ISPOR Patient-Centered Research Summit 2024 Sunday, May 5, 2024 | Atlanta, GA, USA

Session 1: The Power of Patient Voices: Elevating Patient-Centered Outcomes in Research

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DISCLAIMER:

The opinions expressed in this presentation and on the following slides are solely those of the presenter and not necessarily those of LAPA.

AGENDA





LAPA AT-A-GLANCE

✓ A 501c3 non-profit based in Miami FL, officially established in 2018

- ✓ Provides high-level education and training for patient advocacy leaders
- ✓ Has certified over 320 patient advocate leaders from 10+ countries
- ✓ Builds opportunities for multistakeholder collaboration
- ✓ Mentors individual organizations and regional coalitions
- Promotes the patient-based, civil society movement across the region.
- ✓ Relies on an extensive faculty of regional and international experts and KOLs

2019

Programs for Argentina and Colombia. Chile project for cancer law implementation. 77 leaders trained.

2020 Went virtual with Chile and online campus. Reached 218 leaders from 10 for Central countries, 35 total sessions. Andean Developed additional toolkit resources related to Covid-19. Collaboration with projects in Peru **IETS** in Colombia and Colombia. and with COMISCA for Central America.

ÍIníl

2021

finalized electoral Reached 150 process program leaders from 130 in Colombia. organizations in differentiated Peru, Argentina, program for Argentina Colombia. Rare leaders. disease project continued program work in America and Peru with Salud Colectivo. subregions with andHTA project COMISCA and in Brazil. ORAS-CONHU. Electoral process

2022

Began program

for Ecuador.

Establish a Patient Advisory Committee and a platform for Precision Medicine. Provide tailored training and

toolkits..

2023-2024

Latin America Patients Academ

2006 - 2014 "University of the

Patient" program takes shape with support from American Cancer Society

2018 LAPA officially

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2014-2017 established with EUPATI Some pharma as model ..

associations implement

trade

patient group outreach

LAPA ROOTS, HISTORY AND KEY MILESTONES

LAPA has created an academic program to empower the Patient Advocacy community in Latin America. The program aims to improve decision-making and promote better access policies for healthcare systems.

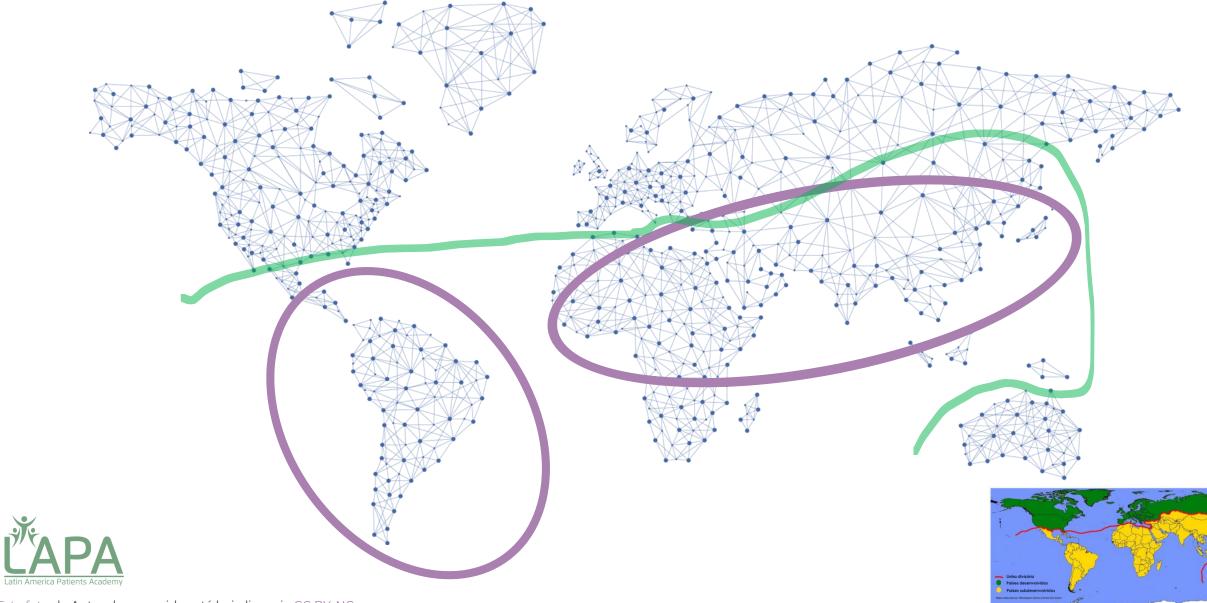


2022 - 2024

PPI working group

2021



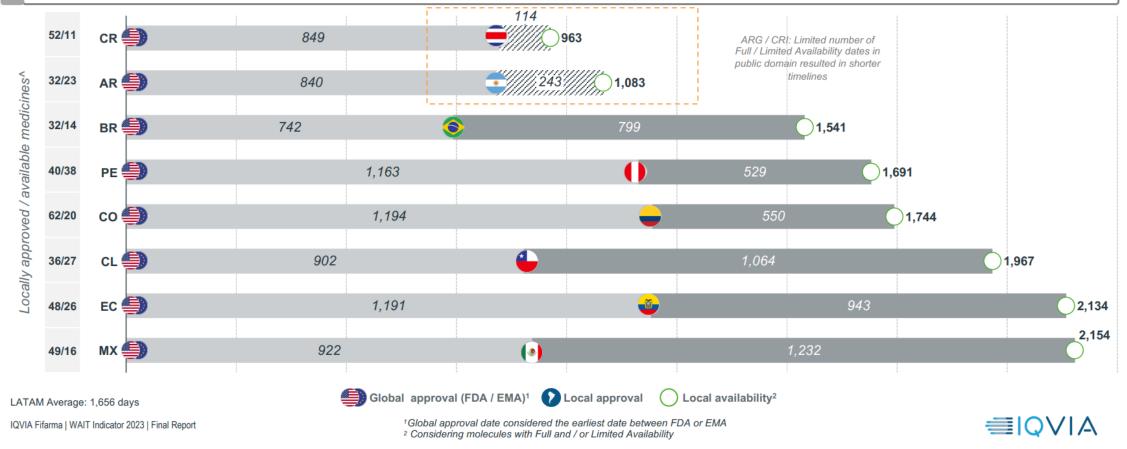


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There is a long pathway for innovation to achieve broad reimbursement through widely a fragmented reimbursement system

Time to availability (2014-2021) – orphan, FDA/EMA, market auth., and local availability dates

- Colombia is the country with longer regulatory approval timelines availability timelines are small as a result of a high degree of limited availability through MIPRES that is granted pretty fast, yet still restricted to only a subset of the population
- Chile and Mexico typically are the first countries to grant regulatory approval in the region, but a complex and fragment environment results in very long timelines until achieving broad reimbursement

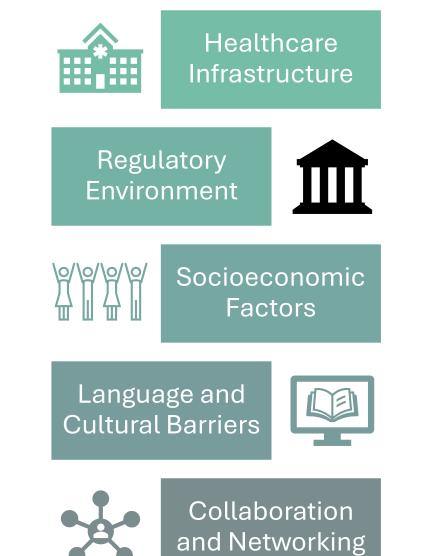


THE POWER OF PATIENT VOICES: ELEVATING PATIENT-CENTERED OUTCOMES IN RESEARCH





Differences in Access to Clinical Research in Latin America:

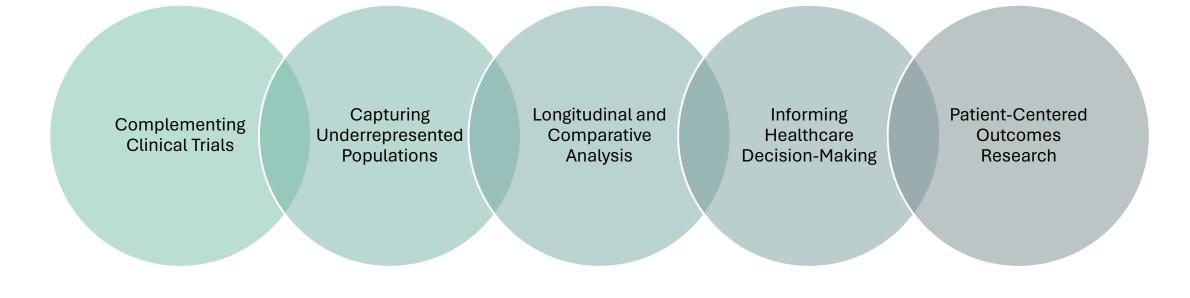




Best Practices for Engaging Patients in HTA process in Latin America :

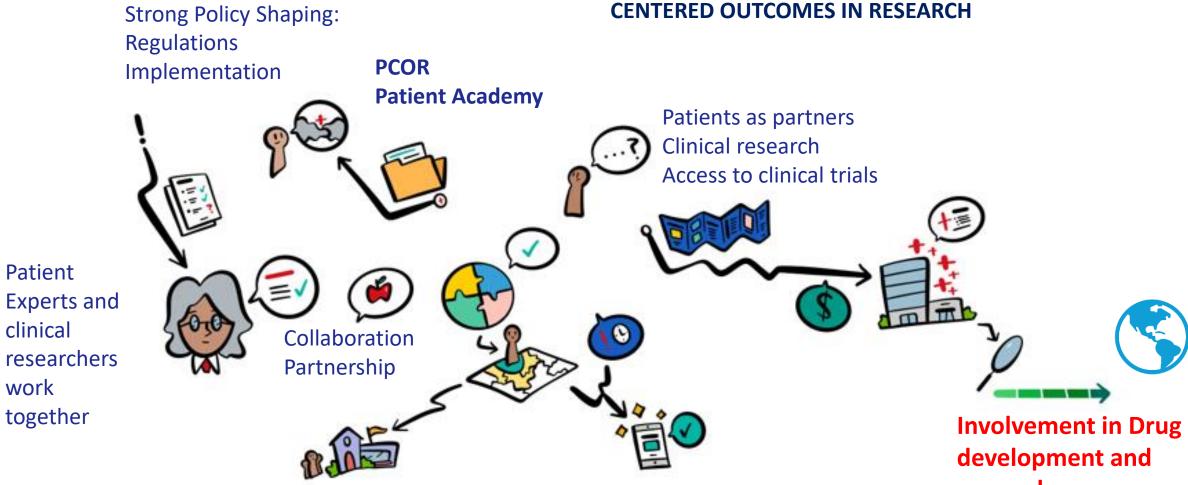
	Early and Meaningful Engagement	 Ensure that patient perspectives are integrated into decision-making at all stages of the healthcare technology assessment (HTA) process.
	Education and Empowerment	• Empower patients to actively participate by offering training, support, and opportunities for meaningful contributions.
	Diversity and Inclusivity	 In recent times, this has changed as the patient's voice becomes part of the HTA decision process
	Transparent Communication	• Clearly articulate the objectives, methodologies, and outcomes of the research or HTA process, and solicit patient feedback to improve transparency and accountability.
	Evaluation and Feedback	Regularly evaluate patient engagement practices and request participant feedback to identify improvement areas.
ΆΦΔ		

Role of Real-World Evidence in Building the Patient-Centered Evidence Base in Latam:



Ideal situation

work



PAGs have strong knowledge to navigate the system and provide RWE

Digital transformation e-health tele-health

research

THE POWER OF PATIENT VOICES: ELEVATING PATIENT-



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