Opinion

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# Process and Outcome of a National UK Pediatric Rheumatic Disease Research Consultation and Consensus Prioritization

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## Description

Paediatric rheumatic diseases include a wide range of illnesses, ranging from relatively common diseases to extremely rare diseases. These include inflammatory diseases (e.g., juvenile idiopathic arthritis, juvenile Systemic Lupus Erythematosus [SLE], vasculitis, and auto inflammatory disorders) and non-inflammatory diseases. The rare nature of pediatric rheumatic diseases poses challenges for both the clinical care and research of these conditions.1 There are many crucial research questions that warrant investigation to improve the lives of children and young people with pediatric rheumatic diseases. To conduct adequately powered trials, national and international collaboration is key to making meaningful discoveries, which would enable changes in clinical practice. Given the degree of unmet need in pediatric rheumatic disease research, it is important to identify the most important research priorities through a systematic and thoughtful process that considers health care, interventions, treatment, and outcomes. These research priorities should be considered important to a range of stakeholders, including medical practitioners, nurses, Allied Health-Care Professionals (AHPs), charities, and most importantly, patients and their families collectively referred to as consumers in this Health Policy paper.

## Wide-Ranging and Multidisciplinary Perspective on pediatric Rheumatic Disease Research Priorities

Over the past 20 years, there has been increasing recognition that consumers are able to, and should, make contributions to shape research agendas and funding. Understanding the key priority areas of all stakeholder groups will help to guide future research directions, decisions, and funding mechanisms. The purpose of our study was to capture a wide-ranging and multidisciplinary perspective on pediatric rheumatic disease research priorities and to identify research questions that consumers and clinicians want to see addressed by research into pediatric rheumatic diseases. This Health Policy paper describes the process and outcome of a national UK pediatric rheumatic disease research consultation and consensus prioritization exercise coordinated by the Paediatric Rheumatology clinical studies group subsequently referred to as the CSG, which was supported by the UK National Institute of Health Research Clinical Research Network: children and Versus Arthritis. The CSG **i**nvolved both consumers and clinicians in the identification and prioritization of pediatric rheumatic disease research ideas. This project was launched at a meeting of the CSG in May, 2019, and continued until November, 2020. The CSG is a national expert group of clinicians, clinical academics, multidisciplinary AHPs, nurses, clinical psychologists, and pharmacists. The CSG has strong consumer representation, supporting the development and conduct of a comprehensive portfolio of clinical studies and clinical trials in the field of pediatric rheumatology. All members of the CSG (health-care professionals and consumers) formed the project steering group, which was responsible for identification of interested parties to be consulted when soliciting research ideas. The steering group also assisted with the process of gathering research priority ideas. The operational group oversaw all stages of the project and included the CSG co-chairs, the CSG trainee representative, a clinical academic foundation trainee, the CSG administrator, and an external expert in consensus decision making and research priority setting.

## Management of Children and Young People with Pediatric Rheumatic Disease

The evidence base that underlies the management of children and young people with pediatric rheumatic diseases is deficient. In this field, there are many crucial unanswered questions. The UK Paediatric Rheumatology Clinical Studies Group, supported by UK National Institute for Health Research Clinical Research Network: children and *Versus* Arthritis, elicited ideas for research priorities from pediatric rheumatologists, trainees, allied health-care professionals, nurse specialists, patients, parents of patients, careers, and charities. These ideas were collected through online surveys and face-to-face meetings. A modified Delphi process was used, which included online research priority ranking surveys and a consensus workshop. A long list of 55 disease-specific research priorities and 37 general research priorities were voted on in the first survey. A list of 11 top general research priorities was produced. The top ten disease-specific research priorities were discussed in depth at a Delphi workshop to determine their final ranking. This Health Policy paper will help to guide clinicians, academics, and funding bodies to prioritize research in pediatric rheumatic diseases, specifically in areas of unmet patient needs.