

THE IMPACT STUDY

Investigating the **M**ental, **P**hysical,
Social **A**nd Financial **CosT**s of
Juvenile Idiopathic Arthritis and
Related Childhood Rheumatic Diseases

ACKNOWLEDGEMENTS

The funders

The Juvenile Arthritis Foundation Australia (JAFA) sincerely thanks Adrian and Charlotte MacKenzie and Five V Capital for their generous donation which enabled JAFA to commission this important study documenting the magnitude of the hidden impacts of juvenile idiopathic arthritis and childhood rheumatic diseases on affected children and young people and their families.

The researchers

JAFA is grateful to the research team for their expert knowledge, skills and dedication to undertaking this research and preparing the report:

Professor Natasha Nassar, Dr Diana Bond, Dr Amy Von Huben, Dr Samantha Lain
Faculty of Medicine and Health, Children's Hospital at Westmead Clinical School
Child Population and Translational Health Research, The University of Sydney

The advisory committee

JAFA thanks the consumer representatives, Paul Cassar and Nicole Myers and paediatric rheumatologist, Dr Georgina Tiller for their valuable advice on the survey questions.

The participants

JAFA is especially grateful for the contribution of the parents who piloted the survey questionnaire and the families and young people who made the IMPACT Study possible by committing their time and emotional energy to completing the survey.

ABOUT THE IMPACT STUDY

Juvenile idiopathic arthritis (JIA) and related childhood rheumatic diseases (CRDs) are a group of painful, inflammatory, autoimmune conditions affecting the joints, eyes and, in some cases, the skin, muscles and internal organs. JIA accounts for approximately 80% of all CRDs with the remaining 20% made up of less common conditions such as systemic lupus erythematosus, chronic relapsing multi focal osteomyelitis, and juvenile dermatomyositis.

Despite low awareness of these diseases, JIA is one of the most common chronic childhood diseases affecting an estimated 6-10,000 children under the age of 16yrs, and up to 30,000 young Australians aged 0-24yrs. However, these are estimates only and primary data on the prevalence and physical, mental and financial impacts JIA and related CRDs is severely lacking.

Such information is vital to understanding the extent of the burden of these diseases, and to inform policy and planning, guide future health service delivery, and targeted research. These data deficiencies were highlighted in the 2022 Interim Report of the Parliamentary Inquiry into Childhood Rheumatic Diseases and have been a high priority among JAJA's strategic priorities. And, in March 2023, along with the Australian Paediatric Rheumatology Group and the Australian Arthritis and Autoimmune BioBank Collaboration, JAJA launched the Australian Juvenile Arthritis Registry (AJAR) for 0 - 24 yr olds with JIA and CRDs.

The IMPACT Study was commissioned by JAJA in 2022 and conducted in 2023 and represents another milestone in JAJA's commitment to measuring the magnitude of the burden of JIA and other CRDs on individuals and families, documenting their lived experience, and establishing a baseline for designing and evaluating future interventions.

Aim

The aim of this study was to describe and document the impact of JIA and CRDs on the lives of affected children and young people and their families with specific regard to:

- Their experience of diagnosis, treatment, healthcare access and interactions
- Their physical and mental health outcomes, social impact, well-being, and quality of life
- The nature and extent of the financial costs associated with treatment and care

Study design and population

A national online survey was undertaken in 2023 to examine the impact of JIA and related CRDs on Australian children and young people aged 0-25yrs and their families.

Demographics

Two hundred and thirty three (233) completed responses were received: 184 for individuals with JIA and 49 for individuals with a CRD

Ethics

Ethics approval for the study was obtained from The University of Sydney Human Research Ethics Committee (2022/902). Participation was voluntary and consent was assumed by return of the completed survey. Surveys were anonymous.

RESULTS AT A GLANCE

Juvenile Idiopathic Arthritis

Diagnosis

- The average age of symptom onset was 5 years.
- The average time to diagnosis was 11 months.

Treatment and Care

Medications

- 97% took a medication for JIA in the past year
- 68% had taken 3 or more medications
- 74% had taken a csDMARD, most commonly Methotrexate
- 53% had taken a bDMARD, most commonly Adalimumab
- 73% had taken a NSAID
- Corticosteroids - oral (38%), injections (45%),
- Overall, 72% experienced side effects – most commonly with Methotrexate (70% of users)
- GI symptoms and malaise were the most common side effects of most medications.

Health Professional Visits

In the past year participants:

- Visited an average of 25 health professionals: 5 GP, 8 clinical specialist, 11 allied health
- Saw an average of 5.6 different professionals
- Additionally, 30% were unable to access a service due to cost eg physiotherapist, psychologist, OT, hydrotherapy.

Medical Tests and Hospitalisations

In the past year:

- 97% had one or more tests eg blood tests (95%) and eye examinations (78%)
- 56% had at least one hospitalisations of which 80% were day-stays
- Average of 2.0 hospitalisations per year
- The commonest reasons for 1 or more nights in hospital were: pain/inflammation (41%) and infections (38%).

Childhood Rheumatic Diseases

(Key findings)

Diagnosis

- Average time to diagnose was 14 months
- 27% were diagnosed after 1 year

Treatment and Care

- 71% were taking csDMARDS, 43% bDMARDS, 49% NSAIDs, and 57% oral corticosteroids.
- Average of 4.0 hospitalisations per year.

Impact

Physical, Emotional and Social

- 50% reported moderate to severe pain over the past week. Only 15% reported no pain.
- 30% required orthotics/splints/braces
- 32% had an eye condition
- 53% a mental health condition
- Students missed an average of 2.6 (12%) school days per month
- Emotional health was impacted in 75% of children and 59% of families participation in leisure activities, (68% of children, 42% of families) and sport (77% of children).

Quality of Life (QoL)

- Children with JIA had a considerably lower QoL score (0.53) than the Australian norm for adolescents aged 11-17 (0.78) and for children with other chronic conditions.

Financial Cost Estimated (AUD 2022)

- Annual cost per participant was AUD 28,688
 - government health care costs: \$24,396
 - participant out of pocket costs: \$ 4,292

Priorities for future research

The three priority areas were:

- long-term health impact,
- medication side-effects and effectiveness
- physical impacts (pain, fatigue, flares).

School

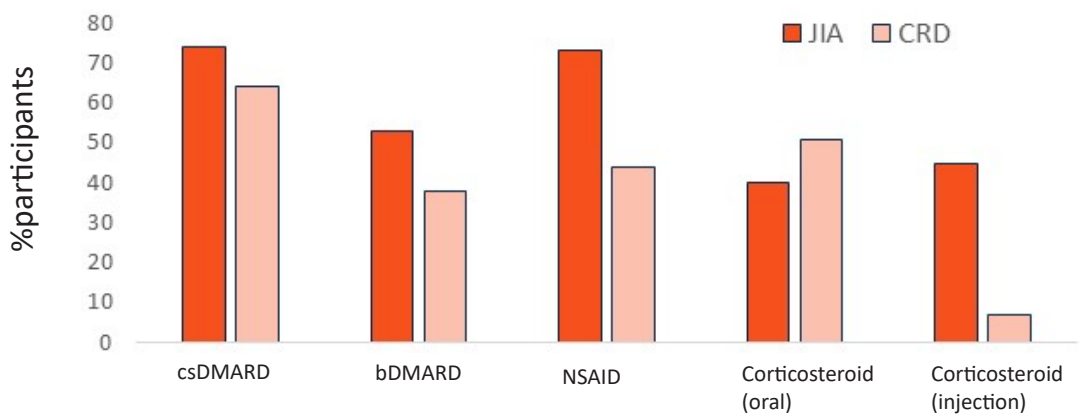
- Students missed an average of 3.1 (15%) school days per month

Financial Cost Estimated (AUD 2022)

- Annual cost per participant was AUD 35,368
 - government health care costs: \$31,189
 - participant out of pocket costs: \$ 4,179

RESULTS AT A GLANCE

DIAGNOSIS	JIA	CRD
Average age of symptom onset	5 years	6 years
Average time to diagnosis	11 months	14 months
TAKING MEDICATIONS	97%	98%
Types of medications		



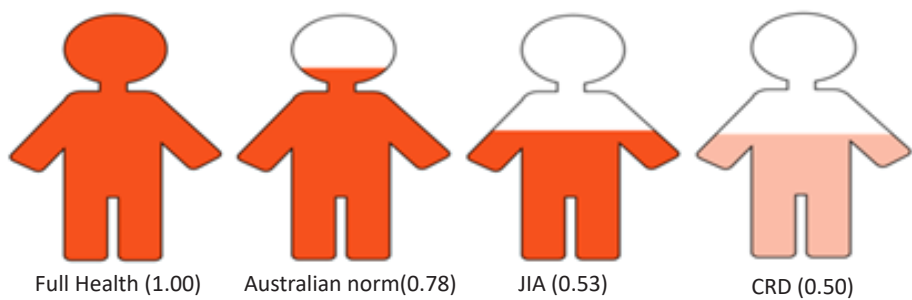
Side Effects	72%	57%
--------------	-----	-----

HEALTH PROFESSIONAL VISITS	JIA	CRD
Average visits per year	25	26
Number of different health professionals	5.6	6.4

HOSPITALISATIONS	JIA	CRD
Hospitalised per year	56%	57%
Average number of hospitalisation per year	2.0	4.0

FINANCIAL COST (AUD 2022)	JIA	CRD
Total cost per person per year	AUD 28,688	AUD 35,368
Government health care costs	AUD 24,396	AUD 31,189
Out of pocket costs	AUD 4,292	AUD 4,179

QUALITY OF LIFE



IN THEIR OWN WORDS

I have aids for her cutlery, and tubing for hand-held items, I give her heat packs etc as gifts so she will have plenty. But she can't cut vegetables- so another life skill that concerns me. I tried full time work at the beginning of the year but for appointments etc I've gone back to part time.

We are a single income family. We are constantly told that \$144k annual salary is enough for a family of 4 living in Sydney AND we have 2 children, 1 is living with an incurable disease that affects every aspect of our lives 24-7.

I've used all my sick and holiday pay and then I have to take leave without pay. I can't pay for my car payments. I have to rely on my parents and that puts a financial impact on them. I can't get a Medical Benefits card and need to pay full price on medication which is expensive. I had Covid 3 times and paid \$100 each time for anti viral medication. I couldn't work and was on unpaid leave.

NDIS requires us to spend \$2000+ on reports for access which is not guaranteed. We needed to choose to spend that money on either reports or medical appointments.

Wondering how JIA will affect my body long term, what to expect through my late twenties and beyond and impact during pregnancy later on. Ability to keep up at work and manage fatigue.

I have been in a flare for months and medications aren't working for me. So I have put many things on hold, and I am unsure if I'll be able to go back to them because my pain needs to reduce before I can do that. Waiting to see if new medications will work is exhausting. Also taking two immunosuppressants medications has really impacted my immune systems I have been getting every possible infection. So I have been sick a lot too, which is hard.

We'd like to increase the frequency of her physio appointments and start her seeing and OT regularly but it is unaffordable at the moment. I'm self employed so when I take time off for my daughter's appointments, or to look after her (pain, flares, fatigue etc), I don't get paid.

ABOUT Jafa

The Juvenile Arthritis Foundation Australia (JAFA) is the primary organisation for children and young people with arthritis. It is a registered charity, established in 2019 in response to the urgent need for a national voice dedicated exclusively to addressing the needs of children and young people with juvenile arthritis and childhood rheumatic diseases and their families and carers.

What we do

- Support, connect and inform families
- Political advocacy to improve services and support
- Raise and leverage research funding for better treatments, prevention and, ultimately, a cure

Connect with JAFA

- We invite you to Join the JAFA community via our website.
- JAFA has no formal membership and no fees – people are free to come and go as they please.
- JAFA is committed to connecting and informing you on upcoming events, programs, campaigns, new treatments and advances in treatments and our Online Symposia Series.

Register for Australian Juvenile Arthritis Registry (AJAR)

If you have a child aged 0-17yrs with JIA or CRD or are a young adult aged 18-25yrs you can change tomorrow by registering with AJAR today.

Click here to see more and register: <https://bit.ly/3P10fcM>

Join JAFA @ www.jafa.org.au/join/



Juvenile Arthritis
Foundation Australia



www.facebook.com/jafa4kidsarthritis



www.twitter.com/jafaforkids



www.instagram.com/jafa4kidsArthritis



www.linkedin.com/company/juvenile-arthritis-foundation-australia

