the multidimensional psycho-physical conditions and the related integrated access to the social health system, as well as with the quality of life, an aspect that has become increasingly relevant in recent years.

A working group on aging has been established with the aim of identifying and understand which is the correct care model and the reference figures for proper aging management, keeping the patient at the centre.

### AIMS

The aim of the action is to set up a care model intended to promote a correct management of aging in HIV, keeping the patient at the centre, on an equal footing with health policy needs.

To identify the most appropriate tool for the implementation of health strategies most suitable to answer to aging PWH needs within a "patient-centred" model and a holistic vision, **a working group on aging with HIV** was established.

## METHOD

To achieve this goal, a complex work plan was elaborated. It started with the establishment of a working group.

- A **dedicated scientific committee** worked on defining the perimeter of aging in HIV.
- A **comparative desk analysis** was then carried out on existing national and European guidelines at this concern, that allowed the elaboration of a synoptic table that includes all the relevant statements for the correct clinical and multidimensional management of frailties in people with HIV.
- Then, to identify unmet needs and criticalities with respect to aging with HIV and to discuss the statements included in the synoptic table, **some interviews were organized with expert patients** belonging to associations to evaluate the state of the art from their point of view.
- To gather a qualitative view on the organizational level of clinical infectious disease centres, a **national survey** was carried out in two parts: one aimed at the centres and one at HIV patients > 50 of the same centres, to consider their well-being, their frailties and quality of life.
- At the end the results of the different actions were discussed in **meetings with a group of stakeholders** that include associations, infectious disease specialists, geriatricians, family doctors, neurologists and head of structures for the elderly to reflect on the importance of managing frailties in elderly PWH.

## RESULTS

The work done has allowed to elaborate a **position paper signed by all the stakeholders involved** to bring this issue to the agenda of national and regional policymakers.

The most suitable care model and tools identified for ensuring the implementation of the recommendations provided for by the guidelines and by the experts is the so called **Diagnostic Therapeutic Care Path (PDTA** in Italian). It is considered of strategic importance in the design of health policies, as it allows to define the best care and management process for each pathology, within a coherent economic, professional, and human framework, providing adequate resources for each person. The evidence is that **an ad hoc PDTA for PWH dealing with aging issues** should be considered as the best solution: the multidisciplinary nature of the diagnostic therapeutic assistance approach promoted by the PDTA in fact considers all the areas inherent to the person's physical and cognitive functional condition, also taking into account the aspect of the poly-pharmacy, social support and paying attention to the area of mental health. The path includes the process that a PWH undertakes from his first contact with the NHS to the therapeutic treatment, and the organisation of all care phases: diagnosis, therapies and assistance in a multidisciplinary and multi-professional perspective.

The PDTA is also the administrative tool for transposing the recommendations contained in the guidelines into practice at local level (the Region).

## RECOMMENDATIONS

It is necessary to involve policy makers so that they consider the new care models in a correct programming logic and that they promote the adoption of tools such as the PDTA to approach the issue of aging correctly. Since today there are few Italian Regions that have adopted a complete PDTA for PWH and that, even among the most performing regions, the aging aspect is not sufficiently developed, it is necessary to sensitise the institutions so that they can fill this gap.



## RECOMMENDATION 3 - FUND COHORT STUDIES TO PROVIDE INFORMATION ON THE LONG-TERM HEALTH OF PEOPLE WITH HIV

### GEPP0 - GERIATRIC PATIENTS WITH HIV/AIDS: A PROSPECTIVE MULTIDIMENSIONAL COHORT<sup>1</sup>

#### CONTEXT

Population of people with HIV is graying: an estimated 60% of HIV patients in Italy are expected to be over 60 years of age by 2030 and 10% over 70 years of age.

There are several cohort studies, monocenter or multicenter, such as the ICONA cohort, addressing PWH and their diseases and treatments, that have included aging individuals, and give important results on HIV clinical course. These cohorts might integrate and/or be comparators with the only cohort addressing only geriatric PWH, i.e. the GEPP0 cohort.

GERiatricPatients with HIV/AIDS (GEPP0) is a prospective observational multi centric cohort of geriatric patients being treated for HIV in 11 centres across northern and central Italy. It aims to describe health status and transition over time in HIV-infected patients above 65 years.

#### AIMS

GEPP0 is a prospective observational multi-centric cohort including geriatric patients with HIV. The purpose of GEPP0 is to determine PWH health status and how it changes over time, to investigate the extent to which the geriatric care model (reduction of polypharmacy and prevention and better management of multiple morbidities) applies to HIV patients and to identify factors affecting their healthy life expectancy.

#### METHOD

GEPP0 gathers patients recruited in eleven different Italian centres of infectious diseases, with the coordination of the Metabolic Clinic of Modena. The cohort was born in 2015 with the aim of evaluating various aspects, including the state of health and its variations in people with HIV aged  $\geq 65$  years, to investigate how to apply geriatric care to this population cluster, and to identify coexisting factors, such as disability, comorbidities and mortality, that influence the quality and life expectancy of elderly HIV subjects.

The inclusion criteria at the moment of recruitment were: age  $\geq 65$  years, HIV Antibodies positive, being on highly active antiretroviral therapy (HAART) for at least 6 months (categorised as multidrug regimens (MDRs) and less drug regimens (LDRs). Multi-morbidity (MM) is defined as the presence of three or more non-communicable diseases, and polypharmacy (PP) as the use of five or more medications in chronic use.

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<sup>1</sup> Sources: <https://penta-id.org/hiv/geppo/>; Nozza et alii (2017), *Antiretroviral therapy in geriatric hiv patients: the geppo cohort study*, <https://pubmed.ncbi.nlm.nih.gov/28605493/> and [https://iris.unito.it/retrieve/e27ce42d-649a-2581-e053-d805fe0acbaa/GEPP0\\_treatment\\_postprint.pdf](https://iris.unito.it/retrieve/e27ce42d-649a-2581-e053-d805fe0acbaa/GEPP0_treatment_postprint.pdf)

GEPPPO cohort is coordinated by a Board of expert geriatric and infectious disease clinicians belonging to participating centres. Pharmacovigilance studies carried out in GEPPPO are funded by pharmaceutical companies.

## RESULTS

The GEPPPO cohort is one of the largest existing geriatric cohorts in HIV. It depicts a well characterised population of people aging with HIV, with a median duration of HIV of 17 years and a homogeneous exposure to decades of HIV infection: <10 years, 10 – 20 years and above 20 years. The expectation is that GEPPPO cohort may help characterise antiretroviral (ARV) prescribing criteria used in real life by Italian infectious disease (ID) physicians.

The study published in 2017<sup>2</sup> describes the results obtained.

- Target reached: 3,100 HIV-positive patients involved and 1,222 included (median age 70 years); females composed 16% of the cohort.
- MM was present in 64% and PP in 37% of the patients.
- Treatment consisted of triple therapy in 66.4%, dual therapy in 25.3%, monotherapy in 6.5% and 'mega-ART' with more than three drugs in 1.64% of the patients.
- Female gender and age were predictors of unboosted ARV regimens.
- One of the most surprising findings in the GEPPPO cohort is the impressive number of different ARV drugs and drug classes.

## RECOMMENDATIONS

Multimorbidities are generally associated with age, and for this reason it is important to choose antiretroviral therapy in order to limit toxicity and interaction with other drugs administered to the patient. In the over 65s, the most common diseases in addition to HIV are cardiovascular diseases and, secondarily, kidney and bone diseases.

At the same time there is little high-quality evidence to guide ARV prescriptions for the elderly HIV population because these patients are generally excluded from clinical trials: medications used to treat chronic and acute diseases are in fact rarely tested in the older population due to the high prevalence of geriatric conditions (ie, cognitive impairment, functional deficits and geriatric syndromes) that can impact on treatment adherence and limit life expectancy.

This acknowledgment suggests that there's an urgent need to work in this direction to arrive to the formulation of ARV prescriptions that are as suitable as possible for the individual patient and his/her problems, including those related to age. Data in fact lead to argue that a tailored approach to drug treatment in elderly HIV positive patients with MM is highly recommended, but there's a high prevalence of non-conventional ARV regimens in elderly HIV patients due to the fact that clinicians tailor ARV regimens according to age, HIV duration, MM and PP.

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<sup>2</sup> Nozza et alii (2017)

## RECOMMENDATION 4: COMBAT STIGMA AND DISCRIMINATION IN HEALTH SYSTEMS

### THE ITALIAN CONSENSUS STATEMENT ON U=U\*

#### Context and method

A good practice from Italy, is the Consensus Statement on U=U, launched in November 2019 at the MoH and elaborated by SIMIT, which is the Italian scientific society, in collaboration with community representatives and supported by the MoH, with the aim of officially acknowledging the scientific evidence behind the U=U messaging.

Local community organizations have welcomed this long awaited official document from the scientific community and health institutions, who have worked closely with civil society in elaborating the document.

The document has been widely disseminated by community organizations, by the scientific society and by the MoH

#### Aims

- Providing HCPs with a tool, based on scientific evidence, they can refer to in their daily work
- Providing correct evidenced-based information to both PLHIV and to the general public.
- A further aim was that of providing guidance on the re-organization of HIV services, such as the use and communication of U=U messaging in clinical practice
- And that of representing a strong scientific tool in fighting stigma and discrimination at all levels: at individual level, at interpersonal level and at societal and institutional level

What was not analyzed was transmission through transfusions, needle exchange, transplants and breastfeeding, where strong evidence is lacking.

#### Recommendations

U=U continues to be a concept that reaches the general population and specific subgroups with difficulty, requiring more targeted interventions.

And still today many clinicians do not routinely communicate the message to their patients, which is unacceptable. They can and should play an important role. Because not all people living with HIV are aware of U=U, and many are not connected with community organizations and to good information channels.

This document has indeed represented a historical moment for the HIV community in Italy, but it is only a first step for further action.

\* [https://www.salute.gov.it/imgs/C\\_17\\_pubblicazioni\\_2903\\_allegato.pdf](https://www.salute.gov.it/imgs/C_17_pubblicazioni_2903_allegato.pdf)

## RECOMMENDATION 5 - UPSCALE INVOLVEMENT OF THE HIV COMMUNITY IN PRIORITY SETTING AT COUNTRY LEVEL

### ASSOCIATIONS SECTION WITHIN THE TECHNICAL HEALTH COMMITTEE FOR THE FIGHT AGAINST AIDS

(It is a modification of the practice: COUNCIL OF THE ASSOCIATIONS)

#### CONTEXT

Italy is at the forefront of involving the HIV Community in policymaking on managing this therapeutic area. In 1990, legislation was created which was dedicated to preventing and battling AIDS. This has seen a National Committee for the fight against AIDS established within the national Ministry of Health that includes members of HIV Associations. This has allowed national and regional decision-makers to adopt a multi-stakeholder approach to their policy choices, drawing on the knowledge and expertise within the Associations. The functions of the former Council of associations for the fight against AIDS in 2021 have been transferred to the Associations section within the Technical Health Committee for the fight against AIDS.

#### INTRODUCTION

The Ministry of Health established a consultative body involving the Associations for the fight against AIDS. The Technical Health Committee (CTS) has been set up within the Ministry of Health, includes a specific section for the fight against AIDS. This section is made up of two macrogroups, L and M: L section includes clinicians and other stakeholders, while M section includes patient associations. A ministerial decree of 15 December 2021 has updated components and specific competences

This initiative is important in allowing HIV Associations to participate directly in policymaking concerning the management of this disease. Since then, direct involvement of the HIV community in policymaking has become widespread practice in Italy.

#### AIMS

The previous Council's and the current Association section mission is to collect and share "*contributions and opinions concerning the design, implementation and assessment of information/prevention programmes in the fight against HIV.*" The same mission is

The expertise of the associations represented on the Council make a vital contribution to the institutions. This puts the institutions in a stronger position to identify unmet health needs and social issues encountered by people with HIV (PWH) and to formulate adequate responses.

## METHOD

The Association section, which consists of representatives from the main associations focused (exclusively or partially) on HIV-related topics, meets at least three times per year. It works closely with the clinician section of national Technical Committee for the fight against AIDS.

The two sections of the Technical Committee coordinate via a continuous flow of information and working documents; in addition a number of members, such as Ministry of Health representatives, belong to both bodies.

## RESULTS

Section M is active in all major HIV initiatives, notably in drafting important dedicated plans, such as the National HIV/AIDS Plan, which is approved jointly by Sections M and L and then submitted to the Ministry. In addition, Section M is working on the revision to the Italian national law on HIV, Law n.135/1990, providing further evidence of the role played by the HIV community in all major decision-making processes that impact the management of people with HIV. Within this process, the associations are providing contributions on aspects including the training of healthcare professionals (dentists, dermatologists, etc.) and the fight against stigma both inside the NHS and in the broader society.

The HIV Council is allowing the HIV community to take a proactive role within the Institutions. Recent initiatives involving the HIV community include:

- 1st Geriatric HIV Medicine Summit (Rome, February 2018). This initiative was promoted by Policlinico Gemelli of Rome and involved a number of clinicians and academics as members of the Scientific Committee and keynote speakers, particularly infectious disease specialists and geriatricians. They exchanged views on topics relating to the aging of PWH receiving ART and on those fragilities specifically related to aging. One of the goals of this workshop was to improve the training of infectious disease specialists and geriatricians with a view to encourage creating multi-disciplinary teams for managing aging HIV+ patients.
- Let's Stop HIV! Più qualità alla durata della vita (Greater quality for a longer life). This conference encourages the exchange of views between charities, patient associations and clinicians from different specialties on various aspects of the daily life of PWH.
- Involvement of Associations in the Retention in Care of PWH in Italy. This research project is part of the activities of Section M of the Technical Healthcare Committee. It is publicly funded, with the National Institute for Infectious Diseases 'Lazzaro Spallanzani IRCCS' playing the role of lead institution. The goal was to contribute to implementing and harmonising the activities of HIV Associations in improving the retention in care of vulnerable PWH. The project conducted a national survey to assess all activities currently in place from HIV associations aimed at improving patients' retention in care. The survey also measured both patient acceptability of the different initiatives in place and the attitude of healthcare professionals on the active role played by HIV associations. The findings provided the basis of a better understanding of patients' needs, ultimately helping achieve an optimal retention in care.

## RECOMMENDATIONS

Cooperation between institutions, clinicians and associations in policymaking for the management of HIV is an example of best practice. It should be retained and promoted further in future, potentially by allowing other associations representing PWH to add their contribution.

This approach to cooperation between a proactive HIV community and policymakers has the potential to be replicated across Europe, particularly in those countries where such cooperation is currently less developed.

## COALITION HIV

### CONTEXT

COALITION HIV is a national network made up of clinicians, academics, associations and pharmaceutical companies that intends to bring HIV, understood as a social and health issue, to the core of the scientific, social, cultural and political debate.

Founded in October 2018, COALITION HIV was officially presented to the Chamber of Deputies on 6 December of the same year, and in that context the Parliamentary Intergroup *L'Italia ferma l'AIDS* was established, promoted by MP Mauro D'Attis.

### INTRODUCTION

COALITION HIV was born in the context of a Think Tank dedicated to HIV in which clinicians, academics, associations and the pharmaceutical industry shared the need of bringing HIV / AIDS issues at the centre of the political debate. Different stakeholders have set common objectives starting from the awareness of how the issue needs to be managed with new tools, suitable for needs that have changed over time, and which include the clinical, economic, social, cultural and political dimensions. COALITION HIV is a hub that has been imagined, since its design, as an open place to be constantly updated and implemented by stakeholders.

### AIMS

COALITION HIV group was born with the aim of bringing the issue of HIV / AIDS in the political agenda, through the realisation of in depth studies on various shared themes, and proposing a common voice capable of developing new and more effective networking strategies with institutions. The aim was to foster the debate on the changes that have taken place, and actions and policies to fight the spread of HIV and to become, for all institutions, a recognised and influential common referent.

### METHOD

COALITION HIV is a multidisciplinary group that, on the basis of the changes occurring in the HIV / AIDS context, identifies the most suitable tools to offer answers and formulate proposals useful for identifying effective operative strategies. COALITION HIV organises plenary meetings at least once a year, and meets in remote periodically to keep a continuous dialogue with the partners and to organise and promote new actions that can be implemented within specific timelines.

These actions are carried out by placing some shared values and principles at the centre of the activities:

- The centrality of PWH, inclusiveness and the fight against stigma.
- The innovativeness and scientific nature of the proposed activities, based on a multidisciplinary and intergenerational approach aimed at ensuring a stringent methodological attention, together with the interest in sharing and enhance clinical and social data.
- The importance of a shared and participatory working method, based on a principle of transparency.

## RESULTS

In 2018 the network was established.

In 2019, a working group was established to work on COALITION HIV identity, on its mission and vision, that have then been published in a shared document. Work was also done on the revision of the national law on HIV / AIDS, the "law 135/90", which was filed at the Chamber of Deputies and then its implementation monitored.

In September 2020, a training course aimed at infectious disease specialists was created to help them write winning grants. The concept of therapeutic innovation in the HIV field was also discussed, with the identification of PROs as endpoints that allow the measurement of therapeutic innovation, then proposed to AIFA which included them among the indicators for assessing the quality of life. This material has then been published in a "Quaderno".

In 2021, the impact of the pandemic on PWH was investigated, and three surveys were carried out aimed at PWH, clinicians and associations to collect ideas for formulating hypotheses of reorganisation of care between hospital and territory.

In 2022, an analysis of the new NRRP in the perspective of HIV, was carried out, through an in-person meeting in March and three online webinars on the topic. In October, a second meeting based on manageable workflow, suggested the tools for a greater understanding of the evolution of HIV both from a clinical point of view and the impact on people's quality of life, through working groups dedicated to identifying possible strategies for a new model of patient management in the HIV context.

During the COALITION 2022 workshop, realised at Catanzaro University (Calabria) in October 2022, three in-depth working groups dedicated to young infectious disease specialists were realised with the aim of providing them tools for a greater understanding of the evolution of AIDS both from a clinical point of view and in relation to the impact on people's quality of life. Each workshop was dedicated to identifying possible strategies for a new model of patient care in the HIV field.

## RECOMMENDATIONS

The activities carried out offer several suggestions for the revision of the health strategies for PWH. The recommendation is that these learnings can be incorporated in a uniform manner at the national level and in all Italian regions.