

May 28-29, 2018

London, UK

Ana Rita Gonzalez, J Healthc Commun 2018, Volume 3  
DOI: 10.4172/2472-1654-C1-005

## PATIENT ASSOCIATIONS AS PROMOTERS OF PEOPLE-CENTERED TREATMENT IN LATIN AMERICA

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**Abstract:** REFASAL (Reunión para Fortalecer el Acceso a la Salud en América Latina [Meeting to Strengthen Access to Health in Latin America]) originated in 2016 with the objective of promoting the role of patient associations in the advancement of patient- and community-focused health systems in the Latin America region. This meeting brought together a representative sample of patient associations in Latin America that work to sustainably improve access and health outcomes for patients through innovative advocacy efforts. REFASAL aimed to strengthen patient associations and empower their representatives to support the sustainable development of health systems focused on people, patients and their communities. This publication is based on information gathered since the above-mentioned meeting, through interactions and interviews with leaders of the eighteen (18) Participating patients associations and additional research on the subject.

**Methodology:** The steps followed to develop this publication were: a) Development of a workshop and strategic plan; b) Review of scientific literature; c) Interviews to leaders of patient associations. Eighteen (18) patient associations were invited to participate in a semi-structured interview about their experiences, practices and activities performed to support the patient community they represent. REFASAL participants were screened and selected according to a convenience sampling, using the following criteria: 1) representatives of different countries in the region; 2) recognized leadership in activities related to person-centered care. Eight associations completed the interview over a period of two months.

**Results:** There is a notable increase in the number of patient associations in the Latin America region that are working to advance people-centered care. A pivotal element in strengthening the capacity of associations to move towards people-centered services is to share experiences with other organizations that have similar interests. This white paper presents five examples of good practices followed by patient associations. In each case, the actions taken and the way in which these organizations achieved their outcomes are summarized, with the intention of serving as an example, support and motivation for other associations that can emulate them and achieve their own objectives. The examples present different strategies used by the associations to achieve the objective of improving, facilitating and promoting people-centered treatment. They are a representative sample of some of the initiatives launched by the REFASAL participants and were selected according to the availability of information on their websites and interviews with their leaders.

**Conclusions:** People-centered care involves considering the vision and perspectives of people who suffer from a condition, as well as that of their caregivers, family members and communities, to allow health system services to be organized based on their essential needs. The connection between community participation and health outcomes shows that this approach is a key factor to improve health, mainly in low-income countries. To move forward with a people-centered treatment model and to ensure the active participation of patient associations, it is necessary to strengthen and improve efforts focused on:

- Developing strategies to strengthen the capacities of patient associations
- Promoting and facilitating interaction and collaboration of patient associations with health system actors

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- **Demonstrating the need for, and positive results of, initiatives favoring a patient-centered approach**
- **Promoting the development of joint initiatives among different patient groups**
- **Developing viable proposals and solutions that address the needs and complaints of patients**
- **Strengthening and providing visibility to the contribution of patient associations**

The organizations involved in the REFASAL meeting in November 2016 continue to develop their mission in the countries and sub regions they represent. Their work inspires others to continue working to ensure access to quality medicines and treatments for thousands of patients.

## **Biography**

Ana Rita Gonzalez graduated from the Johns Hopkins University with a Doctorate of Science in Health Policy and Management, and she holds a Master's Degree in Health Services Administration and a Certificate in Public Health. She is the President and CEO of Policy Wisdom LLC, Florida, USA, an organization that works with government and non-government entities to shape policies on health, safety, and the environment. She holds a PhD in History and Philosophy of Science from Princeton University, USA and is currently the Chief Historian at National Library of Medicine, National Institutes of Health, USA.

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