

Research Priorities in Multiple Sclerosis in Latin America: A Multi-Stakeholder Call to Action to Improve Patients Care

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For which topic were research priorities identified?

multiple sclerosis

In which location was the research priority setting conducted?

South America - Argentina; South America - Brazil; South America - Colombia; South America - Costa Rica; South America - Chile; South America - Ecuador; South America - El Salvador; South America - Guatemala; South America - Mexico; South America - Paraguay; South America - Panama; South America - Peru; South America - Dominican Republic; South America - Uruguay; South America - Venezuela

Why was it conducted at all?

As human and economic resources are limited, especially in Latin America (LATAM), it is important to identify research priorities to improve multiple sclerosis (MS) patients care in the region.

What was the objective?

to generate a multidisciplinary consensus on research priorities in MS for patients care in LATAM by involving healthcare professionals and MS patient associations

What was the outcome?

a list of 11 research questions

How long did the research prioritization take?

9 months

Which methods were used to identify research priorities?

Delphi

How were the priorities for research identified exactly?

Step 1: Delphi round 1: survey: participants were asked to identify up to three research questions of relevance to the field of MS but focusing on unmet needs in the LATAM region, 103 research questions were submitted, removal of identical questions resulted in 85 questions. Step 2: Delphi round 2: participants were sent a compiled list of questions obtained in step 1 and asked to assess if each question was relevant regarding MS research in LATAM, participants were asked for every research question whether this question was a research priority for MS in LATAM, participants were asked to state yes or no, a 75% agreement threshold was set, resulting in list of 56 questions. Step 3: Delphi round 3: survey: list of 56 questions, participants were asked to rate each research questions along five criteria, participants were also asked to comment or add new research questions if considered appropriate, resulting in 11 top research priority questions. Step 4: Delphi round 4: online meeting: participants were asked to discuss the analysis from step 3, during the meeting highest ranked research questions were discussed by participants, after meeting participants were asked to reassess the ranking order of the research questions

Which stakeholders took part?

Neurologists, nurses, physical therapists, neuropsychologists, psychiatrists, psychologists, directors and members of patient associations in LatAm. 62 participants: 35 neurologists, 4 nurses, 12 kinesiotherapists, 7 neuropsychologists, 4 patient association members.

How were stakeholders recruited?

Neurologists, nurses, physical therapists, neuropsychologists, psychiatrists, psychologists, and directors and members of patient associations in LATAM linked to the care of patients with MS were invited. All potential participants were identified through the Latin American Committee and Treatment of MS (LACTRIMS) database as well as MS centers and observational cohort studies databases.

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.