

Dutch Patients, Caregivers and Healthcare Professionals Generate First Nationwide Research Agenda for Juvenile Idiopathic Arthritis

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For which topic were research priorities identified?

juvenile idiopathic arthritis

In which location was the research priority setting conducted?

Europe - Netherlands

Why was it conducted at all?

Involving the end-users of scientific research (patients, carers and clinicians) in setting research priorities is important to formulate research questions that truly make a difference and are in tune with the needs of patients.

What was the objective?

to generate a national research agenda for Juvenile Idiopathic Arthritis together with patients, their caregivers and healthcare professionals through conducting a nationwide survey among these stakeholders

What was the outcome?

a ranking list of 10 research questions

How long did the research prioritization take?

December 2018 - February 2020

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: setting up PSP: scope defined in agreement with steering group. Step 2: collecting questions: survey, focus groups and small group interviews with children 10 to 13 years old to collect relevant research questions, 24 children 9 to 16 years old participated in two focus groups and six group interviews, 506 questions submitted via survey, 81 additional question collected via focus groups and interviews, 17 additional unanswered research questions found in literature, resulting in 604 questions overall. Step 3: data processing: questions reviewed, grouped into categories, steering group summarized questions into summary questions, literature search to check if question unanswered, steering group made final decision whether or not question already identified or not, 519 questions were in scope, resulting in 53 summary questions. Step 4: interim ranking: survey asking participants to choose top 10 questions, young children asked to choose top 5 during focus groups, 3 separate top 10 for patients, carers and clinicians were determined and top 5 of children, resulting in shortlist of 35 questions. Step 5: final prioritization: workshop: before workshop participants were asked to individually prioritize shortlist of questions, small group discussions with nominal group technique and small group rankings, aggregate rankings and plenary discussions

Which stakeholders took part?

Patients, their caregivers, healthcare professionals. Survey: 278 participants: 141 patients, 88 carers, 49 clinicians. Interim ranking: 303 participants: 125 patients, 136 carers, 42 clinicians. Workshop: 20 participants: 5 patients, 5 parents of patients, 20 clinicians: 3 paediatric rheumatologists, 1 ophthalmologist, 2 physical therapists, 3 nurses, 1 psychologist.

How were stakeholders recruited?

Patients and parents were recruited via patient organizations (email and social media) and flyers. Clinicians were recruited via professional organizations' newsletters and flyers.

Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of a steering group. The steering group consisted of 4 young adult JIA patients, 3 parents of JIA patients, 3 pediatric rheumatologists, 1 ophthalmologist, 2 physical therapists, and 1 nurse practitioner. The members oversaw the project and were involved in data processing.