



## Leave no-one behind

# Access to Biotherapeutics in Latin America

18-19 November 2016

Bogota, Colombia



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## 1. Introduction

IAPO held its first Latin American country-cluster workshop on 18-19 November 2016 in Bogota, Colombia.

40 stakeholders participated in the seminar "Leave no-one-behind: Patient access to Biotherapeutics in Latin America". 26 patients' organizations from Colombia, Ecuador, Panama, Peru, and Venezuela actively engaged in capacity building workshops to strengthen their advocacy skills and receive a better understanding of the meaning and implications of the principle of patient-centredness. By taking part in the workshops, patient organizations also strengthened their knowledge as to the role they can play in tackling the challenges and barriers to the availability, accessibility, acceptability, quality and safety of Biotherapeutics in the region.

This report will offer an overview of what was achieved from the preparation phase to the post-event evaluation and will provide inputs for the steps forward to be taken in the development of IAPO's capacity-building activities in the Latin-American region.

The video recordings of the seminar, the speakers' presentations and photos are available on [IAPO's website](#).

## 2. Objectives

This country-cluster capacity-building workshop was a pilot project aiming to improve the level of knowledge of patient advocates on biologic and biosimilar medicines, facilitate cross-stakeholder partnership and networking, and strengthen patients' leadership and engagement at all levels of decision-making.

## 3. Outcomes

This workshop aimed to enable patient advocates to use the resources at their disposal to work on their own strategy and action plan; improve the information shared with patients and their peers; start networking to have an unified voice for advocacy and decision-making at all levels.

## 4. Attendance and members' engagement

IAPO currently has 60 member organizations in 14 countries of Latin America. The size and scope of action of these organizations vary from local to regional, providing patients' support services and/or engaging with policy and advocacy at different levels. They are all part of the same jigsaw, advocating for patient rights and promoting patient-centred healthcare.

As the country-cluster approach aims to facilitate post-event collaborative work, we decided to invite patient advocates from Colombia and neighboring countries presenting certain diversity in terms of drug regulation, patient safety and patients' involvement capacities. We ensured the regional scope of our program through communication, consultations, and further participation in working groups.

### 4.1. Attendance

26 organizations from Peru, Ecuador, Panama, Venezuela and Colombia attended the workshop in total. Among them, 15 are IAPO members (Figure 1).

Patients' advocates from leading countries with an expertise on biotherapeutics were invited (Colombia and Panama) as well as regional umbrella organizations (Latinapso and the Latin Society of Pulmonary Hypertension).

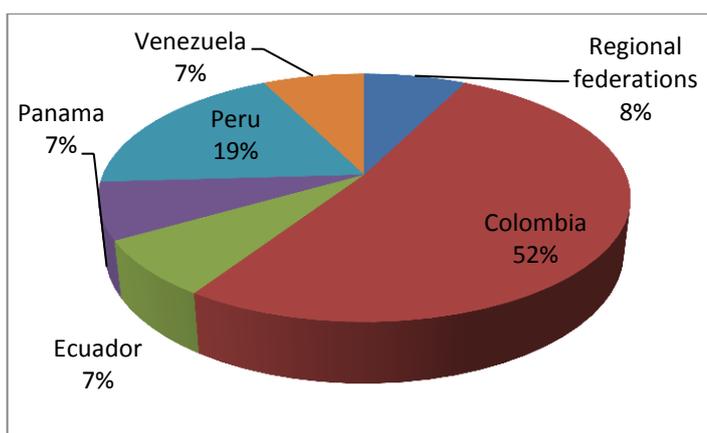


Figure 1: delegates per country

Seven disease areas were represented (Figure 2).

All the material developed in the preparation phase and the outcomes of the event are available to all our members across the region on our website, our platform on biologic and biosimilar medicines and social media.

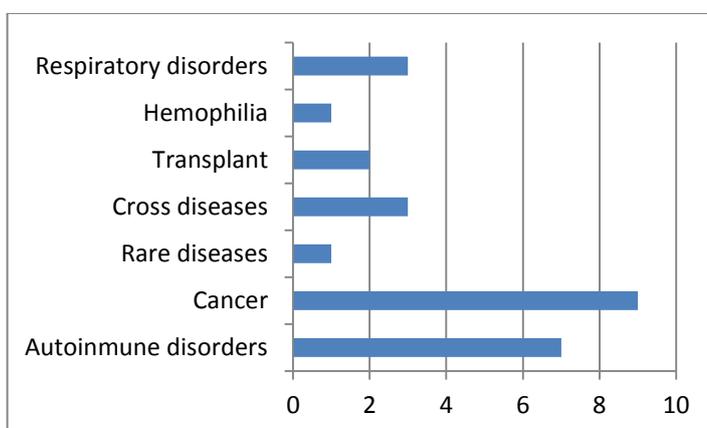


Figure 2: Disease areas

## 4.2 Patient advocates' involvement in the event

*“Excellent experience for the exchange of experiences and knowledge and for strengthening patients’ organizations. The information presented by experts in the area will serve to share this knowledge in our region for the benefit of patients”.*

**AVEDESTRAS, Venezuela**

*“The space provided was very enriching and undoubtedly provides us with tools for decision making”.*

**Fundem, Colombia**

*“Meeting with a good focus that allows improving the lines of action”.*

**Fundación RASA, Colombia**

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The quotes above give an overview of the dynamic of the event and its relevance. It provided a space to learn and exchange.

### *A strong participation*

As mentioned above, the organizations that participated are of different sizes, involved at different levels in patient support and advocacy at various levels. The participants engaged actively in all the workshops.

The difference in response rates between consultation and evaluation can be explained by the fact that consultation was a mandatory step in the event registration process.

Attendance rate: 99%
Consultation response rate: 92%
Evaluation response rate: 54%

Although evaluation response rate was 54%, some organizations have responded in other ways. For instance, the event offered the opportunity to encourage the delegates to take part in [Patient Solidarity Day](#) on the 3<sup>rd</sup> of December. We noticed an active participation of few of them. Details can be provided whilst the event report will be published. Others provided informal feedbacks. Only a long-term evaluation (minimum 6 months) will permit the measurement of the real impact of the event.

### *Members, speakers and facilitators*

As the project also aimed to identify, promote and strengthen leadership, we facilitated IAPO members' participation as speakers and workshop facilitators (see agendas – annex 1). The event allowed our members to highlight their skills and knowledge on different topics by offering them the opportunity to

participate in both seminar panels and to co-host part of the workshops (see the agendas – Annex 1 and the list of contributors).

## 5. Initial assessment and content

The agenda of the event was based on pre-event consultation as well as on [IAPO's policy positions](#) on patient-centred Universal Health Coverage and on safe access to Biotherapeutics.

For both seminars and workshops, the content included the following topics:

1. Patient Centred Universal Health Coverage: current policies, right to health, patients' empowerment;
2. Access to Biotherapeutics: current challenges, patient safety, regulation, patients' empowerment and evidence-based advocacy;
3. Patients' organizations structural must-have skills: governance, communication, transparency, reporting and advocacy, to sustain their actions.

### 5.1. Patient-Centred Universal Health Coverage

*"Universal health coverage imply that all people and communities have access, without any kind of discrimination, to comprehensive, appropriate and timely, quality health services determined at the national level according to needs, as well as access to safe, effective, and affordable quality medicines, while ensuring that the use of such services does not expose users to financial difficulties, especially groups in conditions of vulnerability.."*

[PAHO / WHO, Universal Health Coverage](#)

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Patient-centred Universal Health Coverage means that everyone, including our patient organizations and their members, receive the health services they need without suffering financial hardship when accessing them.

Universal Health Coverage was the focus of the IAPO congress in March 2014. Members developed a set of [Universal Health Coverage principles](#) from the perspective of the patient: accessibility, equity, quality,

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patient-centered, patient empowerment in decision-making, collaboration for the development of health policies, sustainability and the value of health care, responsibility and transparency.

In September 2015, the 194 Member States of the United Nations agreed to develop and put in place practical actions and national frameworks to achieve this and other targets, as part of the 2030 Agenda for Sustainable Development (Resolution A/RES/70/1). Only if all countries and stakeholders work together in close collaboration will it be possible to ensure that no-one is left behind.

*“They listen to us but we have no power of decision. When we see that something is not going to benefit patients, we present our claims to the relevant authorities”.*

## **Asociación Ecuatoriana de Ayuda a Pacientes con cáncer esperanza y vida**

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*“I work with the Venezuelan health authorities at all levels; we are currently working on the creation of the National Program on Haemorrhagic Diseases, which takes considerations from that point of view [Universal Access to Health]”.*

## **Asociación Venezolana para la Hemofilia and CODEVIDA**

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56% of the participants already had the opportunity to use IAPO’s principles on Universal Health Coverage to advocate and/or monitor the situation in their countries (Figure 3).

Among them, 75% had the opportunity to be involved at different levels in the implementation of related policies and programmes (Figure 4). For instance, Esperantra Peru was involved in Plan Esperanza providing a comprehensive access to healthcare to patients with cancer.

Patient representatives usually play a consultative role or work proactively defending patient rights, specifically in case of exclusion (minorities, marginalized and rural populations).

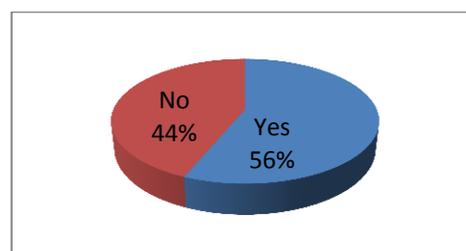


Figure 3: IAPO UHC Principles in advocacy

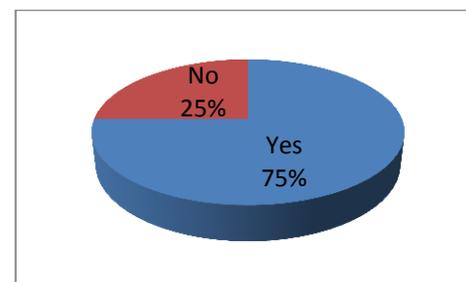


Figure 4: Active participation in policy

The impact in securing access to Biotherapeutics differs from a country to another, and in some cases, the healthcare system offers no such guaranty.

According to patients' organizations, the main barriers accessing healthcare, new treatment options offered by Biotherapeutics and treatment adherence are still the fragmentation of health services, inequality in accessing healthcare facilities and lack of drugs, lack of information and transparency, lack of choice for patients.

Nevertheless, according to 57% of our respondents, some national governments have put in place a framework for patients' involvement at certain levels of decision making. But only 46% were consulted in the elaboration phase of such frameworks.

## 5.2. Safe and equitable access to Biotherapeutics

*“Definitely the advantages for the patient are enormous, however the procedures to access a Biotherapeutics drug is cumbersome and difficult”.*

### **Asociación Peruana Vidas Sin Cáncer**

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Whilst the burden of chronic diseases is increasing worldwide, ensuring access for patients to safe, quality, accessible and innovative medicines, such as biological and biosimilar medicines, is vital to improving healthcare.

As with all medications, patients should be able to make an informed decision about taking biologic or biosimilar medicines, and participate fully in deciding the course of treatment to follow in conjunction with their healthcare team.

IAPO believes that patients should be aware of the biological and biosimilar medicines and what the implications of their increased availability are.

It is generally accepted that the WHO, EMA and FDA guidelines should provide a solid and comprehensive basis for the approval of biosimilar medicinal products. Many countries have developed or are in the process of developing frameworks and guidelines for the development and approval of biosimilar medicines.

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However, not all guidelines meet all WHO requirements (for example, the full comparability exercise), and thus potentially compromising patient safety. Similarly, there is concern that, in some developing countries, the approval process and post-approval quality control need further improvement and safeguard.

More than 64% of patient representatives consider that national regulatory guidelines still do not ensure access to safe medicines (Figure 5).

We note that more than 20% did not have access to the relevant information.

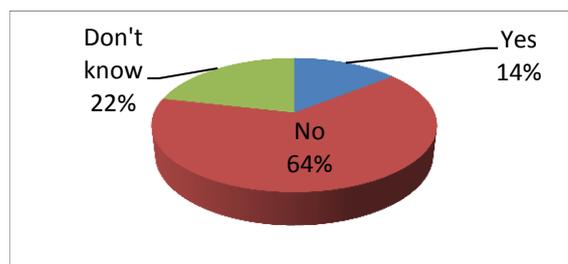


Figure 5: Regulation and safe access

As shown in Figure 6, the main challenges in accessing Biotherapeutics from the patient's perspective are the availability of treatments, the quality of information provided at all levels, lack of involvement in decision-making when switching and cost.

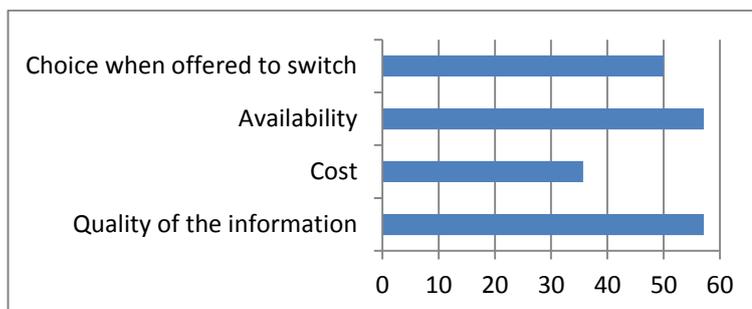


Figure 6: challenges in accessing Biotherapeutics

Patient's groups and therefore patients primarily receive information from other patients' organizations, the industry, online resources and physicians (Figure 7).

This data demonstrate the importance of patients' organizations network but it also shows gaps in the health system insuring access to treatment.

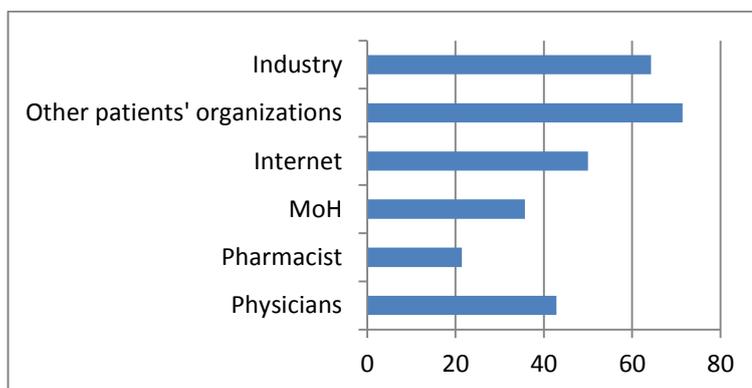


Figure 7: Source of information for patients

The consultation reveals as well gaps in access to information regarding pharmacovigilance system and lack of communication between health care providers and patients.

*“Most physicians do not tell the patient to report it in the event of an adverse reaction or how to do so. It is for this reason that this year the Foundation included this theme in the day of teaching for patients and families”.*

#### **Fundación Psoriasis Panama**

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More than 71% of the respondents consider that they do not have all the information related to the drug-surveillance system and that patients do not receive the necessary support to report adverse effects (Figure 8).

This shows the need to develop further collaborative work between patients' organizations and healthcare providers and decision makers.

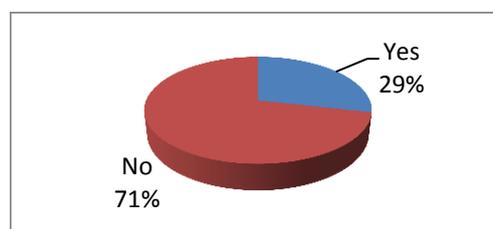


Figure 8: Support to report adverse effect

### **5.3. Strengthening the patient organizations' skills**

In order to face the challenges described in this report, we strongly believe that patients' organizations need to be offered the opportunity to evaluate and strengthen their skills and capacities.

Therefore, the event included sessions on governance, transparency and accountability, communication and online resourcing, networking, and patient support programs.

These sessions have been co-organized with Colombian organizations to ensure the relevance of the content. All the relevant topics were presented in line with the main themes of the event (see agendas – annex 1).

## 6. Impact evaluation

*“The event exceeded my expectations. Good content and good organization”.*

### **FUNARP, Panama**

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90% of the attendees gave a positive feedback on the overall event. The remaining 10% refers to minor logistic issues and we can therefore consider that we reached our initial goals. 93% of them considered that all the topics addressed in the workshop were in line with their work.

### 6.1. Empowerment, networking and partnering

One of the objectives of the event was to provide the means and tools to empower patient groups in advocating for patient-centredness and a safe access to Biotherapeutics.

*“We have strengthened our work with other Peruvian associations; we have already had a working meeting”.*

### **Luz de Esperanza, Peru**

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93% of the attendees established contact with other organizations in order to strengthen their network and collaborative work and 79% successfully did the same with different stakeholders during the seminar.

The event also provided IAPO with the opportunity to strengthen its partnership with ClapBio and FIFARMA, as well as with the High Commissioner for Human Rights in the region.

Even if they were not present at the workshop, contact has been established with the representatives of the International Hospital Federation, the Transparency International Colombia, ISAGS UNASSUR, among others.

Several Industry partners' representatives, AFIDRO (Asociación de Laboratorios Farmacéuticos de Investigación y Desarrollo), the Colombian National College of Pharmacists also attended the seminar.

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### 6.2. Enhancing patients' organizations' engagement on patient-centred universal health coverage, Biotherapeutics and patient safety

100% of the participants said they now have a good understanding of the role and responsibilities of key stakeholders in the health sectors, academic and multi-lateral organizations in Latin America.

They all understood patient-centred Universal Health Coverage and the role of patients' organizations, and agreed to use indicators to monitor the implementation of such policy in their countries (see Next steps).

All delegates confirmed that they have a better understanding of the challenges in accessing Biotherapeutics. For 93%, the workshops provided the information necessary to start or improve advocacy in that niche.

### 6.3. External communication

*"Under the slogan "Leave no-one behind: patient access to Biotherapeutics in Latin America," the seminar facilitated exchanges on the right to health, the challenges and advantages in accessing biotherapeutic medicines, (...) ensure safe and timely access to treatments, (...) promoting the active participation of patients as the axis of Universal Coverage of Health".*

**[Diario del Sur](#), December 12<sup>th</sup> 2016**

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IAPO promoted the event using three different channels: our own website, social media and press releases.

As for the event itself, there were 25 media mentions in the Colombian national newspapers and radio stations webpages, on both national news and health pages. The full report is available on request in Spanish.

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**Pacientes se enfrentan a barreras para acceder a la salud**  
INTERNACIONAL SALUD | 18 DICIEMBRE 12 2016 17:38 PM

Según la Alianza Internacional de Organizaciones de Pacientes, esta sería una problemática que se presenta no solo a nivel nacional sino regional.

La poca disponibilidad de los tratamientos, su pobre calidad, la falta de claridad en torno a los procesos regulatorios y en la trazabilidad de los medicamentos; la falta de normativas que garanticen la debida especialidad de la regulación vigente y la lentitud administrativa, entre otros factores, se han convertido en las principales barreras de acceso para los usuarios de los servicios de salud de países como Colombia, Ecuador, Venezuela, Ecuador y Perú.

A lo concluyeron cerca de 40 representantes de organizaciones de pacientes y otros actores del sector los cuales se reunieron durante dos días en Bogotá para cuestionar el sistema y proponer mejoras en beneficio de los pacientes en un seminario organizado por la Alianza Internacional de Organizaciones de Pacientes IAPO, por sus siglas en inglés.

Bajo la consigna 'No dejar a nadie atrás' El acceso del paciente a bioterapéuticos en América Latina: este congreso facilitó un intercambio de opiniones en torno al derecho a la salud, los retos y ventajas de acceder a medicamentos bioterapéuticos; asegurando que uno de los factores a modificar es garantizar el acceso seguro y oportuno a los tratamientos, sin dejar de lado la relación costo-eficiencia.



IAPO@IAPOvoice

Ricardo Garcia: 'La ciencia tiene que ser a su lado', La información tiene que bajar'. [#BioLatamPacientes](#)



Retorno Vital@Retornovital06

[#biolatampacientes](#) [@NacionesUnidas1](#) invita a trabajar Unidos por los derechos en Salud en LATAM

Launching the post-event activities, we will develop a specific dissemination plan targeting patients' organizations, stakeholders, the general public using several pages and the blog of our online platform [iapoamericas.org](http://iapoamericas.org).

## 7. Next steps

Based on the exchanges with and expectations of both delegates and partners involved in the event, different areas of work are currently being assessed to become part of IAPO's regional programme for 2017.

### 7.1. Evidence-based advocacy

The workshops provided valuable information and gave the opportunity to share strategies and tools. However, further support and collaborative work is needed to help sustaining advocacy and impact significantly public policies at the local and national levels.

Indicators, which can be used by patient organizations, need to be defined to evaluate the implementation of patient-centred Universal Health Coverage, the adequacy of Biotherapeutics

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regulation, the access to innovative medicines and good practices ensuring patient safety (pharmacovigilance).

We are planning to involve our members in the process of reviewing IAPO's policy papers and gathering relevant data with the aim of promoting an evidence-based advocacy.

During the workshops, the uncertainty surrounding Biotherapeutics regulation and safety led to a focus on pharmacovigilance. Participants proposed to work on a strategy to collect data highlighting the different issues in reporting adverse, secondary or absence of effect.

Participants also proposed that relevant tools, strategies and results should be accessible on IAPO's online platform [iapoamericas.org](http://iapoamericas.org). More than 80% of the respondents would like to be involved in the activity.

## 7.2. Multi-stakeholder approach

In order to ensure evidence-based advocacy is meaningful and impactful, participants agreed to adopt a regional multi-stakeholder approach, mapping research centers and key stakeholders to work in collaboration with. This will be an opportunity to coordinate activities with other networks such as the BioReds. Two of the Central American BioRed branch attended the event.

The institutions representatives, who took part in the event or were contacted in the preparation phase, already had shown a clear interest in further collaboration.

## 7.3. Enhancing networking and communication

Several groups in Colombia, Peru, Panama, and further across the region already started using networking strategies to advocate for a safe and affordable access to Biotherapeutics through joint statements and activities.

IAPO online platform [iapoamericas.org](http://iapoamericas.org) offers a space to share data, research, patients' organizations initiatives. The related dissemination plan will be review early 2017.

## 7.4. Further support to patients' organizations

The evaluation shows the need for further support to patients' organizations primarily in the form of webinars, collaboration with experts and tools.

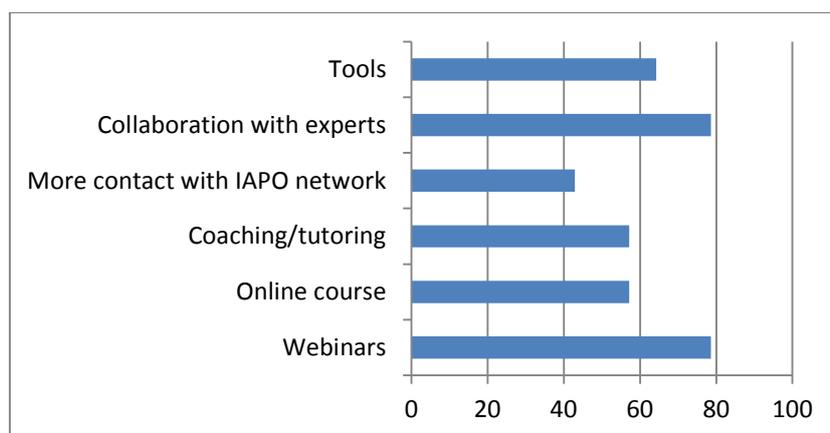


Figure 9: Further support and activities

IAPO is currently working on a webinar program for 2017, involving when relevant the online academy of United Patients and Alianza Latina.

We regularly update and translate into Spanish and Portuguese our toolkits. We are looking forward to more opportunities to create more relevant tools.

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## 8. Conclusion

This country-cluster event was a pilot project to work closer with patients' organizations, facilitating collaborative work with key stakeholders. 93% of the evaluation respondents considered this approach relevant.

All through the event, delegates highlighted the need for patients' groups to strengthen their network at national level, build partnership with different actors of the health sector, academia and industry to face the challenges in accessing biotherapeutics and advocating at all levels for a patient-centred Universal Health Coverage.

The evaluation showed a short-term overview of the impact of the event. In January, we will provide a more robust report and carry out case studies to be published in both English and Spanish.

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## Annex 1: agenda of the multi-stakeholder seminar and workshops

### MULTI-STAKEHOLDER SEMINAR

<b>Moderator:</b> Migdalia Denis, IAPO – co-moderator: Patricia Gaillard Olokose	
<b>9:15</b>	<b>Welcome</b> – Migdalia Denis, IAPO
<b>9:30</b>	<b>Panel 1: Working together towards patient-centred universal health coverage</b>  <b>Invited panelists include:</b> <ul style="list-style-type: none"><li>– Dr. Edgar Castañeda – Director of Office of High Commissioner for Human Rights</li><li>– Antonia Luque from Asociacion Venezolana para la Hemofilia - AVH</li></ul> <b>Questions:</b> <ul style="list-style-type: none"><li>– What do we need to consider guaranteeing the implementation of UHC when we involve patients in decision making?</li><li>– What are the obstacles in access to healthcare in the region with respect to the right to health, health coverage expenditures and access to high quality services?</li><li>– To what extent could different actors in the social sector and health sector can be accountable?</li><li>– What is the role of multilateral bodies and patient organisations in ensuring transparency and the right to health?</li></ul>
<b>11:00</b>	<b>Coffee break</b>
<b>11:30</b>	<b>Panel 2: Guaranteeing security and power of choice of patients when accessing Biotherapeutics</b>  <b>Invited panelists include:</b> <ul style="list-style-type: none"><li>– Luis Villalba, Director, FIFARMA</li><li>– Ricardo Garcia, Director, ClapBio</li><li>– Angela Chaves – Colombian Federation of Rare Diseases</li></ul> <b>Questions:</b> <ul style="list-style-type: none"><li>– How can different stakeholders work together to ensure access to Biotherapeutics?</li><li>– How can the success of a pharmacovigilance system be ensured?</li><li>– How can patients make an informed decision when accepting biotherapeutics?</li><li>– How can patient organisations participate in decision-making and how could this improved?</li><li>– What recommendations do you have for secure access to biotherapeutics, including</li></ul>

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transparency, regulatory processes and patient participation in decision-making?

## WORKSHOPS – DAY 1 & 2

### PATIENT ADVOCATES WORKSHOPS – DAY 1 - Friday 18th Nov.

<b>14:20</b>	Welcome and overview of the agenda: Day 1
<b>14:45</b>	<b>Workshop 1: Health Policy and Patient Centredness</b>
	<p><i>In continuation of the seminar:</i></p> <p><b>Overview on Universal Health Coverage (UHC), SDGs' and patient-centred healthcare in Latin America</b></p> <p><b>Presentation and questions:</b></p> <ol style="list-style-type: none"> <li>1. Key concepts and implications, situation in the region</li> <li>2. How to use some key documents as indicators to monitor patient-centredness?</li> <li>3. What is the impact of these policies on access to Biotherapeutics?</li> </ol> <p><b>Moderator:</b> IAPO – open floor to patients' organizations</p>
<b>15:30</b>	<b>Coffee break</b>
	<p><i>In continuation of the seminar and as an introduction to day 2:</i></p> <p><b>Overview on Biotherapeutics in Latin America (focus on Colombia, Venezuela, Panama, Ecuador, Peru):</b></p> <p><b>Presentations and questions:</b></p> <ol style="list-style-type: none"> <li>1. Feedback on patients' organizations involvement in decision-making (regulation)</li> <li>2. Current challenges in access safe and affordable treatments: power of election in accepting or switching treatment</li> <li>3. Current challenges in term of reporting adverse effect (patient safety)</li> </ol> <p><b>Moderator:</b> ClapBio/IAPO – open floor to patients' organizations</p>
<b>17:30</b>	<b>Wrap-up workshop day 1</b>
<b>19:30</b>	<b>Dinner</b>

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<b>PATIENT ADVOCATES WORKSHOPS – DAY 2 - Saturday 19<sup>th</sup> Nov.</b>	
<b>9:30</b>	<b>Workshop 2: Developing patients' organizations capabilities - Part 1</b>
	<p><b>Presentation:</b> Strengthening organizations' governance, systems, accountability, collaboration, partnerships, networks</p> <p><b>Moderators:</b> Angela Chaves &amp; Gustavo Campillo</p>
<b>11:00</b>	<b>Coffee break</b>
<b>11:30</b>	<b>Workshop 2: Developing patients' organizations capabilities - Part 2</b>
	<p><b>Presentation:</b> Facilitating patients' engagement in decision-making</p> <p><b>Moderators:</b> Angela Chaves &amp; Gustavo Campillo</p>
<b>12:30</b>	<b>Lunch</b>
<b>13:45</b>	<b>Workshop 3: Access to information and health literacy</b>
	<p><b>Presentations and questions:</b></p> <ol style="list-style-type: none"> <li>1. Accessing information</li> <li>2. Disseminating information</li> </ol> <p>In order to empower patients (informed decision) and patients' groups (policy and decision-making) in accessing safe and affordable medicines.</p> <p><b>Moderators:</b> IAPO - open floor to patients' organizations</p>
<b>15:30</b>	<b>Coffee break</b>
<b>16:00</b>	<b>Workshop 4: Strengthening the advocacy network in the cluster</b>
	<p><b>Presentations and questions:</b></p> <ol style="list-style-type: none"> <li>1. Opportunities available for working together</li> <li>2. Methods and channels</li> <li>3. Challenges to be overcome</li> </ol> <p><b>Moderator:</b> IAPO – all participants</p>
<b>17:30</b>	<b>What-ups and commitments (Agenda for 2017)</b>

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## Annex 2: list of participants

### IAPO members

Name	Organization name	Country
Adriana Maria Garzon Pinzon	Fundación SIMMON	Colombia
Juanita Ruiz	Fundación SIMMON	Colombia
Gustavo Adolfo Campillo Orozco	Fundación RASA	Colombia
Angela Chaves Restrepo	FECOER	Colombia
Guillermo Gutiérrez	FUNDAPSO	Colombia
Francisca Reinoso Larrea	Asociación Ecuatoriana de Ayuda a Pacientes con cáncer esperanza y vida	Ecuador
Sebastian Jimenez Lozada	CEPREME	Ecuador
Ana Teresa Meneses	Fundación Psoriasis de Panamá	Panamá
Dalila Esilda Suarez Medina	FUNARP	Panamá
Ñurka magaly Vigil Benavente	Asociación Nacional de Pacientes en Diálisis y Trasplante	Peru
Maria Esther Palma Sebastian	Luz de Esperanza	Peru
Rosa María Bernales Ludeña	Asociación Peruana Vidas Sin Cáncer (APVSC)	Peru
Karla Ruiz	Esperantra	Peru
Carmen Grasso Neyra	Oncovida	Peru
Antonia Luque	Asociación Venezolana para la Hemofilia	Venezuela
Luisa Herrera	LATINAPSO	Venezuela
Ana Rosa Sequera Melendez	Asociación Venezolana para el deporte y salud de los trasplantados y en situación de trasplante	Venezuela

### Members of IAPO staff and governing board

Name	Position	Country
Patricia Gaillard Olokose	Coordinadora Regional	UK
Migdalia Denis	Miembro del consejo directivo	US Based

### Other patients' organizations

Name	Organization name	Country
Silva Denis	Asociación Colombia Saludable	Colombia
Francisco Castellanos	Asociación Colombiana de Esclerodermia	Colombia
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Jairo Becerra	Fundación GIST Colombia	Colombia
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Jorge Ernesto Garcia	Fundación Retorno Vital	Colombia
Dina Luz Grajales Otero	Asociación Colombiana de Hipertensión Pulmonar	Colombia

### Speakers

Name	Organization name	Country
Angela Chaves	Federación Colombiana de Enfermedades Raras	Colombia
Antonia Luque	Asociación Venezolana para la Hemofilia y Alianza Latina	Venezuela
Edgar Castañeda	Oficina del Alto Comisionado para los Derechos Humanos	Colombia
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