INAUGURAL ANNUAL REPORT 2024

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 registry of children, adolescents and young adults with juvenile idiopathic arthritis (JIA) and related childhood rheumatic diseases (CRDs) which was launched in March 2023. The overarching purpose of the registry is to collect national information to fully 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 in order to improve access to diagnosis and care and optimise outcomes.

This first AJAR annual report outlines the background to its establishment, the methodology, and the numbers and characteristics of registrants after the first year of operation.

Acknowledgements

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

NSW Ministry of Health

The Condon Family and friends including Cannons Swimming Club and Melbourne Fire Brigade.

This Report was prepared on behalf of AJAR collaborators by:
Stephen Colagiuri, Fiona Howard, Tom Lynch and Lyn March

Foreword

In March 2023 I was pleased to launch the Australian Juvenile Arthritis Registry during Australia's first Juvenile Arthritis Week. I am now equally pleased to introduce the Registry's inaugural annual report, which presents data on the first 300 registrants.

The Registry was a key recommendation of the 2022 *Interim Report on the Parliamentary Inquiry into Childhood Rheumatic Disease.* It provides previously unattainable data and insights into juvenile idiopathic arthritis and related but less common childhood rheumatic diseases, such as systemic lupus erythematosus, chronic relapsing multifocal osteomyelitis and juvenile dermatomyositis.

I congratulate the Registry partners, the Juvenile Arthritis Foundation Australia, the Australian Paediatric Rheumatology Group and the Australian Arthritis and Autoimmune Biobank Collaborative. The Registry is already showing its potential and its value will grow exponentially over time. It is a much-needed asset to support future research - notably clinical trials - and guide future health policy and planning.

I commend this inaugural report to you and look forward to watching the Registry grow and fulfill its ambitions over the coming years.



The Hon Ged Kearney MP
Assistant Minister for Health and Aged Care



Abbreviations

A3BC	Australian Arthritis Autoimmune Biobank Collaboration
AIHW	Australian Institute of Health and Welfare
AJAR	Australian Juvenile Arthritis Registry
APRG	Australian Paeditric 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
NHS	National Health Survey
NSAID	Non-steroidal ant-inflammatory drugs
PBS	Pharmaceutical Benefits Scheme

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First Year Data at a Glance

302 registrants

11 years – average age of registrants

69% females

90%
Juvenile Idiopathic Arthritis

10%
Other Childhood Rheumatic Diseases

6 years
average age of symptom onset

9.5 months
average time to diagnosis

91%
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 so low among health professionals that children can present with permanent joint damage and loss of vision at the time of diagnosis.(2–4) 80% of children experience daily pain and suffer a high burden of permanent disability, time off school and lost educational opportunity, social and physical marginalisation, and mental ill health including anxiety, depression,(5) and suicidal ideation.(6) 20% of children with oligoarticular JIA have uveitis, an inflammatory eye disease that causes visual impairment and blindness if not detected early and treated.

In 50% of affected children, arthritis continues into adulthood accounting for thousands of adults with severe disability. Adults with arthritis beginning in childhood suffer increased physical and mental health impacts compared with those whose arthritis started in adulthood.(5)

Previous research put the average time from the onset of symptoms to a diagnosis of JIA in Australia at 10 months,(7) with children seeing multiple clinicians and often undergoing unnecessary, expensive and painful investigations. This 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.

The treatment of JIA and CRDs is highly complex and involves the use of powerful immunomodulating medications, steroids and anti-inflammatories, 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.

New Australian research (8) published in November 2023 found that 0-25yr olds with JIA/CRDs:

- average 11-14 months from symptom onset to diagnosis respectively
- incur high government health care costs: >$24k -$31k respectively per child per year (direct costs only and higher than comparable childhood chronic diseases)
- school students average 12-15% missed school days respectively
- 72% suffer medication side effects
- 46% require aids for daily living

Why establish a Registry for JIA and CRDs?

Australia does not have accurate national data on the prevalence, incidence and outcomes of JIA/CRDs. Such information is essential to fully 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 Australian Institute of Health and Welfare (AIHW) has been estimating numbers with JIA/CRDs since 2008.(1,5,9,10) While these estimates provide a guide to numbers with JIA/CRDs, the AIHW has consistently emphasised that there are no national data sources that specifically ask respondents if they have juvenile arthritis and has highlighted that *"the number of cases of juvenile arthritis is difficult to estimate … and the estimate has a wide margin of error"* and that "*in the absence of a disease registry, it is difficult to determine the incidence of a disease".*

The current AIHW estimate is derived from the 2021 Census and 2017-18 National Health Survey (NHS) and is based on self-report of people living with arthritis and assumes that the arthritis is juvenile arthritis if the respondent is aged 0–24 years old. The 2021 Australian Census collected information on the entire population in Australia and included a question which asked people if they had been told by a doctor or nurse that they have any of ten selected health conditions, including arthritis. The 2017-18 NHS was a large, nationally representative sample survey administered by trained interviewers and asked detailed questions about current or long-term conditions. The prevalence of arthritis was reported based on whether the condition was both current and had lasted, or was expected to last, for 6 months or more. The NHS relies on participants self-reporting arthritis, or in some cases another member of the household (including a parent/guardian) reporting arthritis on behalf of an individual. The NHS estimates have a high relative standard of error and given the caution in interpreting prevalence of juvenile arthritis estimated using the NHS, the AIHW reports estimates from both the NHS and Australian Census resulting in a range of 18,500 to 30,100 people aged 0-24 years with presumed juvenile arthritis.

There have been many calls to establish a juvenile arthritis registry, most recently in a recommendation in the 2023 Interim Report of the Parliamentary Inquiry into Childhood Rheumatic Conditions which indicated Committee support for a national registry.(11)

The value of Australian national registries has been demonstrated by other important childhood chronic conditions, for example diabetes and cystic fibrosis. *The Australian Paediatric Endocrine Group (APEG) National Diabetes Register* has collected accurate data on the annual rates of diabetes in young people throughout Australia for over 25 years. The register has led to the *Australasian Diabetes Data Network (ADDN)* which collects de-identified health information allowing national surveillance of clinical outcomes. *The Australian Cystic Fibrosis Data Registry (ACFDR*) began in 1998 with Cystic Fibrosis Australia responsible for the data custodianship. ACFDR provides statistics on cystic fibrosis, supports clinical teams to improve care, monitors the safety of new medicines and provides up-to-date information on patients and families.

Australian Arthritis Databases

Australia has some established purpose specific arthritis related databases.

The Australian Rheumatology Association Database (ARAD)

The Australian Rheumatology Association (ARA) established ARAD in 2003 as a national Australian database to collect important patient-reported outcome measures and health information for Australians who were receiving bDMARD (biologic disease-modifying antirheumatic drug) therapy. The inception of the database coincided with the listing of bDMARDs on the Pharmaceutical Benefits Scheme (PBS) for Australians with inflammatory arthritis including rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis and JIA. The majority of participants in the database are adults.(12)

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

The CLARITY JIA Biobank was established in 2008 by A/Professor Jane Munro and Dr Justine Ellis at the Murdoch Children's Research Institute, Melbourne. Through additional funding CLARITY extended its recruitment to five additional sites across Australia and is now 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.(13)

The Australian Arthritis and Autoimmune Biobank Collaborative (A3BC)

A3BC was formed in 2016 by a group of Australian rheumatologists and researchers, including the ARAD and ANZ CLARITY Principal Investigators, to enable better prediction of prognosis and treatment outcomes in Australian adults and children living with arthritis and autoimmune conditions. The A3BC vision is to identify causes and cures for a wide range of musculoskeletal and autoimmune conditions using biobank-enabled, data-linked, collaborative, and multidisciplinary research. Now merged with ARAD and joining forces with ANZ CLARITY and AJAR under the umbrella of the NHMRC Centre of Research Excellence for Better Outcomes in Inflammatory Arthritis, A3BC aims to identify the biological/environmental causes and phenotypic consequences of musculoskeletal conditions and combine these with a broad range of patient and population health datasets, to uncover unknown patterns and associations for safer, more effective and evidence-based prevention, diagnosis, treatment and prognosis strategies.(14)

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). Over time, it intends to expand biospecimen and data collection to other key musculoskeletal conditions of adults, and childhood and adolescents. Participation in A3BC is flexible and participants can opt-in to completing longitudinal online surveys, clinic-based data collections, donating small samples of blood, tissue or fluids (biospecimens) and permitting access to their linked medical record and health data for research purposes. Biospecimens are stored at biobank 'node' sites around Australia, tracked and managed via a central database hosted at The University of Sydney.(15) Data and samples are securely stored and made available for ethics-approved research, based on strong scientific merit and potential benefits to people with musculoskeletal and autoimmune conditions.

About AJAR

AJAR is a national registry of children, adolescents and young adults with JIA/CRDs. AJAR collects national information on 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.

Objective

The aim of AJAR is 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 registry. The enrolment and data collection processes were co-designed by AJAR partners with iterative consumer pilot testing and feedback from 18 parents/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).

Evolution

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 a national registry for JIA/CRDs was identified by JAFA as a major impediment for evidence-based advocacy and therefore JAFA made establishing and facilitating a national minimum data-set registry a priority.

Discussions followed with the Australian Paediatric Rheumatology Group (APRG) which supported the establishment of the registry after consultation with its membership. After further consultation, it was agreed that utilising the A3BC infrastructure was the most expedient way to facilitate establishing the registry and a partnership was formed between JAFA, APRG and A3BC.

Dataset

The AJAR enrolment form (paper version) 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) or 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

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 bio-specimens such as blood, synovial fluid, saliva, stool; patient reported outcomes and quality of life surveys; and data-linkage that can provide unique and valuable 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 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.
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 currently in progress.

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 will be able to identify participants.

Management

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 will also be responsible for working with A3BC to respond to requests from third parties to use de-identified AJAR data for ethically approved research, in accordance with established A3BC protocols.

Launch

JAFA, APRG and A3BC are grateful to the Hon Ged Kearney, Assistant Minister for Health and Aged Care for her interest and support of AJAR. In particular, for launching AJAR at a dedicated event in Parliament House, Canberra on March 21, 2023 during Juvenile Arthritis Week.

The first enrolment occurred on March 31, 2023 and active recruitment began in October, 2023.





Assistant Minister for Health and Aged Care launching the the Australian Juvenile Arthritis Registry in Parliament House, Canberra, March 21, 2023

Results

Enrolment

There are currently over 300 registrants in AJAR. The results presented in this Report relate to the first 302 registrants.

To date, 100% of the enrolments have been performed by families/young adults via the self-registration pathway. Facebook activities by JAFA have proven successful for this pathway, with upticks in numbers seen within days of posts going live on social media. Media activities such as Juvenile Arthritis Week, posters distributed to health professionals and clinics, and presentations at children's camps are used to raise awareness and encourage registration in AJAR. JAFA has information on its website for families to view, and A3BC also provides links and FAQs on its website.

The second pathway for enrolment directly via a health professional is currently being rolled out as the A3BC team navigates the ethics submissions and site activations for the paediatric rheumatologists in public hospital and private clinic settings. The first private clinic site has recently been activated and others are anticipated to be added soon.

More information about AJAR is available at:

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

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

Consent

Table 1 below shows the high levels of consent being achieved under the different consent options - over 90% consent for contact with the doctor to verify the primary diagnosis and participation in a brief annual survery, and 85% for contact about future ethically approved studies and the biobank project. During year 2, AJAR will begin focussing and implementing activities related to these consented options.

Table 1. Consent to other activities

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.*	**93.3%**
*Further contact from the AJAR-A3BC team for **brief annual surveys** related to my/my child's health condition*	**90.3%**
*Further contact from the AJAR-A3BC team about **future ethically approved studies***	**85.3%**
*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.*	**84.7%**

Participant characteristics

Demographics

Of the 302 registarnts, 69.2% is female and the mean age is 11 years. The youngest registrants are just 1 year old while the eldest is aged 23 years.

Table 2. Demographic characteristics

Characteristic	Total (n = 302)
Age (years; mean, SD)	11 (±5.2)
Gender (n, %)	
Female	209 (69.2%)
Male	91 (30.1%)
Non-binary or prefer not to say	2 (0.66%)
Aboriginal or Torres Strait Islander	
Yes (n, %)	9 (3%)
No (n, %)	291 (96.4%)
Don't know (n, %)	2 (0.66%)
Socio-economic Disadvantage* Quintiles	n=298
1 Most disadvantaged (n, %)	18 (6%)
2 (n, %)	42 (14%)
3 (n, %)	47 (16%)
4 (n, %)	66 (22%)
5 Least disadvantaged (n, %)	125 (42%)

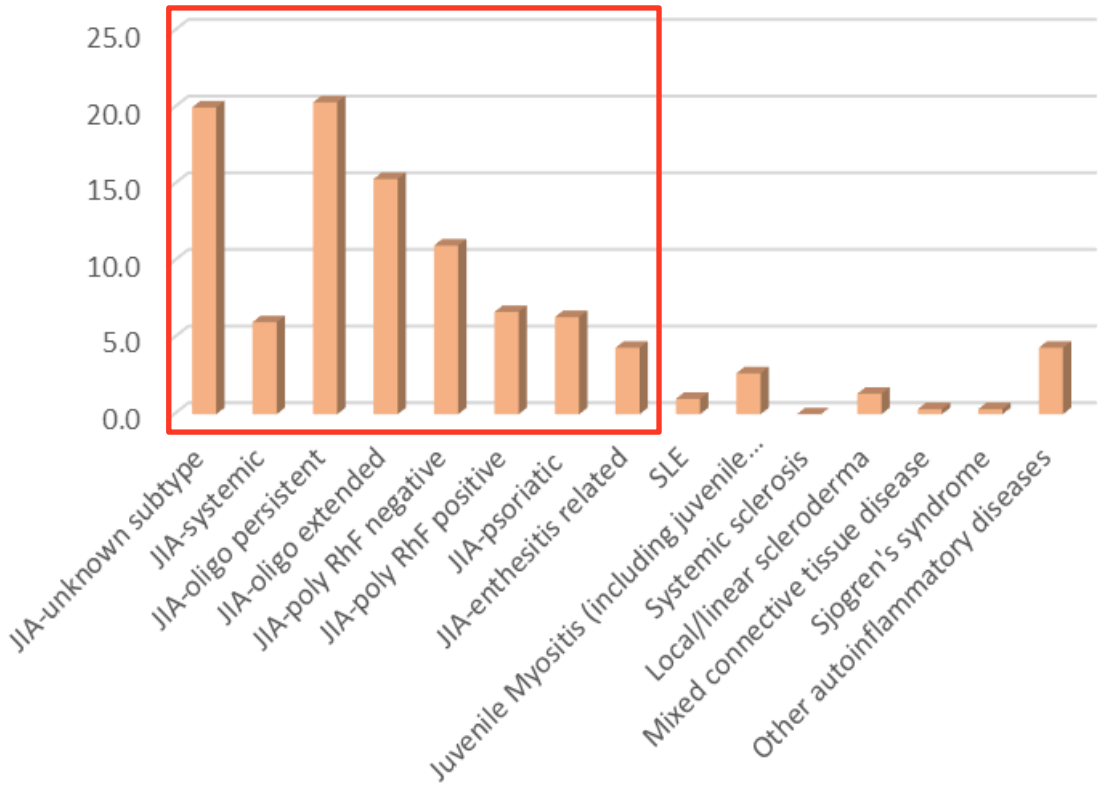
*Index of Relative Socio-economic Disadvantage by Postal Area, SEIFA 2021(16)

JIA and CRD subtypes

90% of registrants have JIA and the remainder have CRDs. Figure 1 shows the breakdown onf diagnoses of AJAR registrants.

Figure 1. JIA subtypes and other CRDs

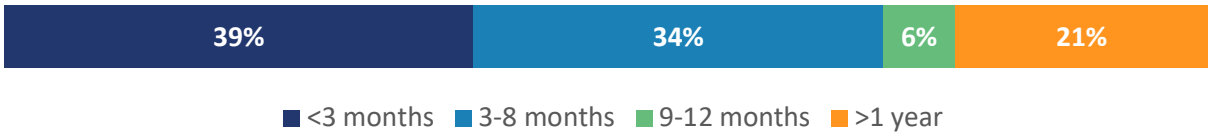
JIA SUBTYPES AND OTHER CRDS-PERCENTAGES



Time to diagnosis

Average age of symptom onset is 6 years and the average time to diagnosis is 289 days (9.5 months). 201 participants were diagnosed within 200 days (between 6-7 months) from the date of first symptoms, while 16 participants recorded a time to diagnosis of more than 1100 days (over 3 years). The range of diagnosis intervals is shown in Figure 2. Of note, only 39% were diagnosed within the first 3 months of symptom onset**.**

Figure 2. Time to diagnosis



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. 276 (91.4%) registrants were currently taking at least one medications for their JIA/CRD (Table 3).

Table 3. Medications currently being taken

Medications	Total (n = 302)
Taking Medications	276 (91.4%)
csDMARDS	
Any	172 (57%)
Methotrexate	156 (51.7%)
Hydroxychloroquine	13 (4.3%)
Mycophenolate	4 (1.3%)
Sulfasalazine	3 (1%)
Leflunomide	6 (2%)
bDMARDS	
Any	94 (31.1%)
Adalimumab	66 (21.9%)
Etanercept	9 (3%)
Infliximab	0 (0%)
Tocilizumab	19 (6.3%)
tsDMARDS	
Tofacitinib	19 (6.3%)
Anti-inflammatories	
NSAIDS	128 (42.4%)
Corticosteroids ORAL	34 (11.3%)
Corticosteroids INFUSION (in last 6 months)	2 (0.7%)
Corticosteroids intramuscular INJECTION (in last 6 months)	1 (0.3%)
Corticosteroids intra-articular INJECTION (in last 6 months)	54 (17.9%)
Other medications	**54 (17.9%)**

Methotrexate was the mosy common medication (51%) followed by non-steroidal anti-inflammatories (NSAIDS) (42%) and Adalimumab (22%). In addition, 18% had had an intra-articular corticosteroid injection in the past 6 months. Of note, 6% were taking Tofacitinib, the new oral tsDMARD.

Clinician data

Clinician data are 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 4 shows the majorityof registrants nominated one of 20 different paediatric rheumatologists, 3 an adult rheumatologist and 10 nominated a GP.

Table 4. Clinician types nominated

Specialists/GPs	Numbers
Paediatric Rheumatologists	**20**
GPs	**10**
Adult Rheumatologists	**3**

State distribution of registrants

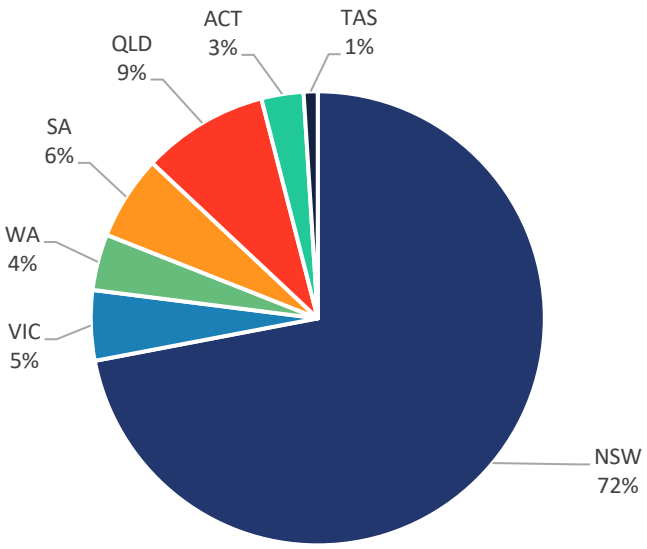
Registrants are currently represented in every State and Territory, except for the Northern Territory.

Figure 3 below illustrates the state and territory enrolment numbers. The largest proportion (72%) is from NSW reflecting both the largest population base and also the state which has most actively promoted AJAR registration. The numbers in other states/territories are expected to increase as ethical approval is obtained for their public and private clinics.

Additionally, other JAFA and A3BC activities will specifically promote and support AJAR enrolment in under-represented States and Territories to ensure the registry's goal of achieving full representation of children, adolescents and young adults living with JIA/CRDs across Australia.

Figure 3. State and Territoy distribution of registrants

NT=0%



Conclusions

Through a concerted and collaborative effort, Australia now has a national registry for JIA/CRDs. As participation in the registry grows the information collected will be of great value to inform health policy, advocacy, research and future paediatric rheumatology service delivery and is expected to lead to better awareness, access to services, treatments and outcomes for children, adolescents and young adults with JIA/CRDs.

The initial data have confirmed the well documented unacceptable delay in diagnosis – average 9.5 months among AJAR registrants, which is consistent with previous reports including the recent IMPACT study (7,8) and underscores the importance of the new federally funded Early Diagnosis program Early Diagnosis Launch 2024 - JAFA

Moving into the second year of AJAR, there will be a focus on increasing registry numbers and growing the number of participating public and private paediatric rheumatologists and clinics across all States and Territories. The additional layers of consent will be used to develop and implement periodic surveys and engage registrants in linkage and biospecimen opportunities and participation in clinical research to answer patient-relevant priority questions to benefit the broad JIA/CRD community.

Aggregate de-identified AJAR results will be presented to health policy makers and will continue to be presented at scientific meetings and published in peer-reviewed journals.

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Appendix A – AJAR enrolment form (Paper template 2 pages)

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 NHMRC CENTRE OF RESEARCH EXCELLENCE

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 (Print version)

JAFA Juvenile Arthritis Foundation Australia

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