Co-creation of a Prioritized Research Agenda for Pediatric Multiple Sclerosis

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Background

People affected by multiple sclerosis (MS) have unanswered research questions but do not have many opportunities to express them. The lack of inclusion of the patient voice in the development of research agendas is even more pronounced for the pediatric MS population, who are infrequently, if ever, asked about their research priorities, which may differ significantly from those of adults with MS. Even when research topics and questions are sourced from the MS patient community, the resulting research studies may not reflect the priorities and needs of those living with pediatric MS, nor address the outcomes of greatest importance to them.

MS affects approximately 5,000 children in the United States. Because of the smaller pool of pediatric MS patients, and because research with children requires additional steps to ensure their protection, the vast majority of MS research focuses solely on adults. There is a lack of information as to the long-term impact of pediatric MS on overall health, quality of life, and family systems. The safety and effectiveness of MS interventions, including lifestyle interventions, in this age group is also poorly understood.

Objectives

The main objective of the initiative was to develop a prioritized research agenda for pediatric MS through engagement of youths with MS, their family members, and researchers, with an emphasis on identifying questions suitable for patient-centered outcomes research (PCOR) and comparative effectiveness research (CER).

The project team (PT) consisted of representatives from Accelerated Cure Project (ACP) and the National MS Society, both research-focused patient advocacy organizations, Mr. Oscar Monkey, a nonprofit dedicated to supporting those living with pediatric MS, and dmw360 Consulting, a facilitation and organizational development firm. The PT partnered with 28 youths and family members affected by pediatric MS, and 5 researchers to develop the research agenda.

Methods

A 12-month collaborative process was implemented involving multiple stakeholders. A steering committee guided the project, while the project team developed and executed specific activities.

Two virtual convenings were held: the first (December 2023) engaged 25 participants (8 youths with MS, 2 siblings, 15 parents/guardians) to source lived experience and research priorities. The topics identified were then prioritized through stakeholder surveys. The second convening (March 2024) brought together 19 family members (7 youths with MS, 2 siblings, 10 parents/guardians) and 5 researchers/clinicians to develop specific research questions within the highest-ranked topics. The meeting transcripts were analyzed to identify key themes and research questions as source material for the resulting research agenda.

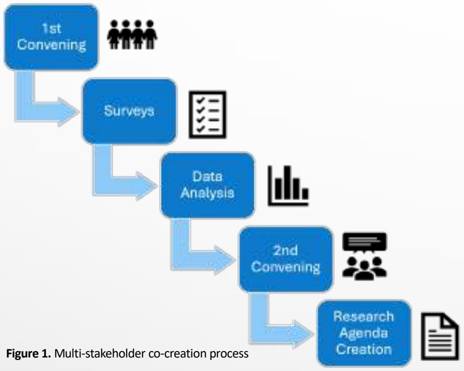

Figure 1. Multi-stakeholder co-creation process

Results

Thirteen research topics were identified and prioritized by the youth and family stakeholders. Four topics ((1) mental health issues in pediatric MS, (2) diet, wellness and other non-drug approaches, (3) factors causing fatigue and brain fog, and how to treat them, and (4) understanding relapse triggers and changes in symptoms) were selected for deeper exploration based on their ranking and alignment with PCOR/CER principles. Collaborative discussions during the second convening among youths, families, and researchers generated specific research questions within each topic area, creating a foundation for future studies that address stakeholder priorities while maintaining scientific rigor.

Weighted Ranking*	Topic
1	Mental health issues in kids with MS: how common are they and how to treat them
2	Impact of a lesion's location on MS symptoms
3	Diet, wellness, and other non-drug approaches to help kids and teens manage MS
4 (tie)	Factors that cause fatigue and brain fog in kids with MS, and how to treat them
4 (tie)	Understanding what triggers relapses and changes in symptoms in kids with MS
5	Repairing damage to myelin in kids with MS
6	New types of treatments including cord blood stem cells
7	Approaches for predicting future changes in a person's MS
8	Accommodations in school and other settings
9 (tie)	Which MS drug treatments can be used in kids, and how to choose the best one for yourself/your child
9 (tie)	Increasing public knowledge and understanding of pediatric MS
10	Genes and other factors that cause MS in kids and teens
11	How MS is diagnosed in kids and teens and factors impacting how long it takes to be diagnosed

Table 1. Weighted ranking of topics sourced at first convening. Topics in BLUE were further explored at the second convening.

Figure 2. A few of the questions posed by youth and family members to be further refined and explored via PCOR/CER studies.

Conclusions

This systematic, stakeholder-engaged process successfully produced a research agenda reflecting the priorities of children, teens, young adults, and their families affected by pediatric MS. By initially focusing exclusively on those with lived experience, we ensured discussions centered on their unique perspectives and needs, fostering an environment free from professional influence. Their insights, when aligned with the interests of pediatric MS researchers and funders, form the basis for a pathway forward for future studies in pediatric MS and demonstrate the value of meaningful patient and family engagement in research prioritization. The process used could serve as a model for developing research agendas in other pediatric conditions.

Next Steps

ACP is eager to advance the research questions of highest priority to those affected by pediatric MS into funded studies. We will:

- Seek out researchers and members of the pediatric MS community who are interested in collaborating on these topics
- Work together to refine the research questions of interest and to design studies and funding applications in support of them
- Enable research through the iConquerMS Kids & Teens platform and community

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Disclosures

The authors have no conflicts of interest to disclose. The views presented are solely the responsibility of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute®, its Board of Governors or Methodology Committee.

For More Information

Please contact Sara Loud (sloud@acceleratedcure.org) to learn more and to discuss ways to accelerate patient-centered pediatric MS research.

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