

Identifying Research Priorities among Patients and Families of Children with Rheumatic Diseases Living in the United States

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For which topic were research priorities identified?

rheumatic diseases

In which location was the research priority setting conducted?

North America - USA

Why was it conducted at all?

To improve the quality and participation in pediatric rheumatology research, patient-prioritized studies should be emphasized.

What was the objective?

to survey patients and caregivers of children with rheumatic diseases to identify what research topics were most important to them

What was the outcome?

a ranking list of 7 research areas

How long did the research prioritization take?

Survey: November 2016 - March 2017. Focus groups: February 2017 - June 2017

Which methods were used to identify research priorities?

focus group; survey

How were the priorities for research identified exactly?

Step 1: survey 1: participants were asked: "What concerns do you have about your/your child's health and wellbeing? What keeps you up at night? Which specific questions or problems do you wish you/your child's doctors could fix? In addition to finding a cure, what specific areas would you like research to focus on in the next five years?". Step 2: focus groups: participants were asked to discuss same questions as in survey 1. Step 3: data processing: responses collated into themes. Step 4: survey 2: participants were asked to rank the 7 themes

Which stakeholders took part?

Patients and caregivers of children with juvenile myositis (JM), juvenile arthritis (JA), and childhood-onset systemic lupus erythematosus (cSLE). Survey 1 participants: 138 JM (77% parents), 57 JA (93% parents) and 47 cSLE (55% parents) participants. Focus groups: 9 parents of children with JM, 4 parents of children with JA. Survey 2 participants: 365 (JM), 44 (JA), and 32 (cSLE) participants.

How were stakeholders recruited?

Surveys were emailed to listservs and posted to social media sites of JM, JA, and cSLE patient advocacy organizations. The ranking survey was emailed to the Cure JM, AF, and LFA listservs and a link was posted on their respective social media sites.

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.