

COUNCIL OF THE ASSOCIATIONS FOR THE FIGHT AGAINST AIDS AND OTHER INITIATIVES TO INVOLVE THE HIV COMMUNITY

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.

Introduction

The Ministry of Health established a consultative body, the **Council of the Associations for the fight against AIDS**. This initiative was the first and most 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 Council's 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 expertise of the associations represented on the Council make a vital contribution to the institutions. This places the institutions in a stronger position to identify unmet health needs and social issues encountered by people living with HIV (PLHIV) and to formulate adequate responses.

Method

The Council, 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 in closely with the national Committee for the fight against AIDS, a multi-disciplinary body of clinicians and scientists.

The Council and the 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.

Following an internal reorganisation of the Ministry of Health, the Council and the Committee are both now sections of the Technical Healthcare Committee, namely section 'M' (the former Council of the Associations for the fight against HIV) and section 'L' (the former National Committee for the fight against AIDS).

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 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 living 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 ageing of PLHIV receiving ART and on those fragilities specifically related to ageing. 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 ageing 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 PLHIV.
- **Involvement of Associations in the Retention in Care of PLHIV 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 PLHIV. 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 PLHIV 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 it is currently less well developed, as is the case in some Eastern European countries.

Author:

Organisation: