

# Establishing a Pediatric Erythromelalgia Registry – A Scoping Review and Priority Setting Project

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## BACKGROUND / AIMS

Erythromelalgia (EM) is a descriptive term for a rare, chronic pain disorder involving an intense burning sensation, warmth, and erythema, usually affecting the distal extremities, typically worsened by heat and partially relieved by cold.<sup>1-3</sup> With an estimated incidence of 1.3 cases per 100,000 per year,<sup>4,5</sup> the rarity of the condition has led to few case series or outcomes studies on pediatric EM, and even fewer with long-term outcomes.<sup>3,6,7</sup>



**Figure 1.** Examples of erythromelalgia flares (Taken from The Erythromelalgia Association’s “A Patient’s Guide to Erythromelalgia”)

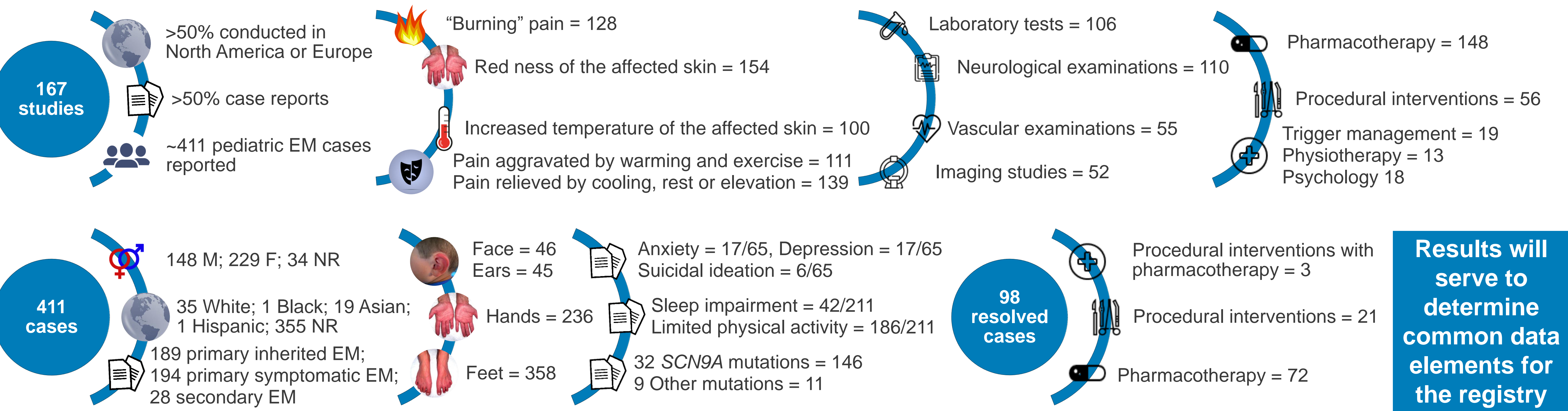
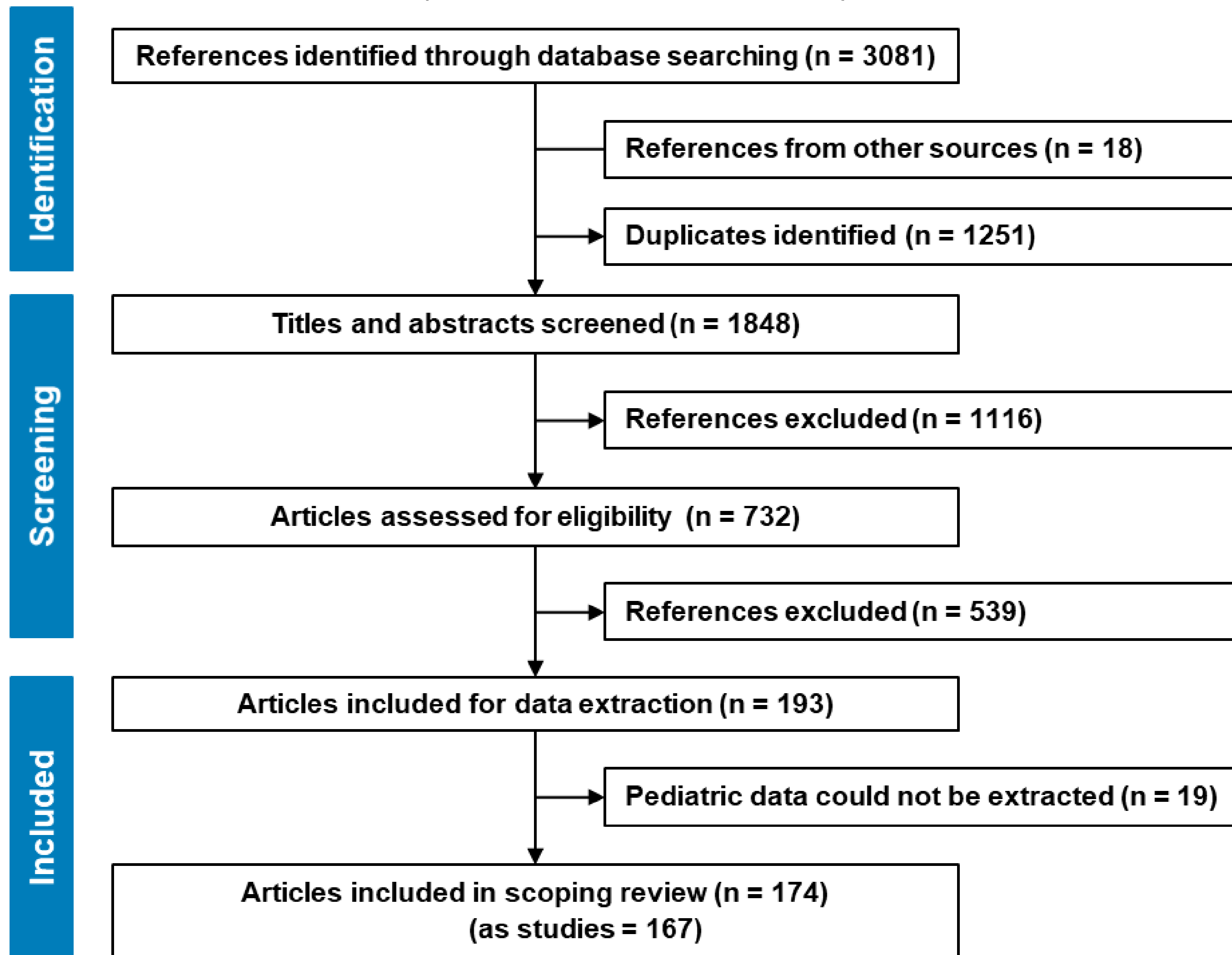
**The ULTIMATE GOAL is to establish a multi-institutional and multi-disciplinary collaboration to gather retrospective and prospective data, via a registry/repository, on pediatric patients with EM.**

### INITIAL STEPS TO CREATE REGISTRY

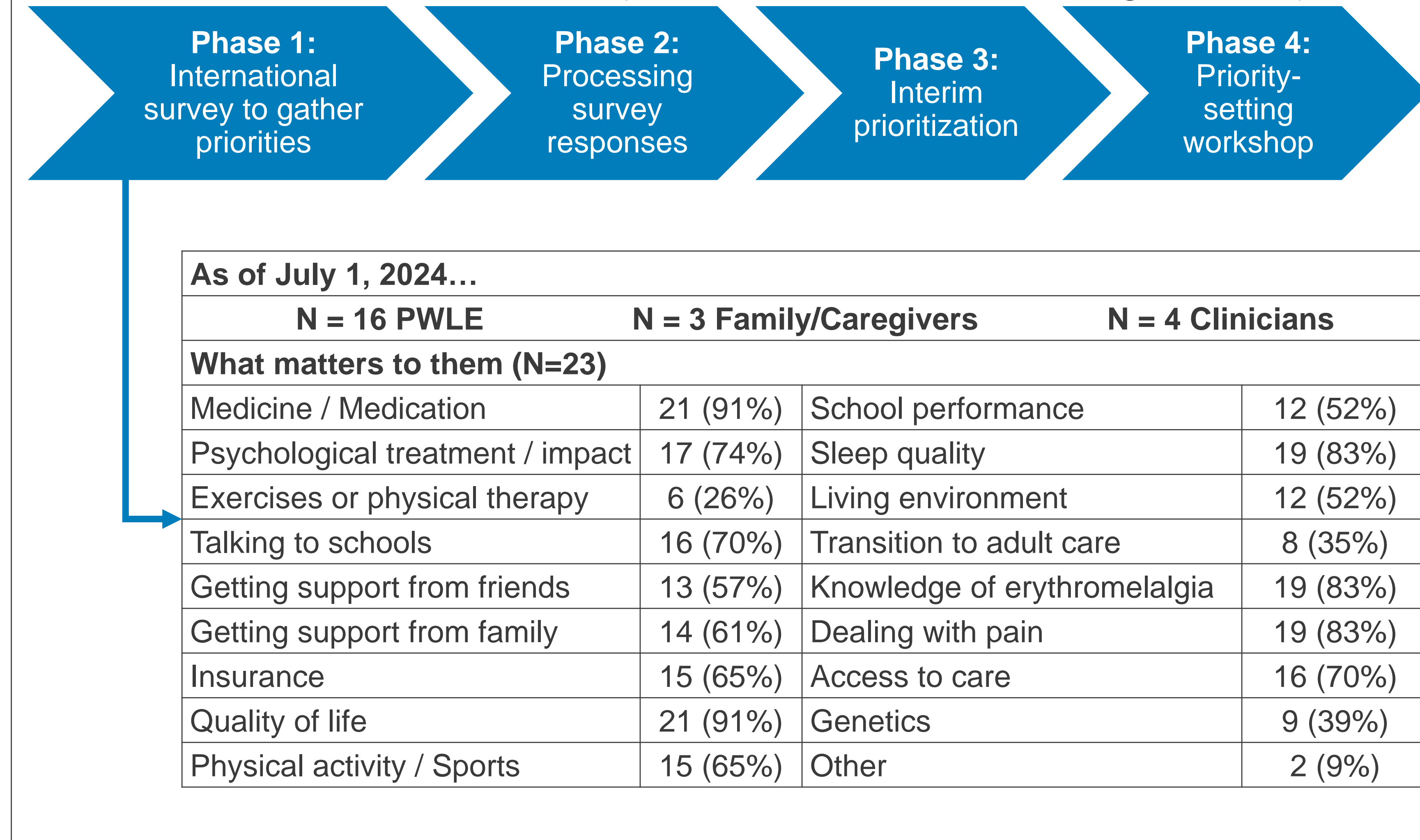
- 1. SCOPING REVIEW:** Summarize the current literature on pediatric EM
- 2. PRIORITY SETTING PROCESS:** Identify priorities for recognition and management from multiple stakeholders such as clinicians, people with lived experience of pediatric EM, and their family members.

## RESULTS

### SCOPING REVIEW (follows PRISMA-ScR)



### PRIORITY SETTING PROCESS (follows James Lind Alliance guidelines)



**Results will serve to determine common data elements for the registry**

**References**  
<sup>1</sup>Parker et al. Clin Exp Rheumatol, 2017. 35(1): p. 80-84.  
<sup>2</sup>Tham et al. J Pain Res. 2018. 11: p. 1689-1698.  
<sup>3</sup>Sun et al. Children, 2023. 10(8): p. 1282.

<sup>4</sup>Alhadad et al. Vasa, 2012. 41(1): p. 43-48.  
<sup>5</sup>Reed et al. J Eur Acad Dermatol Venereol, 2009. 23(1): p. 13-5.  
<sup>6</sup>Arthur et al. J Pediatr, 2019. 206: p. 217-224 e9.  
<sup>7</sup>Cook-Norris et al. J Am Acad Dermatol, 2012. 66(3): p. 416-23.

**We are developing a multicenter PEDiatric ErythoMElalgia Registry Gathering multidisciplinary Experts (PED-EMERGE). To get involved in contributing to this registry or for any other inquiries, please contact: Don Daniel Ocay, PhD - [dondaniel.ocay@childrens.harvard.edu](mailto:dondaniel.ocay@childrens.harvard.edu)**

