

8th Global Patients Congress

24 - 26 May, 2018



International Alliance of
Patients' Organizations
A global voice for patients

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Patient Empowerment for Global Advocacy and Multi-stakeholder Collaboration

Meeting to Strengthen Access to Health in Latin America

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Presentation outline

- Goals and phases of the initiative
- Outcomes
 - Phase 1: Common strategic objectives
 - Phase 2: White paper
 - Trends in people centered care
 - Examples of patient-centric projects
- Conclusion
- Recommendations to move forward

Goals and Phases of the Initiative

Meeting to Strengthen Access to Health in Latin America (REFASAL)

- Stimulate patients and patient groups to **generate ideas**
 - ✓ their role
 - ✓ innovation and technology
 - ✓ way health services are offered, communicated and accessed
- Improve **patient outcomes** through patient-centric advocacy efforts
- Strengthen **empowerment** of PAGs
 - ✓ Participation in policy-making toward patient-centric health systems



PAGs to evolve from one-on-one advocacy to a role of changing policy and having long-term impact on the health system

Phase 1

- Meeting held November 29 - December 1, 2016
- 19 participating patient advocacy groups from 10 Latin American countries
- One academic partner
- Five international presenters
- Policy Wisdom LLC as consulting partner

Phase 2

- Virtual and digital interactions
- Assure continuity to the objectives identified
- Share best practices

Outcomes – Phase 1: Common Strategic Objectives

- 1** Ensure **availability of clinical guidelines**, made with transparency, based on scientific evidence and of mandatory reference
- 2** Have a **legal/regulatory framework** that guarantees the entry and proper management of quality medicines
- 3** Improve **training/capacity** of citizens/patients, the patient caregivers, and the health personnel, in their role as user and provider of health services
- 4** Create an **organization or network of patient groups** to influence and monitor the agenda of inter-governmental groups in the health policy decision-making process, at internal and external level



Outcomes – Phase 2: White paper

“Patient associations as promoters of people-centered treatment in Latin America”

- Focus on the importance of the role, challenges and needs of the PAGs
- Disseminate success stories to serve as example and inspiration to other PAGs
- Establish or strengthen relationships with relevant audiences



Outcomes – Phase 2: White paper Trends in people centered care



Outcomes – Phase 2: White paper Examples of Initiatives



A training strategy for primary care personnel **improves the early disease detection** and helps people to thoroughly **understand the functioning of the health system**

It is essential to collect and present **compelling evidence** demonstrating to health authorities the need to take action on the **review of clinical guidelines**, and to **achieve alliances** with related sectors, both locally and internationally, to add strength to initiatives in favor of patients

Through the creation of a free platform to **disseminate knowledge** regarding **access routes to the health system**, the system's users have access to consultation services to exercise their health rights.



Through teamwork, the union of wills, and the dissemination of knowledge among all stakeholders to address problems of common interest, it is possible to **capture the attention of the authorities** and to **impact important public health issues** in favor of the people.



Through **citizen participation** in advocating in favor of vulnerable groups, the submission of **evidence to support the requests**, and the **collaboration** and efforts with the press and public opinion, great advances are made in favor of patients.



Conclusion:



...for a people-centered treatment model

...for active participation of patient associations

Develop strategies to **strengthen the capacities** of patient associations to facilitate their participation at all levels

Promote the development of **joint initiatives** to ensure a single and **strengthened voice**

Strengthen and **provide visibility to the contribution of patient associations** in the definition of health interventions

generate evidence through surveys and qualitative studies to improve the services for citizens

Demonstrate the need for and positive **results of initiatives** favoring a patient-centered approach

empower citizens with information and allow their participation and oversight in decision-making

Promote and facilitate the **interaction and collaboration** of patient associations with different key actors **in the health system**

Develop viable proposals and solutions that serve as a platform to promote dialogue

Recommendations to move forward

- ✓ **Think-tank meetings** on ways to address the challenges and reach established goals
- ✓ **Methodologies** to conduct and maximize joint work efforts
- ✓ **Prioritized policies** to be influenced
- ✓ Methodologies to increase volunteer base and fund raising, to be able to focus on direct support to patients
- ✓ **Disseminate role, achievements and efforts** of PAGs within organizations related to health, professional associations and advocacy groups, government, academia, pharmaceutical industry



Conventional media (radio, TV and press)



Social media (Twitter, Facebook, LinkedIn, PAG websites)



Congresses, symposia and conventions



Round table meetings



One-on-one meetings and entrevistas



Publications (bulletins, journals)



Continuous education and/or conferences



Mailings/ correspondence (by mail and digital)

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"...to promote the advancement of health systems that are more focused on people and not on diseases, it is necessary for patients to be educated and prepared to actively participate in their care and the decision making that impacts them, and in this sense the role of patient associations becomes more relevant."



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Thank you!