Identification of adult patients diagnosed with rheumatic musculoskeletal disease as children or adolescents in the Australian OPAL dataset

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Background

- Children and adolescents diagnosed with rheumatic musculoskeletal (MSK) diseases have a substantial burden of disease that frequently extends into adulthood
- There are limited data on outcomes in adulthood for these patients
- The OPAL dataset is derived from electronic medical records (EMR) of 113 rheumatologists around Australia (n=219,812 adult patients)
- Data are entered at the point of care using Audit4 software

Aims

- To identify patients in adult rheumatology care in Australia who were diagnosed in childhood or adolescence

Methods

- Patients were included if symptoms of their MSK disease were recorded as starting before the age of 18 years or if their MSK disease contained the term "juvenile"
- Patients initially identified using all diseases within International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) Chapter XIII: Diseases of the musculoskeletal system and connective tissue (codes M00-M99)
- The subgroup of patients diagnosed with an autoimmune disease were also identified

Results

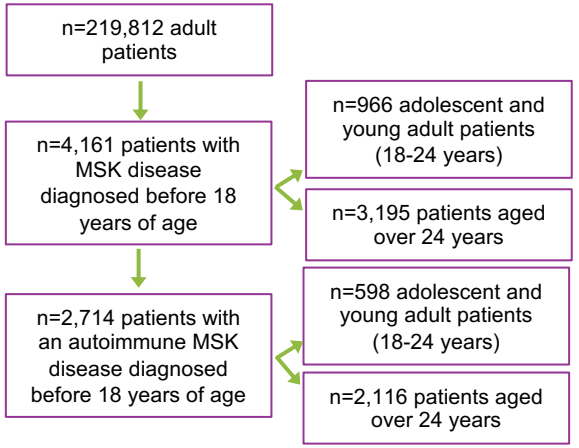

Figure 1. Identification of patients with rheumatic MSK disease diagnosed in childhood or adolescence in the OPAL dataset.

- 4,161 patients with at least one musculoskeletal disease diagnosed before the age of 18 years were identified (Figure 1)
- Of the 4,161 patients, 354 patients had more than one MSK condition recorded
- A subset of patients would be considered adolescents or young adults (n=966)
- The remaining patients were over 24 years (n=3,195)
- Median time since first recorded visit was 6.4 years [IQR 3.5-9.4 years]
- Median duration of disease since symptom onset was 19.8 years [IQR 11.0-32.8 years] for the 3,720 patients with a recorded estimate of symptom onset
- Within the 4,161 patients there was a subgroup of 2,714 patients with at least one autoimmune condition (Figure 2)
- This included 598 adolescent and young adult patients and 2,116 patients over 24 years
- Median time since first visit recorded in the OPAL dataset was 6.8 years [IQR 3.7-10.1 years], and median duration of disease since symptom onset was 21.8 years [12.3-34.3 years]

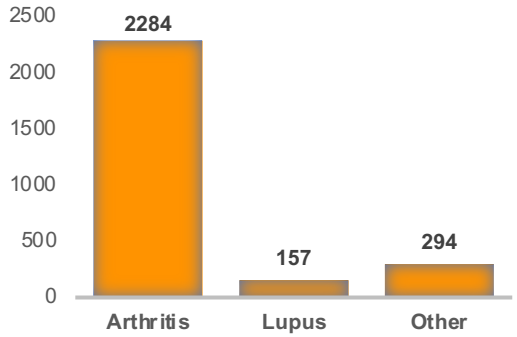

Figure 2. Numbers of patients with an autoimmune MSK disease diagnosed in childhood or adolescence in the OPAL dataset.

- Most patients with an autoimmune MSK disease in the OPAL dataset had inflammatory arthritis (n=2284)
- A smaller number of patients had lupus (n=157)
- The remaining patients had other conditions, which included myositis, Sjogren's syndrome, scleroderma, Behcet's disease and other vasculitides (n=294)

Conclusions

- A large number of adult patients diagnosed with juvenile rheumatic MSK disease were identified
- These data may be a valuable resource for research on long-term outcomes for patients diagnosed in childhood and adolescence
- These patients have had a substantial disease duration since symptom onset, including several years in adult care after transition
- It is vital to understand the burden of disease in this group
- The OPAL model is a powerful, sustainable and scalable solution for long-term research in rheumatology
- Expanding the OPAL Network to include paediatric rheumatologists could eventually lead to the generation of a unique dataset that spans childhood, adolescence and adulthood

Acknowledgements

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Littlejohn GO, Tymms KE, Smith T, Griffiths HT. Using big data from real-world Australian rheumatology encounters to enhance clinical care and research. *Clin Exp Rheumatol.* 2020;38(5):874–80.