

Launching the Colombian Network of Pulmonary Arterial Hypertension “HAPred.co”.

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Introduction:

There are no global epidemiological or clinical data in relation to incidence, prevalence, clinical-functional characteristics, access to treatments or prognosis of pulmonary arterial hypertension (PAH) or Chronic Thromboembolic Pulmonary Hypertension (HPTEC) in Colombia. This implies a need for networking in order to define the clinical characteristics and needs that allow the design of country-specific strategies that allow the resolution of health problems related to PAH and HPTEC in Colombia.

Since 2018, a multidisciplinary professional group conceived and made possible an initiative aimed at establishing a multidisciplinary, inclusive, cohesive and non-profit National Network, which when sharing activities and competences of various degrees, defined activities of various types focused on patients of Pulmonary Hypertension (HP) of Colombia. This initiative received the name of the Colombian Network of Pulmonary Arterial Hypertension (HAPred.co)

AIM. The main objectives of the Network are oriented to (1) characterize the problem of PAH in the country, (2) solve epidemiological, clinical and economic questions, (3) develop research in own population, (4) normalize related knowledge with the diagnosis, treatment and follow-up of PAH in the region, (5) promote fundraising for own scientific and academic activities, and (6) offer advice on particular problems of patients with PAH in Colombia.

RESULTS.

The consensus of the network HAPred.co essence was identified as an initiative framed within 10 particular characteristics that represent its own value in its vision:

1. It reflects a fundamentally academic intention aimed at practical translation,
2. It is of a purely voluntary participation, where conflicts of interest solely individual are ignored;
3. It is feasible, since its scope has the attitude and competencies of health personnel and associates who have agreed on the action;
4. It is of a relevant nature, since it promotes the application of the knowledge and standards of diagnosis and management of PAH in Colombia; ,
5. It is original, because there is no similar initiative in this area in Colombia,
6. It is pertinent, for trying to cover social, clinical, economic and academic aspects of PAH in Colombia;
7. It is inclusive, since it fundamentally invites and promotes a transdisciplinary and multi-institutional nature,
8. It is interdependent, where all researchers and related centers share their experiences and promote common solutions;
9. It is directed by objectives, with the desire to be facilitator and operational with specific products that benefit the management of the disease in the country.

10. And it is our group vision that the work in La Red will be representing an offer of particular and relevant value centered in Colombia, with expanded projection to Latin America in interaction with external referent groups.

To date, a total of n=503 registries of both incident and prevalent PAH cases have been identified as a result of 10 months of launching the initiative.

Members of HAPRed.co and the “HEXAGON” model: The activities of HAPRed.co focus on patients suffering from PAH. For this reason, we develop activities aimed at achieving a "hexagonal integration". The centers of the hexagon are “the patients”, and each vertex represents the different actors in their care system: hospitals (IPS), payers (EPS), Logistics Operators, Patient Support Groups, Patient Associations and Pharmaceutical Industries. For this reason, The Network is a cross-cutting initiative among medical specialties and invites the participation of representatives from each vertex so that the platform is viable and relevant in achieving patient benefits.

Governance and Management Model of the HAPRed.co: Since its inception, the Network has an Operational Core, which is responsible for centralizing and consolidating the contributions of all its members. There are three fundamental ways to participate in the actions of the Network: graduated (member of the common forum of meetings and actions), researcher (principal investigator or collaborator in research actions initiated by a third party), and member of the Operational Nucleus (collaborator in the same network management). During the elapsed time of management, public master documents have been generated in which collaboration strategies with potential financing entities (eg, pharmaceutical industry, state entities) or agreements with international academic entities have been defined.

Conclusions. The actions, governance model and transdisciplinary inclusion policies of the HAPRed.co were agreed upon. As such, it does NOT depend on a single institution, it is NOT a defined time strategy, it does NOT have a unique disciplinary orientation, and it does NOT depend on a single investigator or manager. For these reasons, we believe that La Red constitutes a platform for continuous action that allows the interests of multiple participants to be housed under the sole premise of offering useful elements and potential benefits to patients with PAH in Colombia.