Special articles
Outcome measures in juvenile systemic sclerosis: an unmet need

Introduction

This collection represents the first set of *Special Articles* dedicated exclusively to juvenile systemic sclerosis (jSSc) published in *Clinical and Experimental Rheumatology,* forming part of the journal's annual issue devoted to systemic sclerosis (SSc). By bringing together international experts in paediatric rheumatology, paediatric cardiology, and paediatric gastroenterology, this special collection highlights current advances, ongoing challenges, and future priorities in the assessment of this rare disease.

Juvenile SSc is a rare, multisystem autoimmune disease characterised by vasculopathy, immune dysregulation, and progressive fibrosis. The formal history of jSSc began just over twenty years ago with the establishment of the first preliminary Classification Criteria during International Consensus Workshops in Padova, Italy (1). While research has expanded since then, progress in understanding and managing jSSc has heavily relied on adult SSc frameworks. Consequently, many assessment tools currently used in clinical practice and trials have been adapted directly from adult studies without formal validation in paediatric populations.

The opening article of this collection provides the rationale for a paediatric-specific focus through a comprehensive scoping review comparing juvenile- and adult-onset SSc. The review demonstrates distinct differences in disease phenotypes, autoantibody profiles, organ involvement, and clinical outcomes from onset, reinforcing the critical need for age-tailored management strategies (2).

The absence of standardised, validated outcome measures remains a central barrier to advancing paediatric clinical trials. Previous recommendations, such as those from the SHARE initiative (3), marked critical milestones but were largely based on expert opinion due to limited paediatric data. To address this unmet need, the International Juvenile Systemic Sclerosis Outcome Group (IJOG), in collaboration with the Childhood Arthritis and Rheumatology Research Alliance (CARRA) and the Paediatric Rheumatology European Society (PReS), launched an international initiative to systematically evaluate outcome measures across six major disease domains (4). The ultimate goal is to establish evidence-informed, feasible, and globally applicable consensus recommendations for outcome assessment in jSSc.

This special collection presents the initial findings of the IJOG initiative, featuring four of the six domain-specific scoping reviews: skin/musculoskeletal disease (5), digital vasculopathy/Raynaud phenomenon (6), cardiac involvement (7), and gastrointestinal (GI) disease (8). Across all domains, the findings reveal a remarkably consistent gap: paediatric data remain sparse, most instruments are evaluated solely in adults, and formal paediatric validation is overwhelmingly lacking. Critical gaps persist regarding sensitivity to change, age-appropriate normative values, patient-reported outcomes, and global feasibility across diverse healthcare settings.

Complementing the GI scoping review, a final article offers a practical, multidisciplinary approach to evaluating GI manifestations in jSSc. By pairing available evidence with clinical expertise, it provides pragmatic guidance for symptom management, diagnostic testing, and nutritional monitoring, while highlighting the evidence gaps that continue to shape paediatric care (9).

As novel targeted therapies emerge, the demand for robust paediatric outcome measures is urgent. We hope this inaugural collection serves as both an immediate practical resource for clinicians and a foundation for collaborative research that will refine trial design and ultimately improve outcomes for children living with jSSc.

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