

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



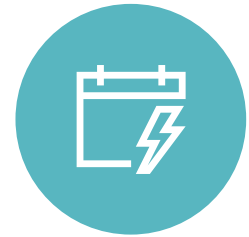
DISPARITIES IN THE
WORLD



TRENDS



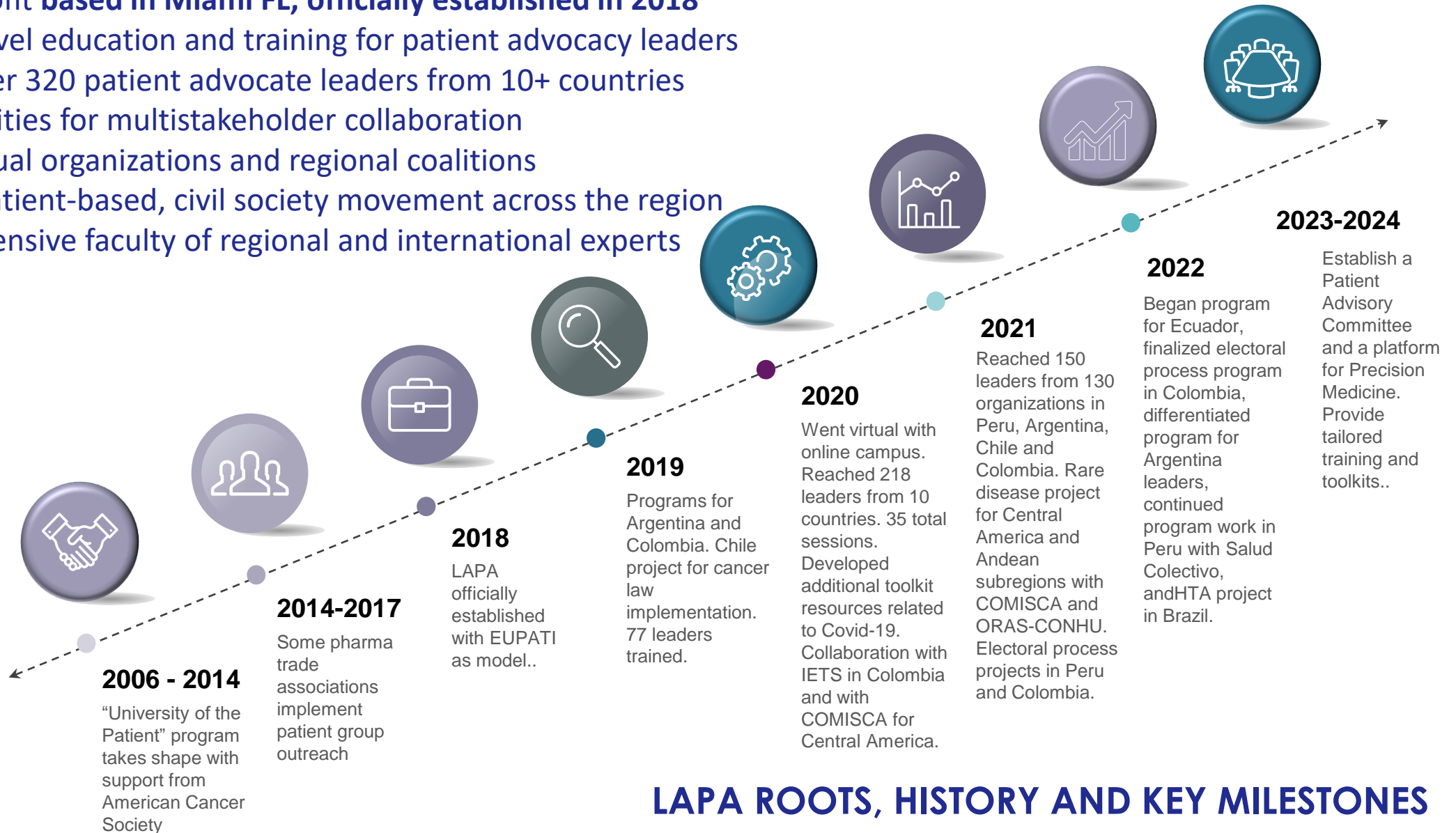
ACCESS TO
CLINICAL
RESEARCH



IDEAL

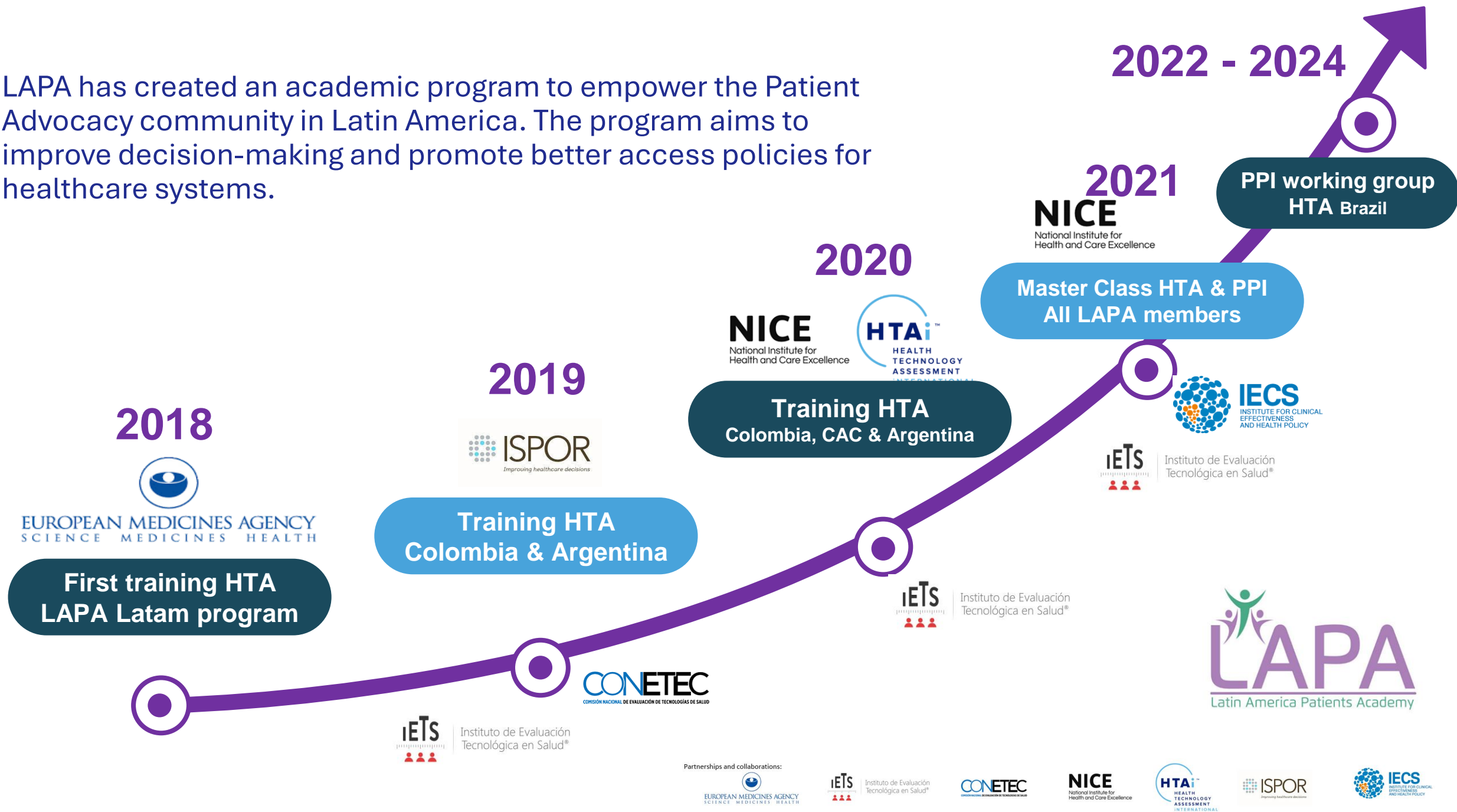
LAPA AT-A-GLANCE

- ✓ 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

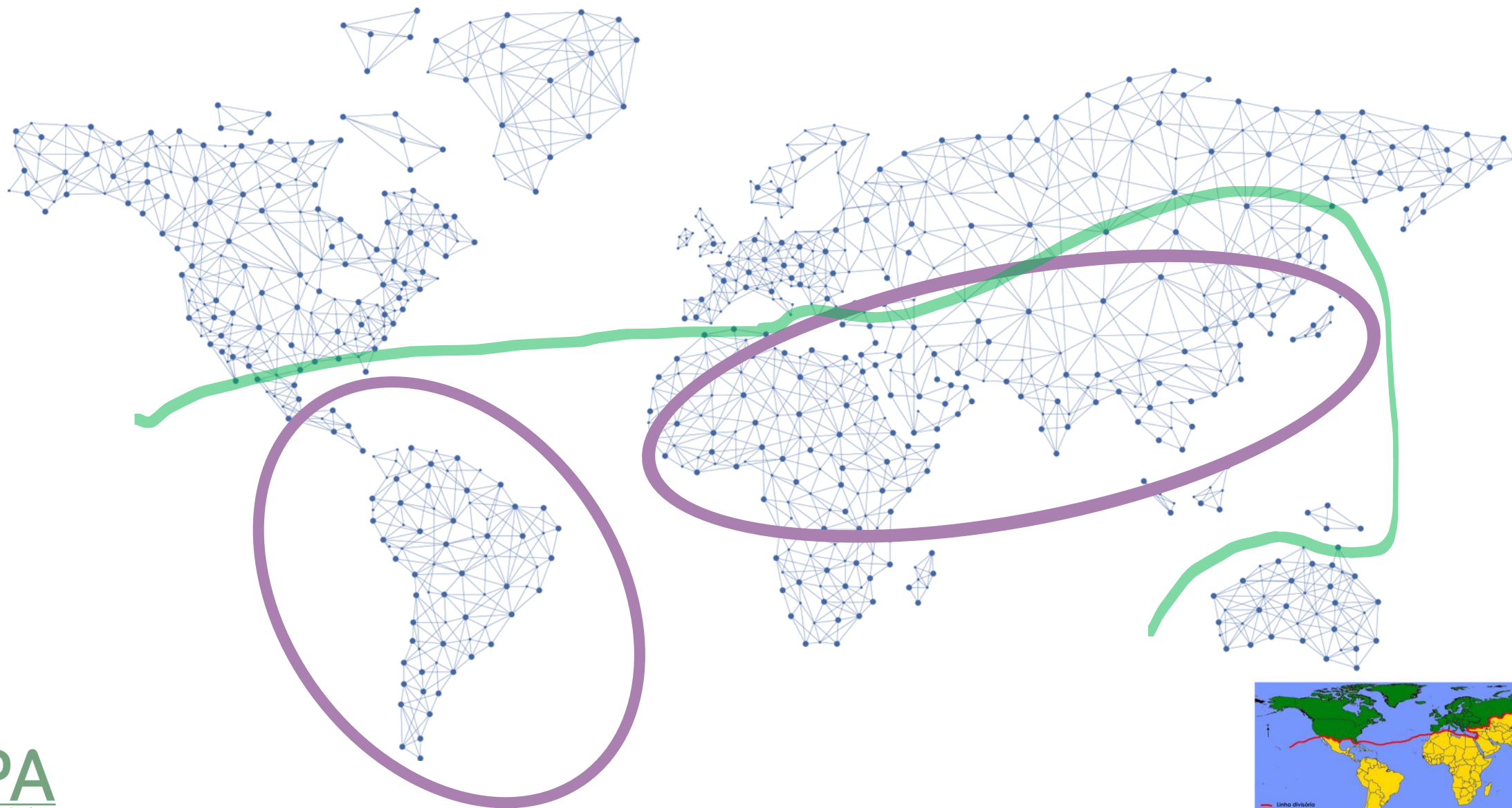


LAPA ROOTS, HISTORY AND KEY MILESTONES

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.



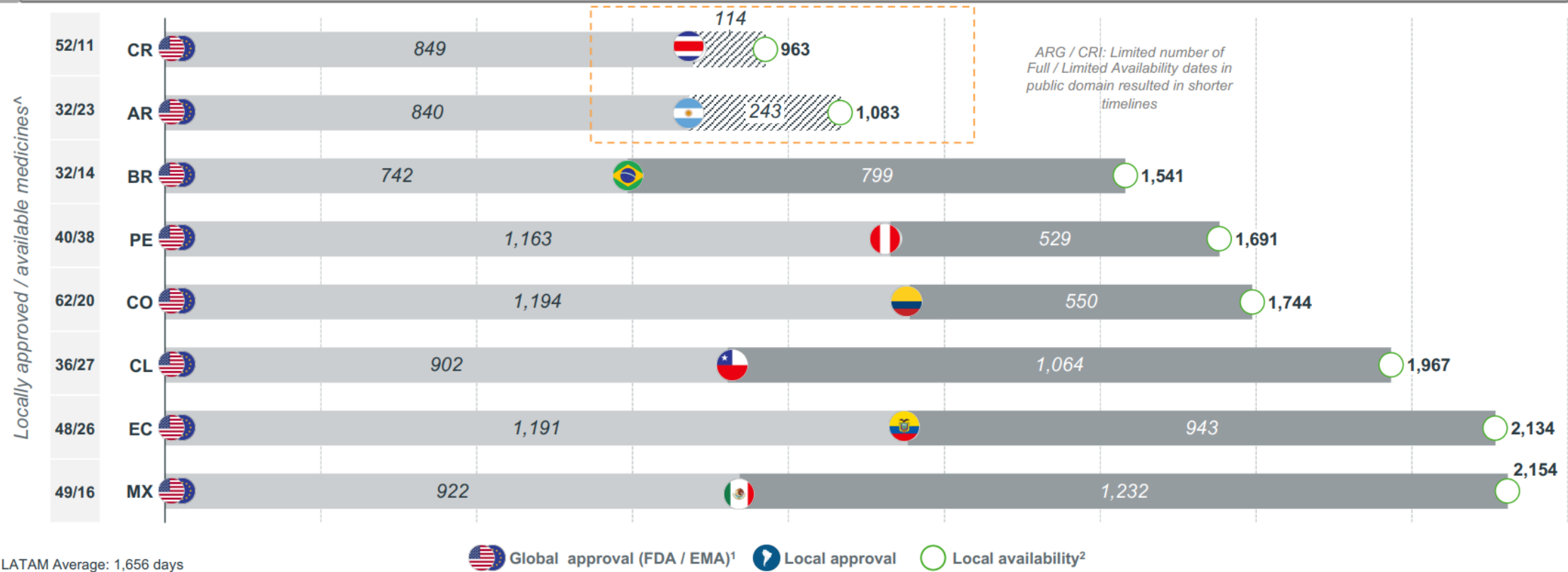
REGION DISPARITIES



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**



LATAM Average: 1,656 days

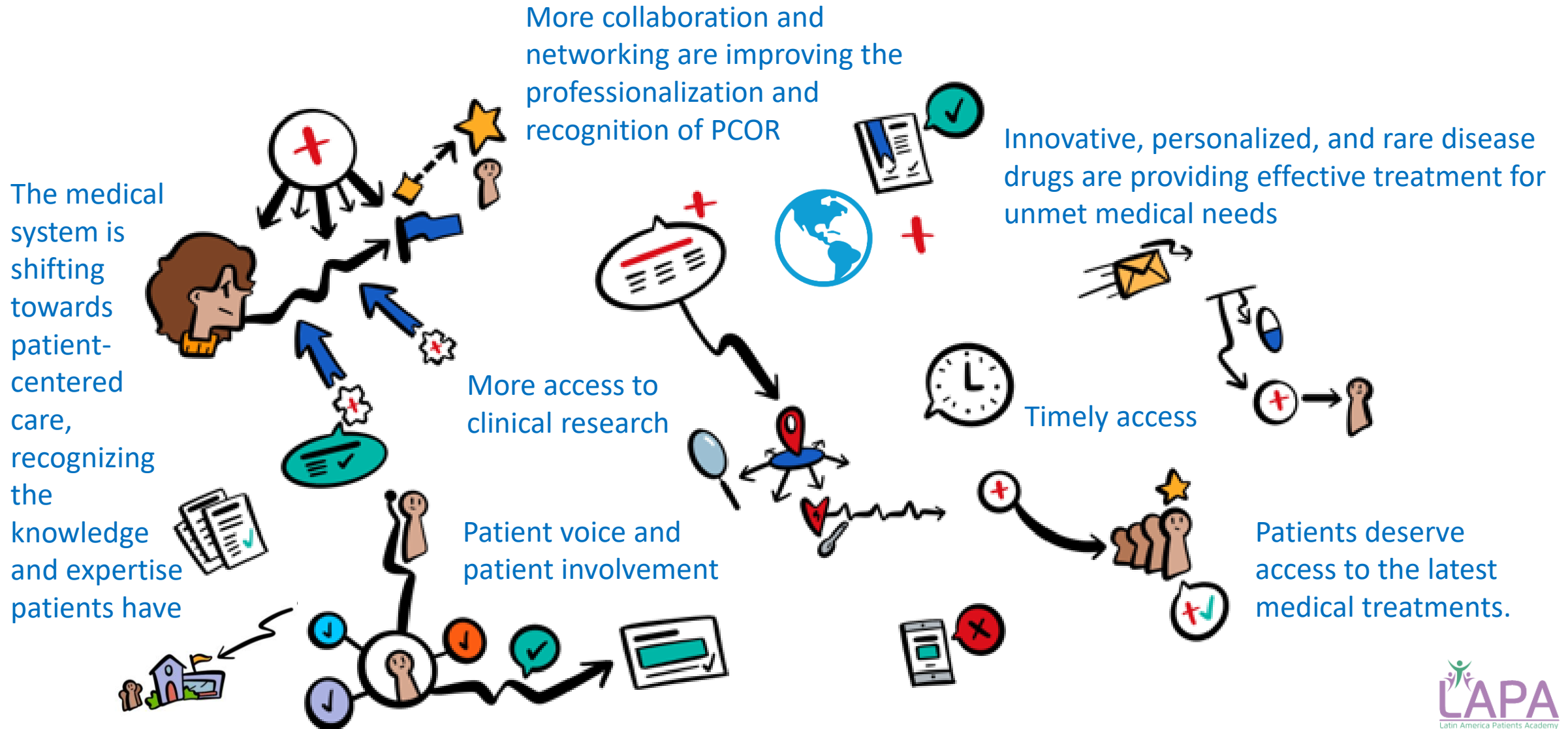
IQVIA Fifarima | WAIT Indicator 2023 | Final Report

¹Global approval date considered the earliest date between FDA or EMA

² Considering molecules with Full and / or Limited Availability

TRENDS

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





Differences in Access to Clinical Research in Latin America:



Healthcare
Infrastructure

Regulatory
Environment



Socioeconomic
Factors

Language and
Cultural Barriers



Collaboration
and Networking

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



CONITEC



CONETEC



IETS



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

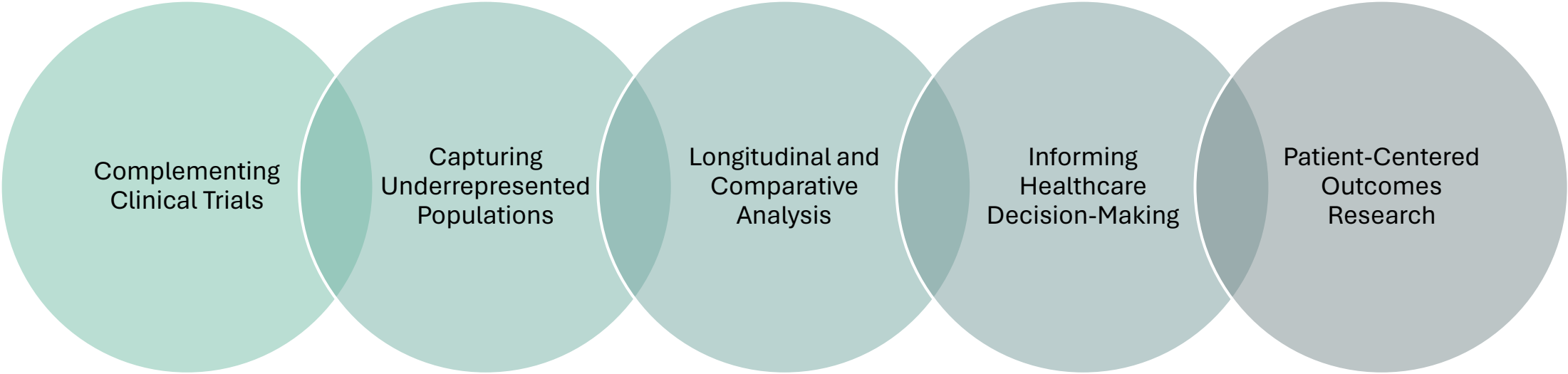
Transparent Communication

- 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

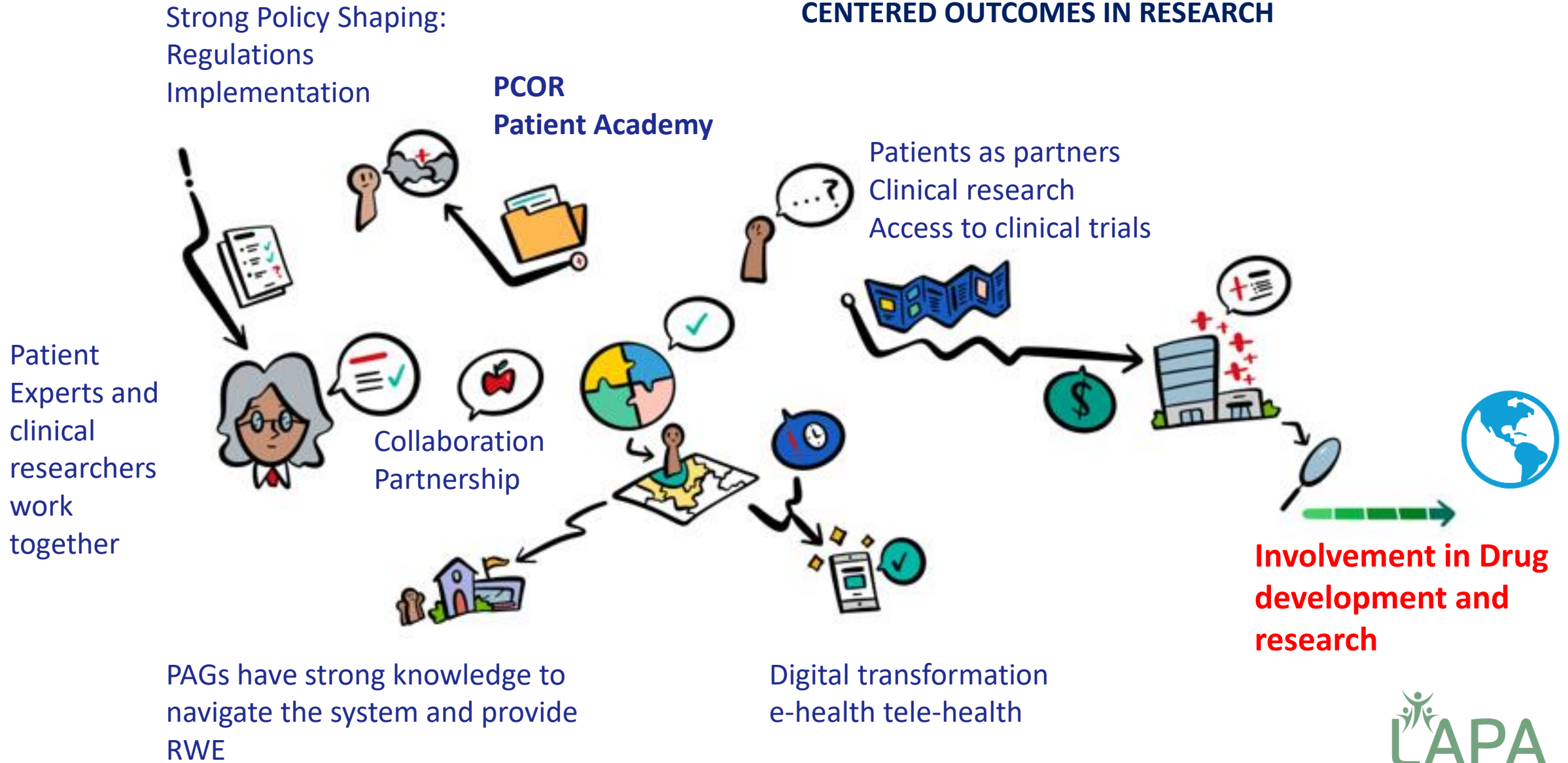
- Regularly evaluate patient engagement practices and request participant feedback to identify improvement areas.

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



Ideal situation

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Thank you!



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