

Decoding diagnosis delay in Juvenile idiopathic arthritis (JIA)

Raju Gautam¹, Ratna Pandey², Radha Sharma³, Shilpi Swami¹

¹ConnectHEOR, London, UK; ²ConnectHEOR, Delhi, India; ³ConnectHEOR, Edmonton, Alberta, Canada.
Email: raju.gautam@connectheor.com

SA28



BACKGROUND

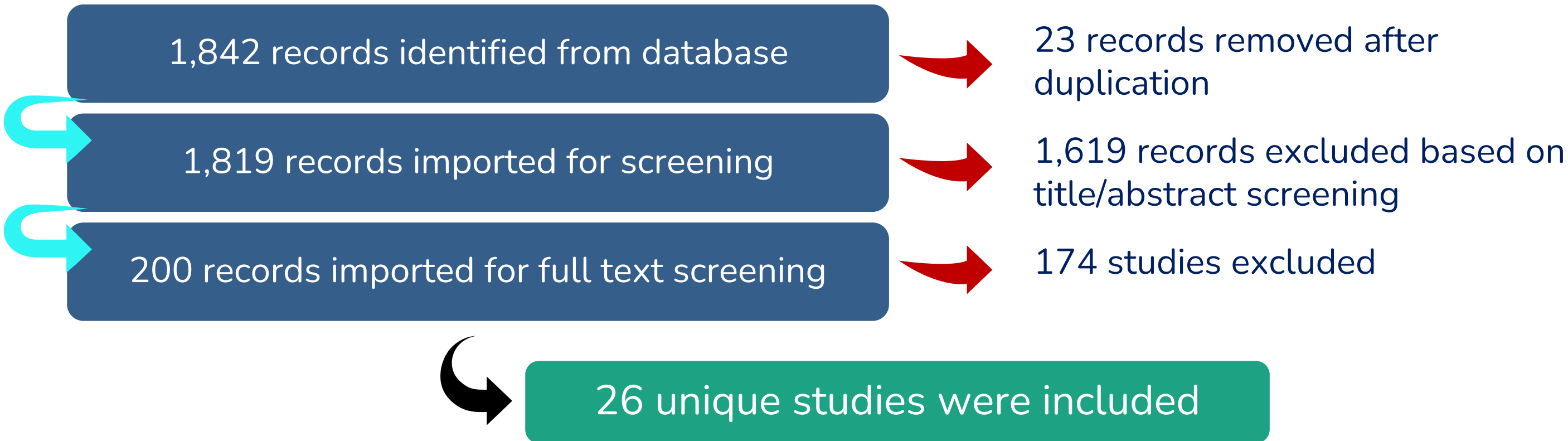
- Context:**
- Juvenile idiopathic arthritis (JIA) is the most common chronic rheumatic disease in children, characterized by heterogeneous clinical manifestations.¹
 - Early diagnosis and initiation of appropriate therapy are critical to prevent irreversible joint damage and disability.²
 - Diagnosing children with JIA remains a significant challenge globally. This directly affects patient outcomes, quality of life, and healthcare efficiency. Understanding its causes helps reduce long-term disability, improve equity of access, and guide strategies for earlier recognition and treatment.
- Objective:**
- The aim of this study was to understand the delay in diagnosing JIA and the reasons for its delay.

METHODS

- A targeted literature review was conducted using Embase and Medline databases to identify the studies published since January 2012.
- The search terms (and relevant MESH terms) comprised 'juvenile idiopathic arthritis' and 'diagnosis delay'. Papers published in English were included.
- Data on study details, clinical characteristics, and diagnosis delay and its factors were extracted.



Embase and Medline database (January 2012-May 2025) was searched to identify studies on diagnostic delay in JIA.



RESULTS

- Of the 1,842 retrieved citations, 26 unique studies were included (21 full-text articles and 5 conference abstracts).
- Figure 1** shows distribution of studies by countries, with most studies being from Turkey (n=6; 23%), followed by China (n=4; 15%) and India (n=3; 12%).
- Eighteen studies (69%) were of retrospective design (**Figure 2**). The most frequently used data source was hospital medical records (62%; **Figure 3**).
- In the majority of included studies, there was preponderance of males, indicating that JIA was more frequently reported in males.
- The mean/median age at diagnosis ranged 9.2 to 13.7 years.
- Diagnostic criteria were reported in 25 studies, of which 23 utilised the International League of Associations for Rheumatology (ILAR) classification.

Figure 1. Distribution of studies by country



Figure 2. Studies by design

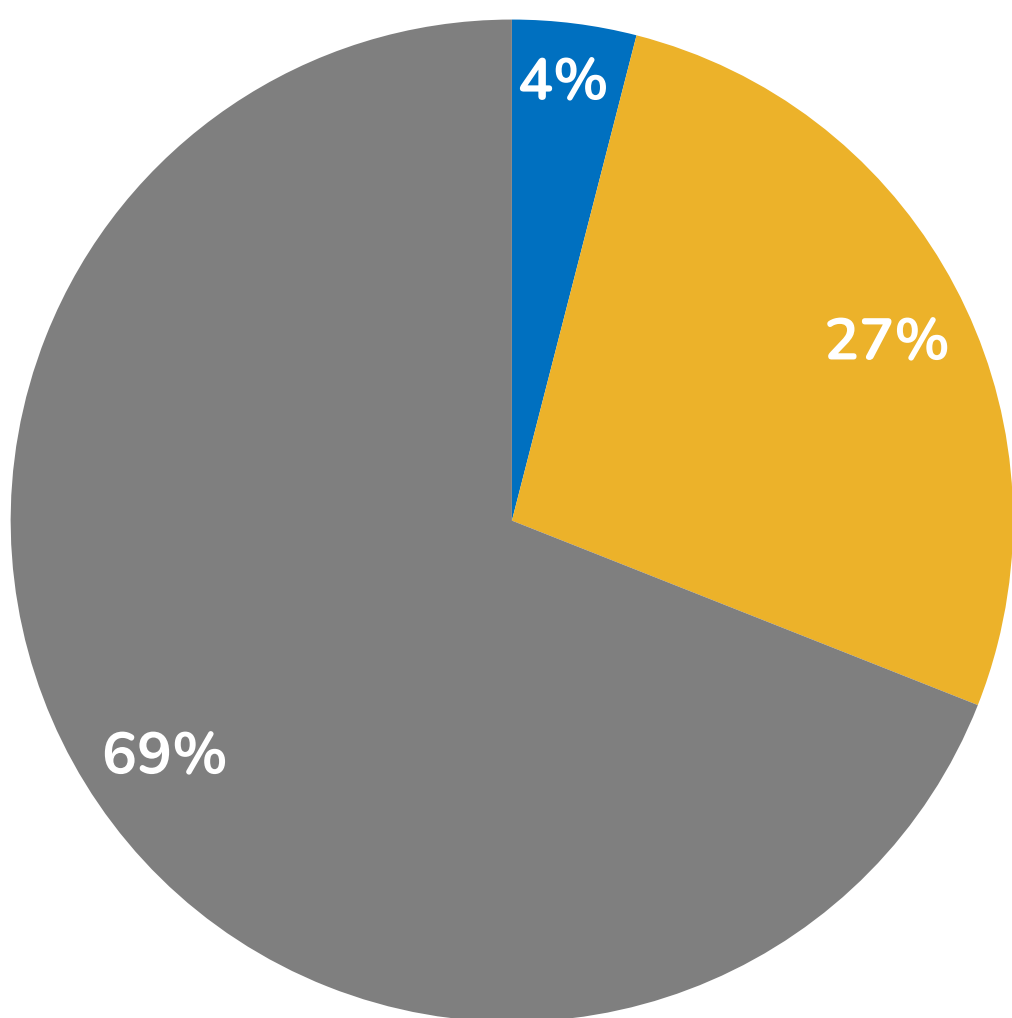
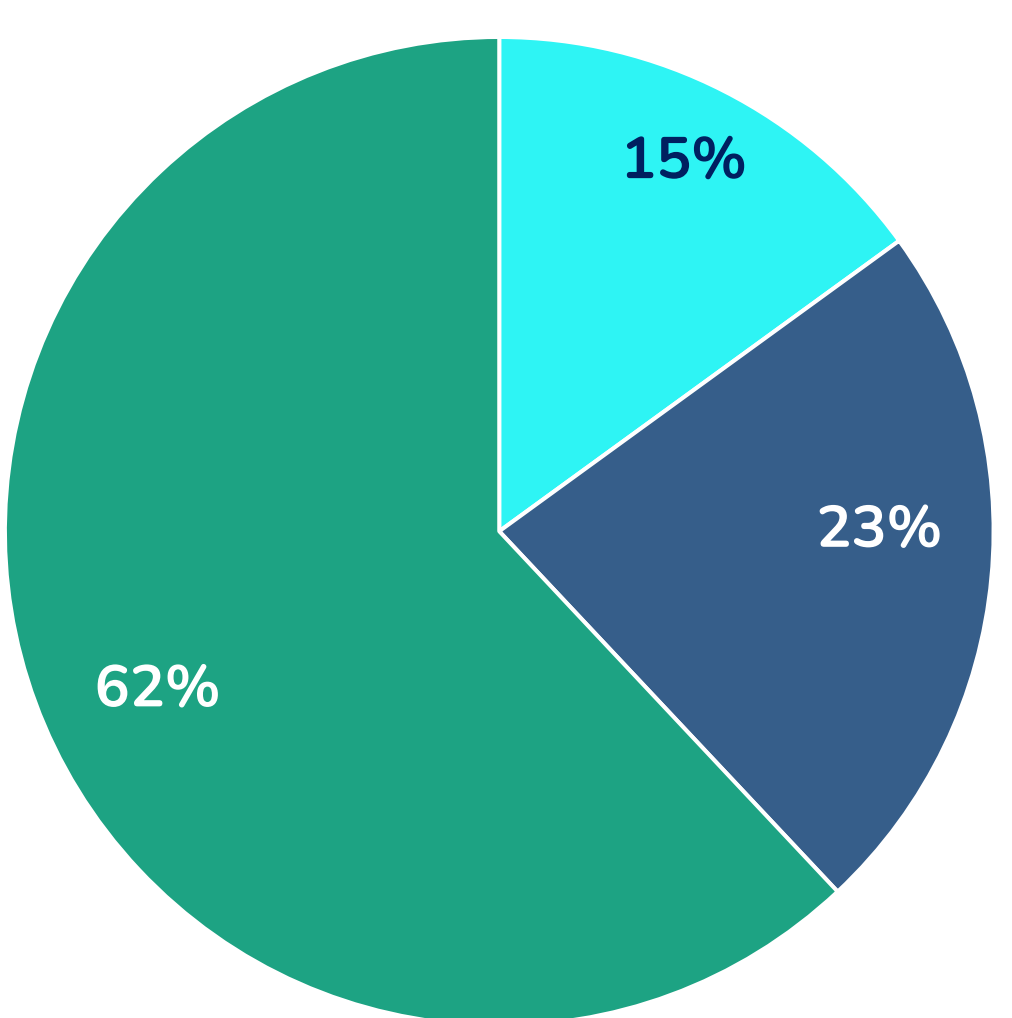


Figure 3. Studies by data sources



■ Ambispective ■ Prospective ■ Retrospective ■ Registry ■ Chart review ■ Hospital Medical records

The study highlights the need for increased clinical awareness, early referral pathways, and improved diagnostic strategies to facilitate timely diagnosis and management of JIA, ultimately aiming to reduce its disease burden and long-term complications.

- The delay of diagnosis varied substantially across different JIA subtypes, ranging from 2.3 weeks to 4.3 years.
- In seven studies that compared different subtypes, the (mean) longest delays were usually observed in enthesitis-related arthritis (ERA; 3.7–13.2 months), followed by polyarticular JIA (2.5–11.5 months), oligoarthritis (1.7–5.6 months), psoriatic JIA (1–6 months), and systemic JIA (0.8–1.9 months) (**Figure 4**). In three studies, however, polyarticular JIA demonstrated longer delays (4–12 months).
- Figure 5** presents the reasons for delay in the diagnosis of JIA. Six studies explored reasons for diagnostic delay, with most common being symptom overlap with more prevalent conditions, heterogeneous clinical manifestations, limited awareness among primary care providers, etc.

Figure 4. Dealy in mean diagnosis (in months) across different JIA subtypes

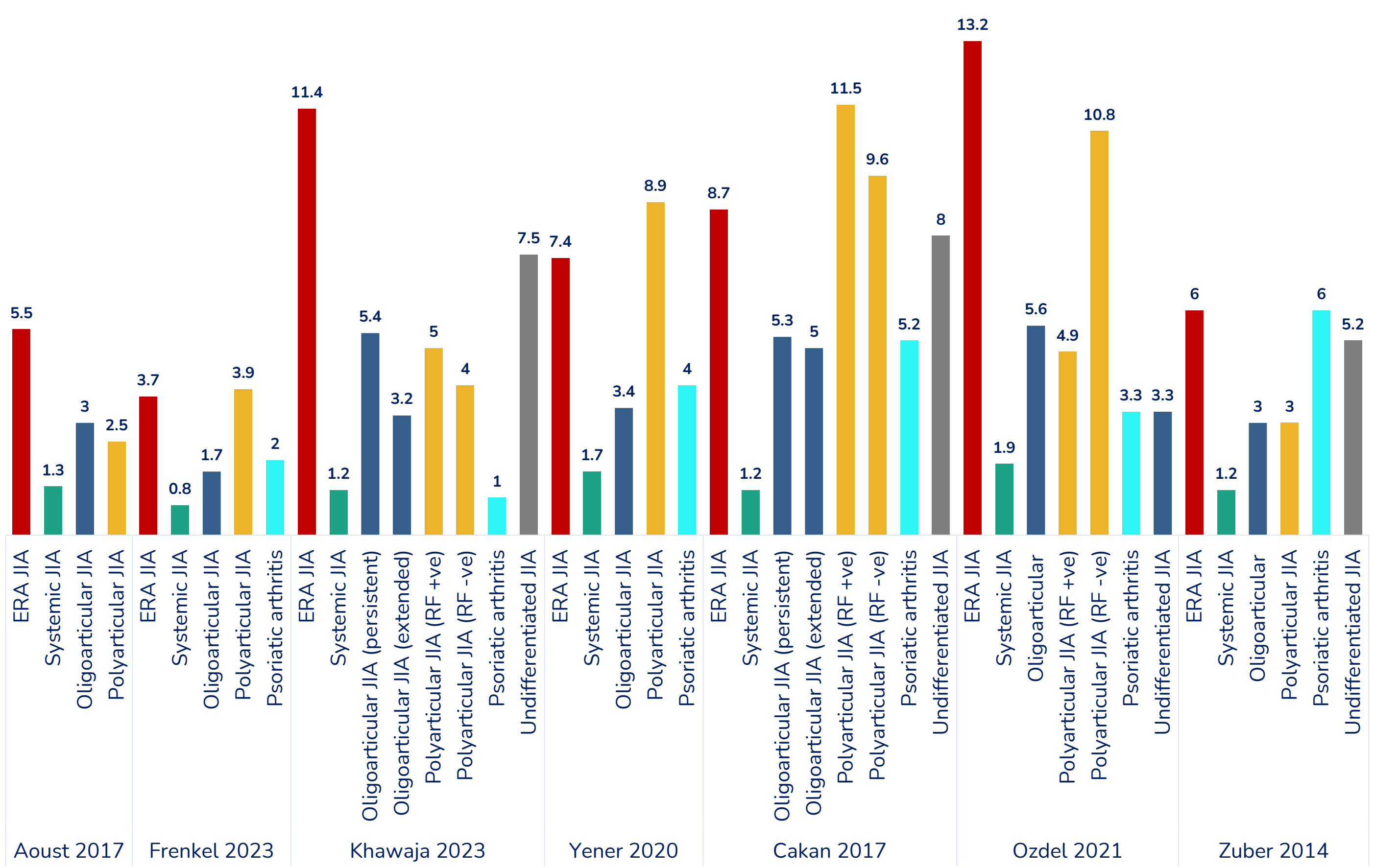


Figure 5. Reported reasons for diagnosis delay

Symptoms overlap with more prevalent conditions

Heterogenous clinical manifestations of JIA

Limited awareness among primary care providers

Repeated consultations with GPs, pediatricians, or orthopedic before specialist

Limited access to diagnostic facilities

Inability of children to accurately describe the symptoms

FINANCIAL DISCLOSURE

All authors are employees of ConnectHEOR Limited and no external funding was received to conduct this research. The authors have no conflict of interest to declare.

REFERENCES

- Ravelli A, Martini A. The Lancet. 2007; 369(9563): 767-778.
- Prince FH, et al. BMJ. 2010; 341.
- Aoust L, et al. Orphanet J Rare Dis. 2017; 12(1): 43.
- Aoust L, et al. Orphanet J Rare Dis. 2017; 12(1): 1-5.
- Khawaja K, et al. Pediatric Rheumatol. 2023; 21(1): 14.
- Yener GO, et al. Turkish Arch Pediatrics. 2020; 55(2): 157.
- Çakan M, et al. Turkish J Pediatrics 2017; 59(5): 548-54.

