

SUCCESS STORY 6: 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 people with HIV (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 patient-reported outcomes as endpoints that allow the measurement of therapeutic innovation, then proposed to *Agenzia Italiana del Farmaco* (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 National Recovery and Resilience Plan 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.