PROGRESS REPORT 2026

Australian Juvenile Arthritis Registry

JAFA
Juvenile Arthritis Foundation Australia

Australian Rheumatology Association
APRG

A3BC
AUSTRALIAN ARTHRITIS & AUTOIMMUNE
BIOBANK COLLABORATIVE
NHMRC CENTRE OF RESEARCH EXCELLENCE

Introduction

The Australian Juvenile Arthritis Registry (AJAR) is a national observational registry of children, adolescents and young adults with juvenile idiopathic arthritis (JIA) and related childhood rheumatic diseases (CRDs) which was launched in March 2023.

AJAR is a partnership between the Juvenile Arthritis Foundation Australia (JAFA), the Australian Paediatric Rheumatology Group (APRG) and the Australian Arthritis and Autoimmune Biobank Collaborative (A3BC).

The overarching purpose of the registry is to collect national information to understand the burden of these diseases, inform policy and planning and support and guide health services planning and consumer-relevant research to facilitate earlier diagnosis, improve care and optimise outcomes.

Since its inception, AJAR registrants have continued to increase steadily and now number over 1,100 registrants. This report provides a snapshot of current registrants.

Acknowledgements

Funding sources:
The Australian Arthritis and Autoimmune Biobank Collaboration (A3BC) – NHMRC Centre of Research Excellence for Better Outcomes in Inflammatory Arthritis.

NSW Ministry of Health

This Report was prepared on behalf of AJAR collaborators by:
Professor Stephen Colagiuri (JAFA), Dr Fiona Howard (A3BC), Tom Lynch (A3BC), Vibhasha Chand (A3BC) and Professor Lyn March (A3BC).

Foreword

I am pleased to introduce the current report on the Australian Juvenile Arthritis Registry (AJAR) which presents data on over 1,000 children and young adults with Juvenile Idiopathic Arthritis and Childhood Rheumatic Diseases.

The Registry was established as a result of a key recommendation of the 2022 Interim Report on the Parliamentary Inquiry into Childhood Rheumatic Disease through a partnership of the Juvenile Arthritis Foundation Australia, the Australian Paediatric Rheumatology Group and the Australian Arthritis and Autoimmune Biobank Collaborative.

The information generated by AJAR has provided valuable insights into these conditions and is guiding health policy and planning. It is also contributing to clinical trials and to the arthritis and autoimmune biobank.

I commend this report to you and the focus it brings on understanding the magnitude and extent of the burden of these prevalent and serious diseases.

Dr Mike Freelander MP

Abbreviations

A3BC	Australian Arthritis and Autoimmune Biobank Collaborative
AIHW	Australian Institute of Health and Welfare
AJAR	Australian Juvenile Arthritis Registry
APRG	Australian Paediatric Rheumatology Group
ANZ-CLARITY	Australian and New Zealand ChiLdhood Arthritis Risk factor Identification sTudY
ARAD	Australian Rheumatology Association Database
CRD	Childhood rheumatic disease
DMARD	Disease-modifying antirheumatic drugs
bDMARD	Biologic disease-modifying antirheumatic drugs
csDMARD	Conventional synthetic disease-modifying antirheumatic drugs
tsDMARD	Targeted synthetic disease-modifying antirheumatic drugs
GP	General Practitioner
JAFA	Juvenile Arthritis Foundation Australia
JIA	Juvenile Idiopathic Arthritis
NSAID	Non-steroidal anti-inflammatory drugs

Contents

Foreword.....1
Abbreviations.....2
Contents.....3
Findings At A Glance.....4
About Juvenile Idiopathic Arthritis (JIA) and Childhood Rheumatic Diseases (CRDs).....5
Australian Arthritis Databases.....6
About AJAR.....7
Development and Launch.....7
Objective.....7
Dataset.....7
Consent Options.....8
Enrolment Procedure.....8
Data Storage.....8
Oversight.....9
Results.....10
Enrolment.....10
Consent Choices.....10
Participant Characteristics.....11
JIA and CRD Subtypes.....12
Medications.....13
Time to Diagnosis.....14
Clinician Data.....14
Other Data.....14
State Distribution of Registrants.....15
State Heat Maps by Registrant Postcodes.....16
A3BC Enrolment.....16
Conclusions.....17
References.....18
Appendix A – AJAR Enrolment Form.....19
Appendix B – AJAR Registration Flyer.....21

Findings At A Glance

1,087 registrants

11.5 years – average age of registrants

67% females

81.2%
Juvenile Idiopathic Arthritis

18.8%
Other Childhood Rheumatic Diseases

6 years
average age of symptom onset

312 days (10.2 months)
average time to diagnosis

87%
taking medications

About Juvenile Idiopathic Arthritis (JIA) and Childhood Rheumatic Diseases (CRDs)

JIA and CRDs are a group of painful, incurable, inflammatory, autoimmune conditions affecting the joints, eyes and, in some cases, the skin, muscles and internal organs with onset before age 16 years. JIA accounts for approximately 80% and CRDs the remaining 20% made up of less common conditions such as systemic lupus erythematosus, chronic relapsing multifocal osteomyelitis and juvenile dermatomyositis.

JIA affects an estimated 6,000 to 10,000 Australian children aged 0-16 years, and 18-30,000 Australians aged 0-24 years, equivalent to diabetes in the same age group. (1) Awareness of JIA is low among health professionals resulting in delayed diagnosis and increased risk of permanent joint damage. (2) Uveitis, a common inflammatory eye complication, can cause visual impairment and blindness if not detected early and treated.

Australian children with JIA/CRDs commonly experience daily pain, time off school and lost educational opportunity (12-15% of missed school days annually), social and physical marginalisation, and mental ill health including anxiety and depression. (3)

Arthritis commonly continues into adulthood accounting for thousands of adults with significant disability. Adults with arthritis beginning in childhood suffer increased physical and mental health impacts compared with those whose arthritis started in adulthood. (4)

Australian data indicate that delays in diagnosis are common (5) with reported average time from symptom onset to diagnosis of JIA of around 10 months (3, 6) with children seeing multiple clinicians and often undergoing unnecessary, expensive and painful investigations. The resulting critical delay in commencing effective therapies narrows the window of opportunity for early remission and positive long-term outcomes and causes distress to families and avoidable pain and suffering for the child or young person. In addition, delayed diagnosis increases health care cost and negatively impacts quality of life. (7)

The treatment of JIA and CRDs is complex and includes powerful immunomodulating medications, steroids and anti-inflammatory drugs, all of which can have serious short and long-term side effects. Many children also require frequent joint aspiration and/or corticosteroid injections under general anaesthetic. Many suffer unpredictable acute ‘flares’ which may require hospitalisation. Ongoing clinical monitoring and access to specialist multi-disciplinary teams, self-care education and behavioural and psychosocial support are essential.

Australian Arthritis Databases

Australian Institute of Health and Welfare (AIHW)

AIHW periodically publishes information on JIA/CRDs. (1,4,8,9) The latest 2024 report estimated that there were 18,500 to 30,100 people aged 0-24 years with presumed juvenile arthritis based on the 2021 Census and 2017-18 National Health Survey on self-report of people living with arthritis and assumed that the arthritis is juvenile arthritis if the respondent was aged 0–24 years old. (1)

The Australian Arthritis and Autoimmune Biobank Collaborative (A3BC)

A3BC was formed in 2016 to better predict prognosis and treatment outcomes in Australian adults and children living with arthritis and autoimmune conditions using biobank-enabled, data-linked, collaborative, and multidisciplinary research. Hosted at the University of Sydney under the umbrella of an NHMRC Centre of Research Excellence for Better Outcomes, A3BC aims to identify biological/environmental causes and phenotypic consequences of musculoskeletal conditions to uncover unknown patterns and associations for safer, more effective and evidence-based prevention, diagnosis, treatment and prognosis strategies. (10)

The current focus of A3BC is on Rheumatoid Arthritis, Psoriatic Arthritis, Juvenile Idiopathic Arthritis, Ankylosing Spondylitis, gout, vasculitis (including Polymyalgia Rheumatica and giant cell arteritis). Participation is flexible and participants can opt into completing longitudinal online surveys, clinic-based data collections, donating biospecimen samples and permitting access to their linked medical record and health data for research purposes. (11)

The Australian Rheumatology Association Database (ARAD)

ARAD was established in 2003 and has now merged with A3BC. It is a national registry focused on collecting patient-reported outcomes and health information on Australians receiving disease-modifying antirheumatic drugs (DMARDs) for inflammatory arthritis, including rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis and juvenile idiopathic arthritis. ARAD has enrolled 6,567 participants, the majority of whom were adults and has generated evidence on treatment outcomes, medication safety and quality of life. ARAD ceased separate recruitment in 2021 and all new participants are now recruited through A3BC.

The Australian and New Zealand ChiLdhood Arthritis Risk factor Identification sTudY (ANZ-CLARITY)

The original CLARITY JIA Biobank was established in 2008 at the Murdoch Children's Research Institute, Melbourne and subsequently extended its recruitment to five additional sites across Australia and became known as ANZ-CLARITY. The study aims to better understand JIA by comparing children and their families with and without JIA. ANZ-CLARITY is examining the relationship between genetic, clinical and environmental/lifestyle profiles to improve understanding of the causes, prevention, diagnosis and treatment of JIA. (12)

About AJAR

Development and Launch

The Juvenile Arthritis Foundation Australia (JAFA) was established in 2019 to provide a national voice dedicated exclusively to representing and addressing the needs of children and adolescents with JIA and CRDs by raising awareness, advocating for accessible and equitable health care and support, and encouraging investment in research. The lack of contemporary national data on JIA/CRDs was a major impediment to JAFA's evidence-based advocacy. Establishing a registry to collect these data was a JAFA priority. In addition, the Parliamentary Inquiry into Childhood Rheumatic Conditions supported a national registry. (13)

AJAR was established as a partnership between JAFA, the Australian Paediatric Rheumatology Group (APRG) and A3BC and operates within the established A3BC infrastructure.

AJAR is a national observational registry of children, adolescents and young adults with JIA/CRDs which was established in 2023 to collect information on the burden of these diseases to inform clinical practice, policy and planning and to support and guide health services planning and targeted research.

AJAR was officially launched in March 2023 by the Hon Ged Kearney, the then Assistant Minister for Health and Aged Care at a dedicated event in Parliament House during Juvenile Arthritis Week.

Objective

To collect a national minimum set of data on Australian children, adolescents and young adults up to age 25 years with JIA/CRDs which they developed before age 16.

AJAR has been developed as a consumer-led observational registry with enrolment and data collection processes co-designed by AJAR partners with iterative consumer pilot testing and feedback from parents and families across Australia.

Ethics approval for AJAR was granted by the Northern Sydney Local Health District Human Research Ethics Committee under the A3BC protocol (2019/ETH10386).

Dataset

The AJAR enrolment form is shown in Appendix A.

The data collected include:

- Name, date of birth, gender, Aboriginal or Torres Strait Islander (ATSI) origin
- Contact details, home suburb, state and postcode
- Primary JIA/CRD diagnosis
- Dates of diagnosis and first symptoms
- Presence of uveitis, anti-nuclear antibodies (ANA) and HLA-B27
- Medications currently being taken
- Parent/guardian details for registrants under 18 years of age

Online data entry is facilitated by a dropdown menu of JIA/CRDs primary diagnoses and a tick box list for medications.

Consent Options

AJAR registrants are offered several levels of consent detailed below. The first consent level is an agreement for their information to be included in the minimum dataset for the AJAR registry. Once this consent is obtained, registrants have four further consent options (Options 2-5 below).

1. My/my child's information to be recorded in the Australian Juvenile Arthritis Registry and for the non-identifiable data to be used by APRG, JAFA and A3BC for awareness and lobbying
2. AJAR-A3BC may contact my/my child's specialist or GP to verify the primary diagnosis, if required. If YES, provide one treating doctor details (Specialist / GP)
3. Further contact from the AJAR-A3BC team for brief annual surveys related to my/my child's health condition
4. Further contact from the AJAR-A3BC team about future ethically approved studies
5. Further contact from the A3BC Project Co-ordinator to explain the biobank project and ask for consent to enter me/my child into the A3BC project.

Subsequent full participation in the A3BC biobank-registry may include permission for collection and use of biospecimens such as blood, synovial fluid, saliva, stool; patient reported outcomes and quality of life surveys; and data-linkage that can provide unique data to improve understanding of the causes of JIA and CRDs and the benefits and risks of treatment.

Children and adolescents under age 18 years enrolled by their parent/guardian are required to re-consent when they turn 18 years if they wish their data to remain in the AJAR registry.

Enrolment Procedure

There are two pathways for enrolment into AJAR:

1. **Self-registration** by the parent or guardian for people aged under 18 years or by the person with JIA/CRD if aged 18 to under 25 years. The secure online enrolment form can be accessed via a weblink or QR code on the AJAR Registration Flyer (Appendix B) to complete the registration online. The AJAR flyer is available on the JAFA website, in clinic waiting rooms or handed out by doctors or other health professionals. It is also advertised through social media.
2. **Clinic-based registration** via a paediatric rheumatologist or other health professional during a routine clinic visit. Clinicians are provided with a secure database login to enable direct entry of enrolment details with the patient in the clinic setting. Ethics approval for individual public and private clinic on-boarding is progressing.

Data Storage

AJAR data are stored in the REDCap data management platform in keeping with the A3BC data storage procedures. The storage of A3BC/AJAR data is located with University of Sydney (Sydney, NSW) managed servers. From a security perspective, the REDCap system complies with the ISO/IEC 27001/2:2005 Code of Practice for Information Security Management. A3BC uses the highest standards of encryption, password protection and operating procedures to minimise the chances of unauthorised persons having access to re-identifiable information. Only a limited number of authorised A3BC collection and processing staff have access to identifiable information. No individual outside authorised A3BC staff is able to identify participants.

Oversight

Oversight of AJAR is provided by an AJAR Steering Committee consisting of the following members:

- JAFA – 2 representatives
- APRG – 2 representatives
- A3BC – 2 representatives
- Consumers – 2 representatives

The primary role of the Steering Committee is to build on the work undertaken to establish AJAR and promote its objective of providing accurate Australian data on JIA/CRDs to understand the magnitude and extent of the burden of these diseases, to inform policy and planning, and to support and guide health services planning and targeted research.

The Steering Committee is also responsible for working with A3BC to assess any requests from third parties to use de-identified AJAR data for ethically approved research, in accordance with established A3BC protocols.

More information about AJAR is available at:

JAFA: www.jafa.org.au/australian-juvenile-arthritis-registry-ajar

AJAR FAQs: https://a3bc.org.au/ajar-faqs/

Results

Enrolment

There are currently over 1,170 registrants in AJAR. The results presented in this Report relate to the first 1,087 registrants.

To date, 95% of enrolments have been directly from families/young adults via the self-registration pathway responding to information about AJAR on JAFA's website and regular posts, various social media platforms, and through health professionals directly providing AJAR information at the time of a clinical visit, bolstered by dedicated staff located in some public hospitals and private clinics.

Consent Choices

Table 1 below shows the high levels of consent achieved for the different consent options - over 94% consent to contact with their doctor to verify the primary diagnosis, 91% for participation in a brief annual survey, 87% for contact about future ethically approved studies and 84% for contact by the A3BC team about the biobank project.

Table 1. Consent choices

Consent Option	Percentage agreeing to this option
*AJAR-A3BC may contact my/my child's specialist or GP to **verify the primary diagnosis,** if required.*	94.6%
*Further contact from the AJAR-A3BC team for **brief annual surveys** related to my/my child's health condition.*	91.0%
*Further contact from the AJAR-A3BC team about **future ethically approved studies.***	87.3%
*Further contact from the A3BC Project Co-ordinator to explain the **biobank project and ask for consent** to enter me/my child into the A3BC project.*	84.0%

Participant Characteristics

Demographics

Of the 1,087 registrants, 67% are female and the mean age is 11.5 years. The youngest registrant at the time of enrolment was under 1 year old while the eldest were aged 24 years (Table 2).

Table 2. Demographic characteristics of AJAR registrants

Characteristic	Total (n = 1087)
Age (years; mean, SD)	11.5 (±5.0)
Gender (n, %)	
Female	728 (67 %)
Male	356 (32.8%)
Non-binary or prefer not to say	3 (0.2%)
Aboriginal or Torres Strait Islander	n=1084
Yes (n, %)	41 (3.8%)
No (n, %)	1029 (94.9%)
Don't know (n, %)	14 (1.3%)
Socio-economic Disadvantage* Quintiles	n=1084
1 Most disadvantaged (n, %)	118 (10.9%)
2 (n, %)	147 (13.6%)
3 (n, %)	239 (22.0%)
4 (n, %)	216 (19.9%)
5 Least disadvantaged (n, %)	364 (33.6%)

*Index of Relative Socio-economic Disadvantage by Postal Area, SEIFA 2021(14)

JIA and CRD Subtypes

Just over 81% of registrants have JIA and the remainder have CRDs. Figure 1 and Table 3 show the breakdown of diagnoses of AJAR registrants.

Subtypes were available for 648 registrants with JIA and 203 registrants with CRDs. The commonest forms of JIA in registrants with known subtypes were oligoarticular (persistent and extended – 25.5%) and polyarticular RhF negative (9.9%), reflective of the general JIA population. (15) The unknown subtype represents registrants who did not know their subtype or the subtype had not yet been verified. The most common forms of CRDs were autoinflammatory diseases (49%), juvenile myositis (18%), systemic lupus (16%) and local/linear scleroderma (8%).

Figure 1. JIA and CRD subtypes (%)

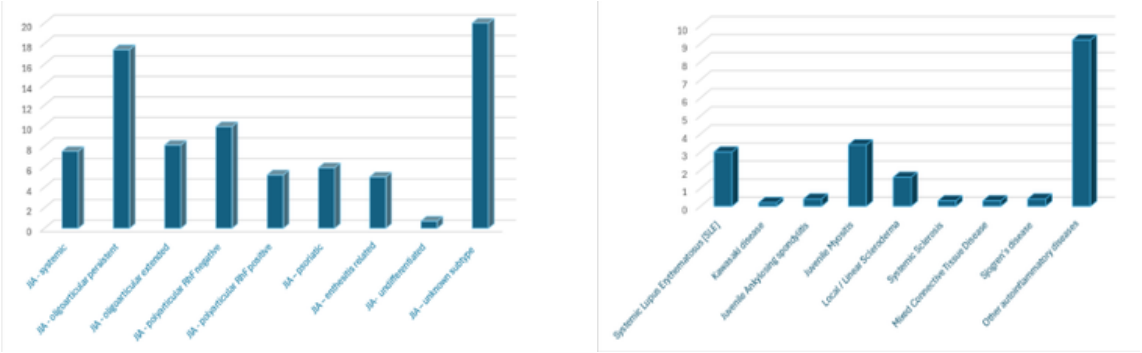


Table 3. JIA and CRD subtypes

Juvenile Idiopathic Arthritis	Total (n = 883)
JIA - systemic (n, %)	81 (9.2%)
JIA - oligoarticular persistent (n, %)	189 (21.4%)
JIA - oligoarticular extended (n, %)	88 (10.0%)
JIA - polyarticular RhF negative (n, %)	108 (12.2%)
JIA - polyarticular RhF positive (n, %)	56 (6.3%)
JIA – psoriatic (n, %)	64 (7.2%)
JIA – enthesitis related (n, %)	54 (6.1%)
JIA – undifferentiated (n, %)	8 (0.9%)
JIA – unknown subtype (n, %)	235 (26.6%)
Childhood Rheumatic Diseases	**Total (n = 203)**
Systemic Lupus Erythematosus [SLE] (n, %)	33 (16.3%)
Kawasaki disease (n, %)	2 (1.0%)
Juvenile Ankylosing Spondylitis (n, %)	4 (2.0%)
Juvenile Myositis (n, %)	37 (18.2%)
Local / Linear Scleroderma (n, %)	17 (8.4%)
Systemic Sclerosis (n, %)	3 (1.5%)
Mixed Connective Tissue disease (n, %)	3 (1.5%)
Sjogren's disease (n, %)	4 (2.0%)
Other autoinflammatory diseases (n, %)	100 (49.2%)

Medications

The most common medications available to Australian children/adolescents for the management of JIA/CRDs were listed as checkbox options in the AJAR enrolment form and participants/families could tick as many medication options applicable which were currently being taken. 948 (87.2%) registrants were currently taking at least one medication for their JIA/CRD (Table 4).

Table 4. Medications currently being taken

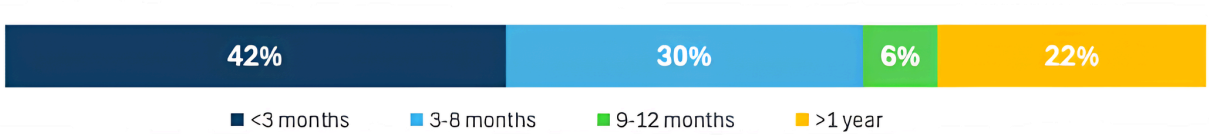
Medications	Total (n = 1087)
Taking Medications	948 (87.2%)
csDMARDS	
Any	581 (53%)
Methotrexate	492 (45.3%)
Hydroxychloroquine	58 (5.4%)
Mycophenolate	36 (3.3%)
Sulfasalazine	8 (0.7%)
Leflunomide	30 (2.8%)
bDMARDS	
Any	306 (28%)
Adalimumab	205 (18.9%)
Etanercept	37 (3.4%)
Infliximab	6 (0.6%)
Tocilizumab	59 (5.4%)
tsDMARDS	
Tofacitinib	45 (4.1%)
Baricitinib	2 (0.2%)
Anti-inflammatories	
NSAIDS	415 (38.2%)
Corticosteroids ORAL	158 (14.5%)
Corticosteroids INFUSION (in last 6 months)	9 (0.8%)
Corticosteroids intramuscular INJECTION (in last 6 months)	5 (0.5%)
Corticosteroids intra-articular INJECTION (in last 6 months)	164 (15.1%)
Other medications	162 (14.9%)

Methotrexate was the most common medication (45%) followed by non-steroidal anti-inflammatories (NSAIDS) (38%) and Adalimumab (19%). In addition, 15% had had an intra-articular corticosteroid injection in the past 6 months. Of note, 4% were taking Tofacitinib, the new oral tsDMARD.

Time to Diagnosis

The average age of symptom onset was 6.3 years and the average time to diagnosis was 312 days (10.2 months) with a median time of 116 days (3.8 months). Figure 2 shows the range of diagnosis intervals with 42% diagnosed within the target interval of 3 months of symptom onset, 36% between 3 and 12 months, and 22% taking more than 1 year to be diagnosed. The delay in diagnosis and initiation of effective treatments is a major contributor to JIA/CRD related disability. Reducing the time to diagnosis is the focus of a current national federally funded JAFA program. (16)

Figure 2. Time to diagnosis



Clinician Data

Clinician data were available for the 93.3% of registrants who consented to their doctor being contacted to verify the primary diagnosis, with the registration form giving participants the option of nominating a specialist or GP. Table 5 shows the majority of registrants nominated one of 26 different paediatric rheumatologists, 5 an adult rheumatologist and 11 nominated a GP.

Table 5. Clinician types nominated

Specialists/GPs	Numbers
Paediatric Rheumatologists	26
GPs	11
Adult Rheumatologists	5

Other Data

AJAR asks registrants about Uveitis and blood test results for anti-nuclear antibodies (ANA) and HLA-B27, if known.

Uveitis is a serious complication of JIA which can result in loss of vision and even blindness. Children and young adults with JIA require regular monitoring for uveitis since it is often asymptomatic. Among JIA registrants who responded to this question and in whom JIA subtype was known, 13.9% reported uveitis. This was most common in oligoarticular (persistent/extended) JIA and polyarticular RhF positive JIA and was associated with the presence of ANA positivity, consistent with previous reports. (17)

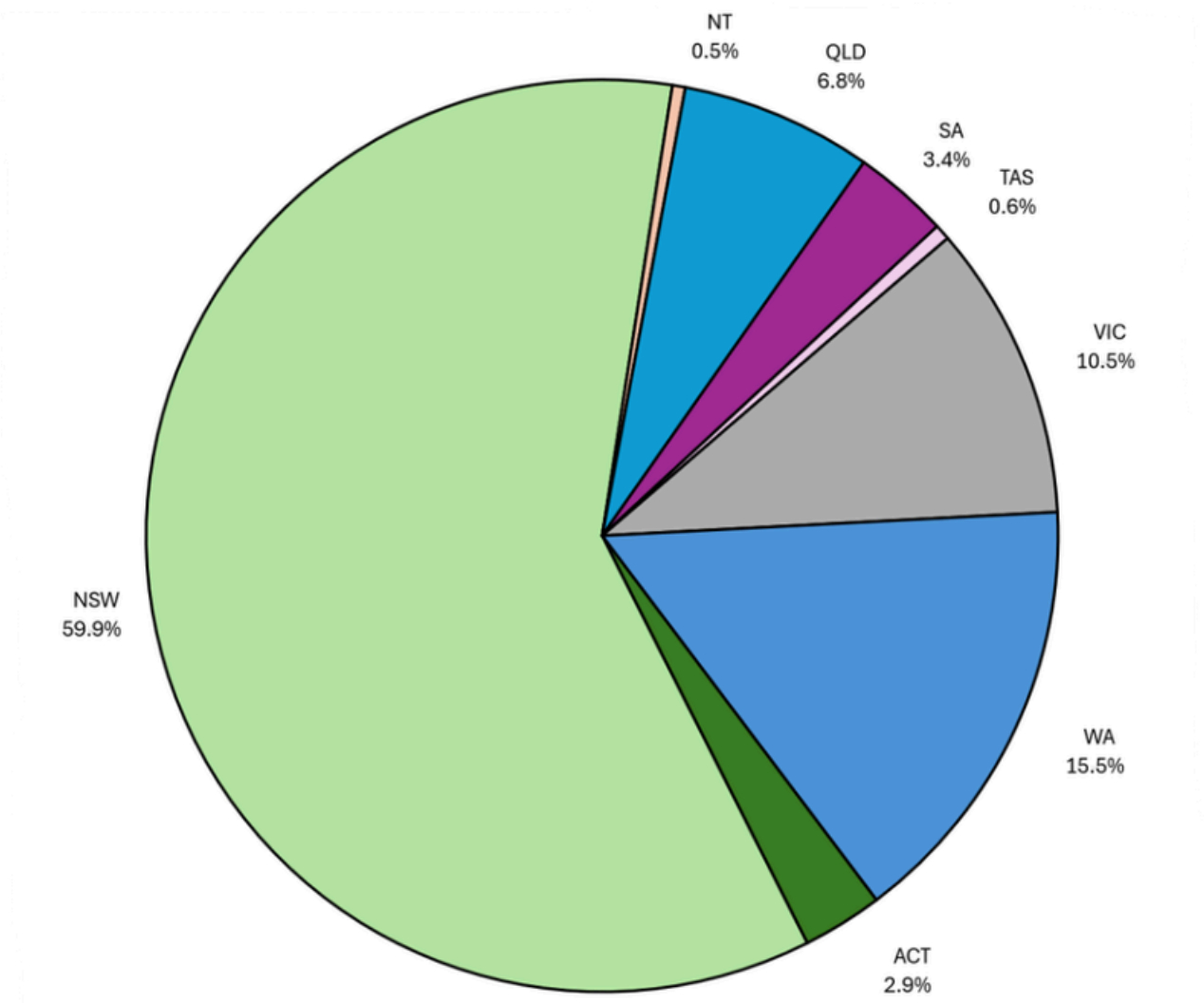
As expected, HLA-B27 positivity was associated with enthesitis-related JIA.

State Distribution of Registrants

Registrants are currently represented in every State and Territory.

Figure 3 below illustrates the state and territory enrolment. The largest proportion (60%) is from NSW reflecting both the largest population base and also the state which has most actively recruited AJAR registrants. The numbers and contribution in other states/territories are increasing.

Figure 3. State and Territory distribution of registrants

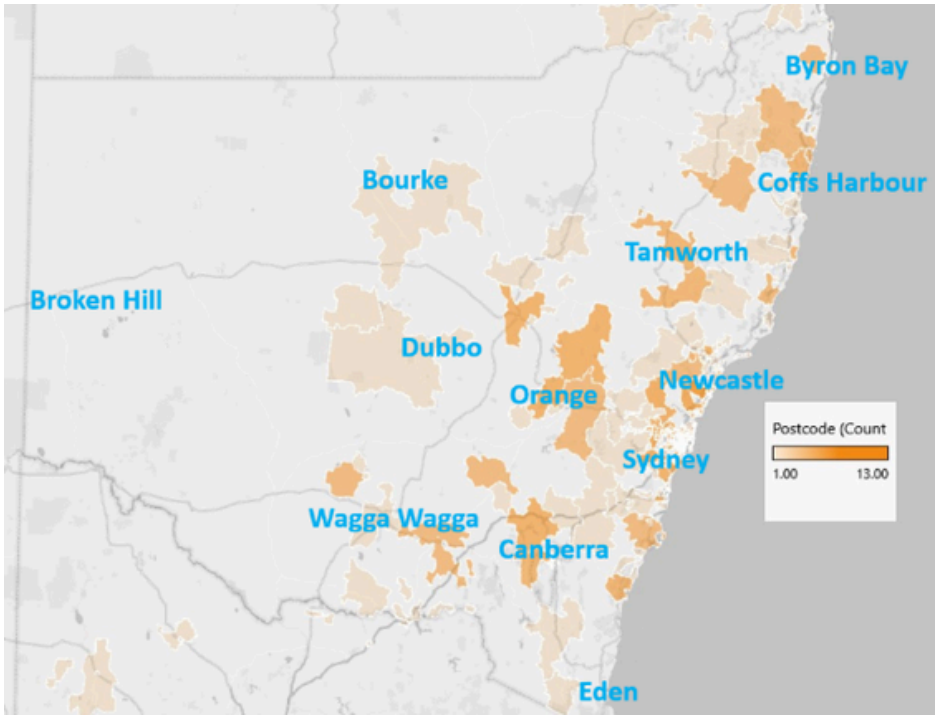


State Heat Maps by Registrant Postcodes

AJAR data can be used to generate heat maps of residential postcodes of registrants which can guide service planning for the location of clinics and specialist outreach services.

Figure 4 illustrates the heat map capability of AJAR for NSW/ACT registrants which has the largest number of AJAR registrants (651). This information is contributing to the NSW Paediatric Rheumatology Services Model of Care (18) currently under revision.

Figure 4. Heat map of residential postcodes of NSW/ACT registrants



A3BC Enrolment

A major objective of AJAR was to facilitate engagement and enrolment in A3BC. The AJAR registry has proved effective in recruiting children and young people with JIA/CRDs in the A3BC project. The first JIA enrolled participant occurred in 2023 soon after the launch of AJAR. To date a total of 212 AJAR registrants have consented to join some aspect of A3BC which constitutes 22% of A3BC participants.

A3BC offers various levels of participation including surveys and biospecimens (blood, stool and oral). Consent levels have been highest for participation in surveys and collecting blood samples.

Conclusions

AJAR is now well established as Australia's national observational registry for JIA and CRDs with registrant numbers continuing to increase steadily across Australia. AJAR is a valuable source of data for advocacy, paediatric rheumatology health service planning and research.

AJAR information is providing a national picture of these conditions. It confirms the well documented unacceptable delay in diagnosis – averaging over 10 months, which is consistent with previous reports. (3,6) Reducing time to diagnosis is being addressed through JAFA's Australian Government funded health professional and consumer early diagnosis program. (16) AJAR data also underscore the clinical and personal burden of JIA/CRDs in treatment requirements, medicines and joint injections, and the serious complication of uveitis.

The postcode heat maps are beginning to provide important data on the location of specialist paediatric rheumatology services in relation to place of residence of children and young people with JIA/CRDs and illustrate the considerable distances which many travel to access specialist care. The requirement for regular screening and specialist treatment for uveitis highlight the potential benefits of co-located specialist paediatric and specialist ophthalmological services to improve access and management of this vision threatening complication of JIA.

The potential to expand AJAR information through data linkage with the AIHW National Health Data Hub is being explored. Data linkage would provide additional valuable aggregate information on access to health services, hospitalisation and medication use as well as important health outcome data. Should this prove feasible, an additional consent option will be added for AJAR registrants willing to participate in the data linkage.

Plans are also underway to conduct a survey of AJAR registrants who have consented to participate in a periodic survey to collect information about the impact of JIA/CRDs on patient relevant outcomes.

Overall, AJAR related activities and information are well placed to increase awareness, access to services, treatments and outcomes for children, adolescents and young adults with JIA/CRDs.

References

1. Australian Institute of Health and Welfare [Internet]. 2023 [cited 2024 Mar 11]. Chronic musculoskeletal conditions : Juvenile arthritis. Available from: https://www.aihw.gov.au/reports/chronic-musculoskeletal-conditions/juvenile-arthritis

2. Anderson J, Ede K, Goswami N, Shishov M, Thiele G, Vaidya V, Wershba E. A comprehensive report of disease complications of juvenile idiopathic arthritis using a prospective cohort study. Pediatr Rheumatol 2025; 23: 130.

3. Bond DM, Von Huben A, Lain S, Colagiuri R, Chaitow J, James R, Tiller G, Singh-Grewal D, Colagiuri S, Nassar N. Investigating the Impact of Juvenile Idiopathic Arthritis on Health, Costs, and Quality of Life in Australia: The IMPACT Study. J Pediatr. 2026 Jul 20; 298: 115246.

4. Australian Institute of Health and Welfare [Internet]. 2008. Juvenile arthritis in Australia, Summary. Available from: https://www.aihw.gov.au/reports/children-youth/juvenile-arthritis-australia/summary

5. Coda A, Jones J, Grech D, Singh-Grewal D. Survey of parent and carer experiences and expectations of paediatric rheumatology care in New South Wales. Australian Health Review. 2017;41(4):372–7.

6. Manners PJ. Delay in diagnosing juvenile arthritis. Med J Aust. 1999 Oct 4;171(7):367–9.

7. Von Huben A, Bond DM, Lain S, Singh-Grewal D, Colagiuri R, Colagiuri S, Nassar N. The impact of time to diagnosis on health service use, cost, and quality of life for patients with juvenile idiopathic arthritis: a cost-utility analysis. Pediatr Rheumatol 2026; 24, 12.

8. Australian Institute of Health and Welfare. Juvenile Arthritis. Cat. no. PHE 258. Cat no PHE 258 [Internet]. 2020 [cited 2022 Feb 1]; Available from: https://www.aihw.gov.au/reports/chronic-musculoskeletal-conditions/juvenile-arthritis-1

9. Australian Institute of Health and Welfare [Internet]. 2014 [cited 2024 Mar 13]. Arthritis and other musculoskeletal conditions across the life stages, Table of contents. Available from: https://www.aihw.gov.au/reports/chronic-musculoskeletal-conditions/across-life-stages/contents/table-of-contents

10.A3BC - ANZCTR Registration. ACTRN12621001564842. [cited 2022 Feb 10]. ANZCTR Registration - A3BC. Available from: https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=381379&isReview=true

11.Willers C, Lynch T, Chand V, Islam M, Lassere M, March L. A Versatile, Secure, and Sustainable All-in-One Biobank-Registry Data Solution: The A3BC REDCap Model. Biopreservation and Biobanking. 2022 Jun 1;20(3):244–59.

12.Ellis JA, Ponsonby AL, Pezic A, Chavez RA, Allen RC, Akikusa JD, et al. CLARITY - ChiLdhood Arthritis Risk factor Identification sTudY. Pediatr Rheumatol Online J. 2012 Nov 15;10(1):37.

13.Commonwealth of Australia. Inquiry into childhood rheumatic diseases: Interim report [Internet]. Canberra; 2022 Mar [cited 2024 Mar 13]. Available from: https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/rheumaticdiseases/Interim_Report

14.Australian Bureau of Statistics. Socio-Economic Indexes for Areas (SEIFA), Australia, 2021 [Internet]. 2023 [cited 2024 Mar 13]. Available from: https://www.abs.gov.au/statistics/people/people-and-communities/socio-economic-indexes-areas-seifa-australia/latest-release

15.Sandborg CI, Schulert GS, Kimura Y. Juvenile Idiopathic Arthritis. N Engl J Med 2025;393:162-174.

16. Juvenile Arthritis Early Diagnosis Program. https://jafa.org.au/hcphub/

17.Angeles-Han ST, Pelajo CF, Vogler LB, Rouster-Stevens K, Kennedy C, Ponder L, McCracken C, Lopez-Benitez J, Drews-Botsch C, Prahalad S; CARRA Registry Investigators. Risk markers of juvenile idiopathic arthritis-associated uveitis in the Childhood Arthritis and Rheumatology Research Alliance (CARRA) Registry. J Rheumatol. 2013 Dec;40(12):2088-96.

18.Model of Care for the NSW Paediatric Rheumatology Network - Agency for Clinical Innovation. Model of Care for the NSW Paediatric Rheumatology Network. Sydney, Australia: Agency for Clinical Innovation; 2013 May.

Appendix A – AJAR enrolment form

JAFA Juvenile Arthritis Foundation Australia

Australian Juvenile Arthritis Registry (AJAR)
Self-Enrolment and Permission to Contact Form

A3BC Australian Arthritis & Autoimmune Biobank Collaborative

Key information

Thank you for your interest in the Australian Juvenile Arthritis Registry (AJAR). The Juvenile Arthritis Foundation Australian (JAFA) and the Australian Paediatric Rheumatology Group (APRG) have partnered with the Australian Arthritis and Autoimmune Biobank Collaborative (A3BC) to establish the Registry.

The primary aim of the Registry is to collect information on the number of children and young adults living with one of the many different types of juvenile arthritis, autoimmune or musculoskeletal problems in Australia. This information is essential to raise awareness of these conditions and advocate for better services and funding for research.

The A3BC is a collaborative network of Australian doctors and scientists who are researching arthritis and autoimmune diseases to develop new knowledge, better treatments, improved prevention and hopefully cures for these conditions in both children and adults. As well as registering your child or self on the Registry, you can use this form to give permission for the AJAR-A3BC team to contact you for brief annual surveys, and the possibility of participating in other research studies.

Participation is entirely voluntary and you can withdraw at any time by contacting the AJAR-A3BC team. Neither you nor your child's identity will ever be revealed in any publicly available data i.e. the data will be de-identified and aggregated for publication.

Registry enrolment is currently limited to participants under the age of 25 with a juvenile rheumatic disease diagnosis. If you are older than 25 and/or have an adult rheumatic disease diagnosis, please visit the A3BC website and complete the A3BC Adult Permission to Contact Form instead (https://a3bc.org.au/how-do-i-participate/).

For more information about AJAR please see the Frequently Asked Questions (https://a3bc.org.au/ajar-faqs)

PRIMARY DIAGNOSIS

Please select the participant's primary childhood diagnosis. Select only one CIRCLE below

Juvenile Idiopathic Arthritis (unknown subtype)	○	Juvenile ankylosing spondylitis	○
Juvenile Idiopathic Arthritis - Systemic	○	Kawasaki disease	○
Juvenile Idiopathic Arthritis - Oligo persistent	○	Systemic Lupus Erythematosus	○
Juvenile Idiopathic Arthritis - Oligo extended	○	Juvenile Myositis (incl. Juvenile Dermatomyositis)	○
Juvenile Idiopathic Arthritis - Poly RhF negative	○	Systemic Sclerosis / Scleroderma	○
Juvenile Idiopathic Arthritis - Poly RhF positive	○	Local / Linear Scleroderma	○
Juvenile Idiopathic Arthritis - Psoriatic	○	Mixed Connective Tissue Disease	○
Juvenile Idiopathic Arthritis - Enthesitis related	○	Sjogren's Syndrome	○
Juvenile Idiopathic Arthritis - Undifferentiated	○	Paediatric Cutaneous Scleroderma	○
		Undifferentiated connective tissue disease	○

Other auto-immune/inflammatory: Write name of disease

Date of Diagnosis: / / *Date of first symptoms:* / /

If you are unsure please provide your best possible estimate in DD-MM-YYYY format. Approximate days, months and years are fine.

Other features and test results (if known): Anti-nuclear antibodies (ANA): Positive○ Negative○ Unknown○

Uveitis: Yes○ No○ Unknown○ HLA-B27: Positive○ Negative○ Unknown○

CURRENT MEDICATIONS

Please *select one or more box(es) below* for any medications the participant is CURRENTLY taking

Conventional Synthetic Disease-Modifying Anti-Rheumatic Drugs (csDMARDS)		*Biological & Targeted Synthetic Disease-Modifying Anti-Rheumatic Drugs (b/tsDMARDS)*	
Methotrexate (Methoblastin, Trexject)	☐	Adalimumab (Amgevita, Hadlima, Humira, Hyrimoz, Yuflyma)	☐
Hydroxychloroquine (Plaquenil)	☐	Etanercept (Brenzys, Enbrel, Erelzi)	☐
Sulfasalazine (Salazopyrin, Pyralin)	☐	Infliximab (Inflectra/Remsima)	☐
Leflunomide (Arava, Arabloc)	☐	Tocilizumab (Actemra)	☐
Mycophenolate (Myfortic, Cellcept)	☐	Infliximab (Remicade, Renflexis)	☐
		Tofacitinib (Xeljanz)	☐
Corticosteroids and anti-inflammatories			
Corticosteroids (oral) e.g. Prednisolone (Panafcortelone) / Prednisone (Panafcort) tablets	☐	Corticosteroid infusion/s i.e. via a drip into the vein (in the past 6 months)	☐
Corticosteroid injection/s into the joint or tendon (any in the past 6 months)	☐	NSAIDs (e.g. Nurofen, Brufen, Mobic, Celebrex, Naprosyn, Orudis, Arcoxia, Voltaren)	☐
Corticosteroid injection/s into the muscle (any in the past 6 months)	☐	Other_____	☐
		No current medications	☐

JAFA Juvenile Arthritis Foundation Australia

Australian Juvenile Arthritis Registry (AJAR)
Self-Enrolment and Permission to Contact Form

A3BC Australian Arthritis & Autoimmune Biobank Collaborative

PARTICIPANT'S DETAILS

Given Name: *Middle Name:*

Surname: *Gender:* Male ○ Female ○ Non-binary ○ Prefer not to say ○

Are you of Aboriginal or Torres Strait Islander origin? Yes ○ No ○ Don't know ○ Prefer not to say ○

Date of Birth (DD-MM-YYYY) :* / /

Phone (home): ( )

Suburb / Town:

Mobile Phone:

State: *Postcode:*

E-mail address (if applicable, please print clearly):

**Registry enrolment is currently limited to participants under the age of 25 with a juvenile rheumatic disease diagnosis. If you are older than 25 and/or have an adult rheumatic disease diagnosis, please complete the A3BC Adult Permission to Contact Form instead.*

PARENT/GUARDIAN'S DETAILS (only required for participants aged under 18 years)

Given Name: *Surname:*

E-mail address (please print clearly):

Phone ( ): *Mobile Phone:*

CONSENT TO RELEASE OF INFORMATION (Parent/Guardian to complete for under 18s)

I understand that the information provided above will be kept highly secure and will only be used as authorised below.

I hereby authorise:

Please check one box per row

1) My/my child's information above to be recorded in the Australian Juvenile Arthritis Registry, and for the non-identifiable data to be used by APRG, JAFA and the A3BC for awareness and lobbying. Yes ☐

2) The AJAR-A3BC may contact my/my child's Specialist or GP to verify the Primary diagnosis, if required. Yes ☐ No ☐

If YES provide one treating doctor's details below.

Name of your/your child's Specialist:

Hospital or clinic name (if known):

Specialist phone number (if known):

Name of your/ your child's General Practitioner (GP):

GP clinic name (if known):

GP phone number (if known):

3) Further contact from the AJAR-A3BC team for brief annual surveys related to my/my child's health condition. Yes ☐ No ☐

4) Further contact from the AJAR-A3BC team about future ethically approved studies. Yes ☐ No ☐

5) Further contact from an A3BC Project Co-ordinator to explain the biobank project and ask for consent to enter me/my child into the A3BC research project. Yes ☐ No ☐

Today's date (DD / MM / YYYY): / /

If you have any questions you can talk to your specialist, the A3BC team (email info@a3bc.org.au), the JAFA team (email info@jafa.org.au), JAFA's lead paediatric (kids) specialists, Dr Jane Munro on (03) 9345 6437 or Dr Davinder Singh-Grewal on (02) 8212 4123, or Lead National A3BC Investigator Professor Lyn March on (02) 9463 1891. This study has been approved by the Northern Sydney Local Health District Human Research Ethics Committee (HREC) – 2019/ETH10386

Appendix B – AJAR Flyer

JAFA Juvenile Arthritis Foundation Australia

Australian Rheumatology Association APRG

A3BC Australian Arthritis & Autoimmune Biobank Collaborative

Australian Juvenile Arthritis Registry (AJAR)

Do you, your child, or a relative have juvenile arthritis or another childhood rheumatic disease?

Do you want to help make a difference?

The Juvenile Arthritis Foundation Australia (JAFA) has partnered with the Australian Paediatric Rheumatology Group (APRG) and the Australian Arthritis and Autoimmune Biobanking Collaborative (A3BC) to develop the first national registry for juvenile arthritis and related childhood rheumatic diseases.

This will enable a more consistent approach to information, diagnosis and treatment for juvenile arthritis and childhood rheumatic diseases across Australia.

- We are looking for people under the age of 25 to join the registry – basic information will be collected to help us better understand juvenile arthritis, other childhood rheumatic diseases and current treatments.

- You can also join additional research studies (optional) to help improve our collective knowledge and treatments – e.g. surveys, trials, specimen collections and data links.

Please visit a3bc.org.au/ajar-faqs to find out more and scan the QR code to register your details.

Data custodian organisation: The University of Sydney
This study has been approved by the Northern Sydney Local Health District Human Research Ethics Committee (HREC) – 2019/ETH10386
AJAR Flyer v1.1 27-Feb-2023

JAFA
Juvenile Arthritis
Foundation Australia

Australian Rheumatology Association
APRG

A3BC
AUSTRALIAN ARTHRITIS & AUTOIMMUNE
BIOBANK COLLABORATIVE
NHMRC CENTRE OF RESEARCH EXCELLENCE