

Research Priorities in Childhood-Onset Lupus: Results of a Multidisciplinary Prioritization Exercise

Ardoin et al. (2019)

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For which topic were research priorities identified?

childhood-onset systemic erythematosus lupus

In which location was the research priority setting conducted?

North America - USA

Why was it conducted at all?

Childhood-onset systemic erythematosus lupus (cSLE) is characterized by more severe disease, widespread organ involvement and higher mortality compared to adult-onset SLE. However, cSLE is largely underfunded to carry out necessary research to advance the field. Few commonly used SLE medications have been studied in children, and important knowledge gaps exist concerning epidemiology, genetics, pathophysiology and optimal treatments for cSLE.

What was the objective?

to explore and better understand clinicians' and investigators' main research priorities for children with lupus which should guide future research decisions and funding mechanisms

What was the outcome?

a list of 5 research topics

How long did the research prioritization take?

May 2018 - August 2018

Which methods were used to identify research priorities?

survey

How were the priorities for research identified exactly?

Step 1: collecting research priorities: based on literature review, clinical expertise of team members and based on review of a previous unpublished consensus exercise in this area. Step 2: survey: participants were asked to rate 17 research domains and to rank each domain rated as high, participants also asked to indicate the five most important research topics for the top two domains

Which stakeholders took part?

Pediatric rheumatologists, dermatologists and nephrologists with expertise in lupus. Overall, 256 stakeholders participated.

How were stakeholders recruited?

The survey was distributed by email to 752 members of CARRA, MWPNC and PeDRA. Each group distributed electronic survey links to its membership and electronically sent reminders.

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.