RESULTS OF THE ONLINE SURVEY. BUILDING BRIDGES IN PERSONALIZED MEDICINE BETWEEN LATIN AMERICA/CARIBBEAN AND EUROPE

EULAC-PerMed has been funded by the European Union’s Horizon 2020 Research and Innovation Programme under Grant Agreement (GA) No 825173
Background and methods

• We conducted an online survey consisting of three sections, 14 questions and 60 items.
• Sections:
  • Situation of PM in Latin America and the Caribbean (LAC) region
  • Challenges and future perspectives of PM in LAC
  • Strengthening EU-LAC collaboration in PM
• A total of 41 participants answered the survey
Section 1
Situation of PM in Latin America and the Caribbean (LAC) region
Which type of organization do you work at?

- 29.27% Ministry/public agency - Healthcare
- 19.51% Public research organization
- 17.07% University
- 14.63% Ministry/public agency - Research
- 9.76% Business / private sector
- 7.32% Non-profit organization
- 2.44% Interregional/international organizations

Total=41
In which country are you currently working?

![Bar chart showing the number of respondents from different countries. The countries are ranked from lowest to highest number of respondents: Honduras, Guatemala, Argentina, Cuba, Jamaica, Ecuador, Mexico, Peru, Brazil, Venezuela, Italy, Panama, Paraguay, United States, Colombia, Spain, Uruguay, Costa Rica, Brazil, Chile. The chart indicates that Brazil and Chile have the highest number of respondents, each with 5 respondents.]
Is PM an issue of interest?

RESULTS OF THE ONLINE SURVEY. BUILDING BRIDGES IN PERSONALIZED MEDICINE BETWEEN LATIN AMERICA/CARIBBEAN AND EUROPE
Level of adoption and implementation in your country

![Bar chart showing adoption levels: I do not know, Very low, Low, Medium, High, Very high. The Medium category has the highest number of respondents.]

RESULTS OF THE ONLINE SURVEY. BUILDING BRIDGES IN PERSONALIZED MEDICINE BETWEEN LATIN AMERICA/CARIBBEAN AND EUROPE
In terms of research and knowledge, what is the situation in your country in terms of...
Section 2
Challenges and future perspectives of PM in LAC
In your healthcare system, what is the level of importance for the following items:

- **Screening** (mean = 3.1 points)
- **Disease prevention** (mean = 2.8 points)
- **Treatment** (mean = 2.6 points)
Most relevant disease area/medical specialty for personalized medicine

- Auto-immune diseases
- Degenerative diseases
- Non-communicable diseases
- Palliative care
- Genetics
- Infectious diseases
- Neurology/neurodevelopmental disorders
- Cardiovascular diseases
- Rare diseases
- Oncology

Number of respondents
Who should be responsible for most of the costs related to PM?

- Shared costs (government-private insurance companies-patients)
- Shared costs (government-external funding-civil society-academia)
- Shared costs (governments-NGOs-patients)
- Shared costs (government-private sector)
- Government (public health system)

Number of respondents
How do you perceive the importance of addressing the following issues in order to advance and develop PM in your country

• Block A. Scientific and technological issues
• Block B. Operational issues
• Block C. Economic issues
• Block D. Governance/regulatory/ethical issues

• We used a Likert scale for each item: (1) not important at all, (2) slightly important, (3) important, (4) fairly important, (5) very important, and then calculated a score
### Block A. Scientific and technological issues

<table>
<thead>
<tr>
<th>Most important issues</th>
<th>Score (out of 5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase the participation of LAC institutions in PM-related clinical trials</td>
<td>4.4</td>
</tr>
<tr>
<td>Better understanding of the genomic epidemiology of diseases in LAC populations</td>
<td>4.3</td>
</tr>
<tr>
<td>Promote economic evaluation of precision drugs to help regulatory agencies make evidence-based decisions</td>
<td>4.3</td>
</tr>
<tr>
<td>Increase funding and support for PM-related research</td>
<td>4.3</td>
</tr>
<tr>
<td>Increase transnational collaborations in PM-related research</td>
<td>4.3</td>
</tr>
</tbody>
</table>
## Block B. Operational issues

<table>
<thead>
<tr>
<th>Most important issues</th>
<th>Score (out of 5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strengthen research capacity from a technical perspective</td>
<td>4.4</td>
</tr>
<tr>
<td>Improve awareness and knowledge about PM in healthcare providers</td>
<td>4.3</td>
</tr>
<tr>
<td>Facilitate sharing of knowledge related to the integration of genomics in diagnosis/treatment among clinicians</td>
<td>4.3</td>
</tr>
<tr>
<td>Facilitate the setting up of multidisciplinary teams in hospitals</td>
<td>4.3</td>
</tr>
<tr>
<td>Support needs in information technology</td>
<td>4.3</td>
</tr>
</tbody>
</table>
## Block C. Economic issues

<table>
<thead>
<tr>
<th>Most important issues</th>
<th>Score (out of 5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Making available and accessible to the population costly innovative treatments without risking the sustainability of the health systems</td>
<td>4.6</td>
</tr>
<tr>
<td>High cost of drugs in LAC</td>
<td>4.6</td>
</tr>
<tr>
<td>High-value tests or services not covered by public or private system</td>
<td>4.4</td>
</tr>
</tbody>
</table>
## Block D. Governance/regulatory/ethical issues

<table>
<thead>
<tr>
<th>Most important issues</th>
<th>Score (out of 5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop coherent and comprehensive national precision medicine strategies</td>
<td>4.5</td>
</tr>
<tr>
<td>Improve awareness and knowledge about PM in policy makers</td>
<td>4.4</td>
</tr>
<tr>
<td>Develop governance frameworks applied to personal genetic data</td>
<td>4.4</td>
</tr>
<tr>
<td>Provide local regulatory and HTA agencies with resources to conduct scientifically sound assessments</td>
<td>4.4</td>
</tr>
</tbody>
</table>
Section 3
Strengthening EU-LAC collaboration in PM
How do you rate the need for strengthening EU-LAC collaboration in PM?

RESULTS OF THE ONLINE SURVEY. BUILDING BRIDGES IN PERSONALIZED MEDICINE BETWEEN LATIN AMERICA/CARIBBEAN AND EUROPE
At what level do you think that it is important to foster EU-LAC collaboration?

<table>
<thead>
<tr>
<th>Levels</th>
<th>Score (out of 5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Policy level</td>
<td>4.6</td>
</tr>
<tr>
<td>Scientific level</td>
<td>4.4</td>
</tr>
</tbody>
</table>
## Benefits of EU-LAC collaboration in PM

<table>
<thead>
<tr>
<th>Benefits</th>
<th>Score (out of 3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Implementation of joint research programs (e.g. ERA-PerMed)</td>
<td>2.9</td>
</tr>
<tr>
<td>Collaborative research projects</td>
<td>2.9</td>
</tr>
<tr>
<td>Exchanges of practices and experiences in PM implementation</td>
<td>2.8</td>
</tr>
<tr>
<td>Training for research and healthcare professionals</td>
<td>2.7</td>
</tr>
</tbody>
</table>
Take-home messages
Situation of PM in Latin America and the Caribbean (LAC) region

• According to the respondents, PM is an issue of interest mostly for the academic sector and the private healthcare sector.

• A third of the respondents considered that the level of implementation of PM in their countries is “medium”.

• The areas of research and knowledge in PM where countries are doing better are the existence of research projects and infrastructure.

• Only half of the countries had training programs or specific funding programs for PM.
Take-home messages
Challenges and future perspectives of PM in LAC

• In terms of importance for the healthcare system, respondents valued screening higher than prevention and treatment.

• Oncology, rare diseases and cardiovascular diseases were the most relevant disease areas.

• The government should be responsible for most of the costs related to PM, followed by public-private funding modalities.
Take-home messages
Challenges and future perspectives of PM in LAC

• Most important issues to be addressed

<table>
<thead>
<tr>
<th>Scientific and technological</th>
<th>Operational</th>
<th>Economic</th>
<th>Governance/regulatory/ethical</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Increase the participation of LAC institutions in PM-related clinical trials</td>
<td>• Strengthen research capacity from a technical perspective</td>
<td>• Making available and accessible to the population costly innovative treatments without risking the sustainability of the health systems • High costs of drugs</td>
<td>• Develop coherent and comprehensive national precision medicine strategies</td>
</tr>
</tbody>
</table>

RESULTS OF THE ONLINE SURVEY. BUILDING BRIDGES IN PERSONALIZED MEDICINE BETWEEN LATIN AMERICA/CARIBBEAN AND EUROPE
Take-home messages
Strengthening EU-LAC collaboration in PM

• Seven out of ten participants rate the need to strengthen the EU-LAC collaboration in PM as “Very important”
• This collaboration should happen more importantly at a policy level
• The highest rated benefits were the implementation of joint research programs and collaborative research projects
Thank you

www.eulac-permed.eu