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Submission to the Standing Committee on Health, Aged Care and Sport Inquiry into childhood rheumatic diseases

ABOUT US

Arthritis Australia is the peak arthritis organisation in Australia and is supported by affiliate organisations in ACT, New South Wales, Northern Territory, Queensland, South Australia, Tasmania and Western Australia.

Arthritis Australia provides support and information to people with arthritis as well as their family and friends. It promotes awareness of the challenges facing people with arthritis across the community, and advocates on behalf of consumers to leaders in business, industry and government.

In addition, Arthritis Australia funds research into potential causes and possible cures as well as better ways to live with the disease.

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Introduction

Thank you for the opportunity to make a submission to the Standing Committee on Health, Aged Care and Sport's Inquiry into childhood rheumatic diseases. Arthritis Australia has primarily focussed on the Terms of Reference concerning impacts on consumers and access issues.

Arthritis Australia conducted a consumer survey to inform our submission, which was open between 23 December 2021 and 24 January 2022, and was promoted to consumers via Arthritis Australia and state and territory affiliates' contact lists and social media/newsletters. The survey received 82 responses. While we acknowledge limitations due to the sample size and respondents being self-selected, our respondents have contributed important insights into the experiences of children, parents and families living with juvenile arthritis, as well as adults who were diagnosed with arthritis as a child. We sincerely thank them for their willingness to share their stories, which at times make harrowing reading and attest to the need for more awareness, access and support than is currently available - in the health system, in schools and from the community more broadly.

Discussions with our state and territory affiliate arthritis organisations and Musculoskeletal Australia, who have long experience supporting and providing services to many consumers and families across the states and territories, have also informed this submission, and a number of these organisations will be making submissions on the situation in their own state or territory. We have also consulted with our Consumer Advisory Panel and Scientific Advisory Panel.

Key themes that arose from our survey included:

- Community awareness is very poor, and families have encountered a lack of understanding and support particularly in educational settings
- Health professional awareness is viewed as poor and this is believed to have contributed to some delayed diagnoses
- There are major physical, emotional, educational and social impacts for children and families, including disability, pain that is not well managed, social and educational disadvantages and exclusion, and mental health impacts
- Access to best practice multidisciplinary care is variable, and improved access particularly to pain management, psycho-social support, allied health and medicines is needed
- Cumulative out of pocket costs are a significant issue for many families

Detailed responses to the Terms of Reference are below.

We asked consumers what supports are needed, and what changes a national inquiry could recommend that would make the biggest difference for them. Their responses included:

- Improved awareness and education of health professionals, particularly around diagnosis and the importance of early diagnosis and treatment on health outcomes
- Better and more affordable access to specialist and multidisciplinary care, including pain mangement and psycho-social support
- Better access and affordability of medicines
- Better access to financial support for out of pocket costs
- Easier access to the NDIS
- Improved community awareness, particularly in educational settings
- More information and support for children and families, including opportunities such as kids camps where they can meet others in a similar situation.

In 2019 the National Strategic Action Plan for Arthritis (the Action Plan) was launched, based on a review of the evidence and extensive consultation with consumers, clinicians and researchers. The Action Plan is a comprehensive national plan for all levels of government and other key stakeholders to better manage and prevent arthritis, which is one of the most common, costly and disabling of all chronic conditions, affecting over 4 million Australians. There are a number of actions specifically for juvenile arthritis, and the broader recommendations are also highly relevant.

The Commonwealth has provided funding to implement a number of key actions from the Action Plan. Arthritis Australia, in partnership with a range of stakeholders including clinical groups and state and territory affiliate organisations, is delivering a range of initiatives relevant to this inquiry including:

- Working with the Australia and New Zealand Musculoskeletal Clinical Trials Network (ANZMUSC), in collaboration with the Australian Paediatric Rheumatology Group to develop living guidelines for the treatment of Juvenile Idiopathic Arthritis
- Development and promotion of online health professional education modules on arthritis, including a focus on earlier diagnosis
- Enhancing and promoting the National Arthritis Infoline
- Expanding access to kids camps
- Developing a consumer care guide for juvenile arthritis
- Developing consumer resources including Aboriginal and Torres Strait Islander resources, exercise, arthritis pain and fibromyalgia.

We also have a number of existing resources on juvenile arthritis.

While significant progress has been made in implementing the Action Plan, it is clear that more needs to be done to fully implement the plan and ensure that the right care, treatment and support is in place for all children, families and adults with arthritis. Where juvenile arthritis is not diagnosed early and treated optimally, there is the risk of significant and preventable illness and disability. Not only does this rob children of life opportunities, and rob our community of some of the contribution these children could otherwise make as they grow up, but it is likely to lead to increased costs to the health and social support systems.

We strongly welcome the recent Medical Research Future Fund investment of up to $20 million over 4 years into research into chronic musculoskeletal conditions in children and adolescents. However, there has been a chronic underinvestment in arthritis and musculoskeletal conditions in Australia, with funding disproportionately low relative to the disease burden and cost of these conditions. These conditions affect people of all ages including children and young adults, and account for 13% of the total disease burden[1], incur the highest spending of $14 billion (10.3%) in 2018/19[2] and are a leading cause of disability, chronic pain and early retirement due to ill-health in Australia.

In 2020, NHMRC funding for research in the field totalled only $46.1 million, less than half the investment in disease groups such as cardiovascular and mental illness which have a similar burden of disease. An MRFF research mission is needed to provide strategic funding of high-quality research projects and infrastructure that will lead to improved prevention, diagnosis and treatment, and support the search for cures.

Recommendations

Our key recommendations are summarised as follows, many of which have arisen from the National Strategic Action Plan for Arthritis:

1. Improve the education of health professionals including GPs and allied health workers, particularly around the importance of early diagnosis:
    a) Fund the development of online continuing professional development (CPD) modules on juvenile arthritis – this could build upon modules currently in development by the consortium led by Arthritis Australia
    b) Establish an advisory group to oversee the development and implementation of information, training and education programs, in collaboration with relevant professional bodies, educators and stakeholder groups. Tasks could include:
        - Identify priority educational needs relating to arthritis care across clinical disciplines, including GPs, nurses, allied health professionals and pharmacists.
        - Review and enhance content relating to evidence-based arthritis management in university curricula for medical students, nurses and allied health practitioners.
        - Define skill sets and competencies for components of arthritis management and care across clinical disciplines, care settings, and levels of professional practice.
        - Identify the education needs of specific health professional groups such as Aboriginal and Torres Strait Islander health practitioners and workers and those working in rural and remote areas.

        - Address the educational needs of relevant non-health professionals such as school staff
        - Consider certification or recognition programs (micro-credentialing) for health and non-health professionals, who acquire additional arthritis management skills and competencies beyond their professional training.
    c) In collaboration with relevant professional bodies, develop a toolkit for GPs to support the delivery of best-practice arthritis care. Make the toolkit available in a range of formats and embed it into clinical practice software (e.g. Medical Director) and incorporate into local clinical pathways e.g. via HealthPathways. The toolkit would include:
        - A decision support tool to enhance early diagnosis and referral for children who may require specialist care.
        - Template management plans to assist in developing comprehensive care plans

2. Ensure that paediatric rheumatology services are sufficient to meet the community need:
    a) Expand funding for public paediatric rheumatology services in identified areas of need across Australia to reduce waiting lists and improve equitable access to timely and affordable specialist services, and to enable referral to appopriate multidisciplinary care.
    b) Expand public funding for best practice multidisciplinary care, including paediatric rheumatology nursing, pain management, occupational therapy, social work, physiotherapy, and mental health support.
    c) Provide dedicated funding for paediatric rheumatology training
    d) Provide funding through the Specialist Training Program to support rheumatology training in non-traditional settings such as non-tertiary hospitals and private practice.
    e) Increase funding for both public and private paediatric rheumatology outreach and telehealth services into areas of identified need, including Aboriginal and Torres Strait Islander communities.
    f) Provide funding for outreach and telehealth services delivered by appropriately-skilled nurses and allied health professionals, to support team-based care, including Medicare and private health insurance rebates for allied health telehealth services.
    g) Upskill health professionals in rural and regional areas to provide appropriate care
    h) Fund appropriate transition care services for young people moving from paediatric to adult rheumatology services – this could be integrated as part of a broader approach to children with chronic illnesses and draw on pockets of best practice such as in Cystic Fibrosis.

3. Support the trial and evaluation of models of care to improve services and referral pathways and build capacity, particularly in rural and regional settings, and scale up those with evidence of benefit:

   a) Provide dedicated funding to PHNs to commission programs to address the needs of children with arthritis in their area.
   b) Fund arthritis educators within the public and private health systems to integrate the provision of patient-centred education, support and care co-ordination into health service delivery.
   c) Appropriately-skilled rheumatology nurse specialists or nurse practitioners to triage urgent cases and undertake less complex management tasks within their scope of practice.
   d) Trial and evaluate a rheumatology nurse service offered through arthritis organisations, PHNs, LHDs or community health services for people being managed in private practice (similar to the McGrath breast cancer nurse model).
   e) Support the provision of culturally appropriate services.

4. Improve affordable access to medicines:
   a) Review paediatric access to arthritis medicines via the Pharmaceutical Benefits Scheme as well as other arrangements to ensure there is equitable, timely and affordable access to the best available treatment options for all children across Australia.
   b) Make the TGA’s medicines shortage task force a permanent feature to anticipate and manage current and future medicines shortages.

5. Address out of pocket costs:
   a) Increase the number of allied health services that can be accessed by children with chronic conditions under the MBS Chronic Disease Management Plans.
   b) Develop a comphrehensive plan to reduce out of pocket costs for people with chronic illnesses, including expanded access to the Extended Medicare Safety Net and Health Care Card.

6. Provide more information and support for children and their families:
   a) Develop and disseminate standards of care for juvenile arthritis
   b) Fund the development of child appropriate education on chronic pain management
   c) Fund community-based arthritis educators to deliver targeted national information, education and support programs for children and adults with arthritis.
   d) Fund a national nurse-run telephone information and support line for families of kids with juvenile arthritis.
   e) Provide mental health support for parents of children with chronic conditions.
   f) Fund opportunities for children and families to meet each other both in person and online.

7. Improve community and educator awareness:

a) Fund a national community awareness and education campaign to increase consumer and health professional knowledge of symptoms and the importance of early diagnosis and rapid referral to specialist care
b) Fund the development of educational materials and educational visits or sessions on juvenile arthritis for teachers and early childhood educators, as well as NDIS planners.

8. Fund an MRFF arthritis and musculoskeletal research mission to provide strategic funding of high-quality research projects and infrastructure that will lead to improved prevention, diagnosis and treatment, and support the search for cures.

Response to the Terms of Reference

1. Research into the causes of childhood rheumatic diseases, including prevalence levels of childhood rheumatic diseases in Australia

The Australian Institute of Health and Welfare estimates that juvenile arthritis affects around 1 child in every 1,000 aged 0–15, but acknowledges there is wide margin of error. It appears to affect girls more than boys[3]. 50% of those diagnosed will continue to have active disease into adulthood. Improved epidemiological data on children with juvenile arthritis is an important step in ensuring that the right services and support are available. While we have focussed our submission on juvenile arthritis, it is important to note that chronic primary musculoskeletal pain in children and adolescents is also a significant issue.

As a consumer organisation Arthritis Australia has responded primarily on issues of access and impacts on consumers, and refers to the expertise of the Australian Rheumatology Association (ARA) and Australian Paediatric Rheumatology Group (APRG) for more information on causes and prevalence.

2. The health, social, educational and economic impacts on children and adults who developed rheumatic diseases in childhood, their families and the broader community

Children affected by juvenile arthritis, even if the condition goes into long term remission or resolves, often experience lifetime impacts from the disease or its treatment, including poorer physical health and wellbeing, and lower educational attainment and employment prospects.[4] Australian children with juvenile arthritis

show a trend towards poorer physical fitness and less physical activity compared with their peers. These children and their parents experience significant physical and psychosocial impairments compared to their healthy peers.[5]

A 2018 qualitative study on young people's experiences of persistent arthritis pain, care needs and service gaps indicated that pain negatively impacted multiple aspects of a person's life, including study, workforce participation, sleep, physical activity and daily life. Participants reported being in fear of living the rest of their life in pain and felt daunted at the prospect of managing the condition in the future. Participants reported experiences with health professionals as mostly negative, and felt overwhelmed about the varying information provided. They reported a lack of age-related information on pain management.[6]

Our affiliates report that there can also be significant impacts on parents and families, with issues including the difficulties of navigating the health and NDIS systems, lack of understanding and support in the education system, travel and time off work, mental health impacts and relationship breakdowns.

The Arthritis Australia survey asked a number of questions in relation to physical, emotional, social, education and economic impacts. Responses made clear that these impacts were very interconnected. We have provided many of the free text comments from respondents below, which vividly describe impacts on children and families, including pain and fatigue, mental health issues, social exclusion and a lack of community understanding, particularly in educational settings. It is clear that children with juvenile arthritis need more support to manage these impacts.

Physical impacts

There were a wide range of physical impacts in the survey question, which respondents were asked to rank either 'no impact', 'low impact', 'medium impact' or 'high impact'. In the survey analysis, no impact and low impact were combined as were medium impact and high impact. Physical impacts are listed from highest to lowest impact below:

- Pain in joints (80% said this was medium or high impact)
- Fatigue (69%)
- Flare-ups (64%)
- Joint stiffness (63%)
- Pain at rest (57%)
- Poor/broken sleep (53%)
- Medication side effects (50%)
- Mobility disruptions (48%)
- Nausea (34%)

24 comments were received covering a number of themes. It was noted that physical impacts can vary according to whether there is a flare up or not, and whether optimal treatment is in place.

The many ways in which physical symptoms affected children's ability to participate in learning and play was outlined:

> *Unable to play football with friends because of the impact on ankle joints. Fatigue when playing sport. Unable to write stories in class because hand becomes sore and stiff. Unable to sit cross legged in class with her peers.*

Pain and fatigue were frequently mentioned, including some harrowing stories of severe and long term pain:

> *It impacts both his hips and one knee so he is unable to walk even one step during flares. He always walks with some kind of limp, sometimes on tip toes or crawls and leans his head on ground to reduce weight through his legs. We bought a bigger pram which we often need for long distances if not using it like a wheelchair on bad days.*
>
> *He can sometimes not rest his legs and knee comfortably at all, tries it bent or straight and it still hurts and he will hold it crying.*
>
> *Just having to deal with ongoing joint pain, daily medication and frustration as it never seems to go away. It's been a number of years now and still reliant on medication and daily pain. She's working now and some days are physically challenging for her but she is resigned to dealing with it.*
>
> *Chronic pain in foot even though her arthritis is in remission. Can't get through a day of school without pain medication. Can't walk long distances. Can't keep up with her peers although she tried her best.*
>
> *Sometimes in the middle of the night a flare hits and he literally has his knees locked into position so that he can't walk. On one occasion we have suffered profoundly, we have found him on the floor trying to crawl to our room one night he actually had an accident and I didn't wake up till 5am and he was in such a state. It was so traumatic for him to be a teenager and not able to get to the toilet not being able to wake us up and not being able to help himself for me to have to pick him up off the floor bath him and dress him, he was so traumatised he slept in our room for the next 6 weeks and even now when winter comes he sleeps in our room. He has permanent damage to his knees not being able to extend and hyper extend because as a child (before he turned 8) the pain in his knees was so bad he wouldn't walk with is legs straight that the muscles and tendons had shortened due to the way he walked for pain relief.*
>
> *He has suffered terribly with pain and stiffness for 2 years before a doctor actually listened to me. He would wake every night crying in pain that his legs hurt, he could barely walk of a morning/evening, he would limp, he'd have to sit out of activities because it hurt too much, or he'd be in pain after during flares. Then when he started treatments he would get sick easily with infections (pneumonia, chicken pox, school sores from broken skin, inflammation in his eyes, infections from psoriasis) then he got diagnosed with IBD on top of the arthritis and psoriasis so he had to stop the treatment he was on the was working and switch to another that would help all the conditions. This lead to a needle phobia because the… injections hurt so bad. Now we have to go*

> *to hospital 6 weekly for infusions. He's only 9 and has already suffered mental health problems because he doesn't feel normal or want to be in pain. He has missed out on a normal childhood.*

Physical impacts included long term health issues that may require surgery or other interventions:

> *My daughter was diagnosed with Systemic JIA at 3 years old and now she is 20 years and is booked into have a hip replacement. She has Avascular Necrosis caused from steroid use to stop flares.*
>
> *She is 15 years old and will be having a complete knee replacement in the next few months. She has never been flare free and is currently suffering in 10 joints. Over 70 joint injections, 2 knee operations, no ability to stand/walk/or have a first job, severe pain and is on the last medication available (on compassionate use as not licensed for use in kids and this is her 3rd drug on compassionate). Nothing has made her flare free and she gets every awful side effects.*
>
> *We lived with 4 years of poorly controlled arthritis before finding a drug that worked. My daughter stopped sport and most other activities. She cried and was angry and exhausted every day. She could only walk for about 10 minutes and we were using a wheelchair part time. Sitting on the floor was difficult at school. Handwriting continues to present some challenges. It is OK for a while but fatigue cuts in after 10 minutes. Gastroesophageal complications have resulted in ulcerative esophagitis and duodenal disease and constant discomfort.*

Impacts on broader health were raised by several commenters, including weight gain from reduced physical activity, and side effects of medication such as ulcers and stomach upsets.

Mental or emotional impacts

Respondents were asked to rank a range of mental or emotional impacts from 'no impact', 'low impact', 'medium impact' to 'high impact'. In the survey analysis, no impact and low impact were combined as were medium impact and high impact. Mental or emotional impacts are listed from highest to lowest impact below:

- Anxiety (64% said this was medium or high impact)
- Mood changes (57%)
- Difficulty concentrating (brain fog) (53%)
- Anger/aggression (45%)
- Rumination/obsessive thinking (38%)
- Clinginess (33%)
- Depression (30%)
- Catastrophising (25%)

22 comments were received. Some comments highlighted serious mental health impacts and stress both for the child and their family, including when confronted by a lack of understanding from health professionals:

> *We have been extremely worried about our child's mental health. She is constantly having to justify her illness, explain herself and condition and work out who she can and can't trust or confide in. She gets frustrated and angry very quickly and this causes great stress to our family. I also worry about the impact it has on her younger sister.*
>
> *He's already stated more than once to friends and family that he wishes he could die so he could be pain free and not have to worry about being sore or sick.*
>
> *The pain at times sends him off the emotional ride and then to add side effects of steroid use it's bad. For years being told by doctors and emergency departments that I was over reacting, that my son was over reacting, that this was all in his head that it was just growing pains, that I didn't know anything the emotional impact on our family was huge as they tried to tell us he was making it up and attention seeking. If we had believed them the overall detrimental effect it had just hearing them say it was horrendous.*
>
> *HUGE! All of the above are daily challenges for our entire family. Explosive anger and severe anxiety. Refusal to engage in counselling.*
>
> *My daughter is a different person to the one prior to her diagnosis. She used to be full of energy and now she is depressed and will spend much of her day lying on the couch.*

The impacts of treatment mentioned, include development of anxiety and needle phobia:

> *The medication and administering of medication has a huge impact on our child's trust of other people, emotional wellbeing and general happiness and moods. It impacts all aspects of his life and he finds it unfair that his friends and family don't get needles every week. He thinks he is the only one. He has become a very anxious child from the impacts of the meds. He has developed a needle phobia.*
>
> *Severe anxiety regarding needles and the smell of alcohol swabs. Vomits when she smells hand sanitizer. Vomits when she has her weekly and bi weekly needle.*
>
> *Son is only 3 years old so hard to interpret behaviours directly related to arthritis at this stage. Definitely some anxiety around doctor's visits and tests.*

However, the resilience of children is also mentioned by several commenters:

> *It… has taught her to be resilient but the constant niggling pain and daily meds gets to her on occasion.*

> *Initially he googled his condition daily and read stories and worried about his future but now his condition has settled he feels better.*

Social or educational impacts

Respondents were asked to rank a range of social or education impacts from 'no impact', 'low impact', 'medium impact' to 'high impact'. In the survey analysis, no impact and low impact were combined as were medium impact and high impact. Social or educational impacts are listed from highest to lowest impact below:

- Difficulties with lack of community awareness/understanding (59% said this was medium or high impact)
- High absenteeism from school (due to medical management) (56%)
- Difficulty talking to peers/friends about their condition (54%)
- Feeling isolated because they don't know others in their situation (i.e. with the condition) (53%)
- High absenteeism from school (due to physical or emotional challenges) (45%)
- Difficulty engaging in group activities (at school or in the community) (45%)
- Difficulty at school (requiring special support) (38%)
- Difficulty engaging with other children (36%)

24 comments were received. Lack of support and continuity in school and childcare settings is mentioned, with at times poor understanding of the condition from teachers, requiring families to keep retelling their story:

> *Every year we have to go through the same routine of informing teachers of my daughter's condition and how it's best managed.*
>
> *Again we needed to pay for private schooling to get the support he needed in class. This isn't available in the public system.*
>
> *We have had several weeks absent from daycare where he misses his friends and activities. We have had no access to support when he has severe reduced mobility, been asked to take pram home and to collect him if he is unable to lift himself as they cannot lift him. One of his teachers last year has arthritis so was very understanding and I have bought some books aimed at kids his age to take to his new kindy class this year to try and help improve understanding. I have talked to some of his classmates saying he has a sore leg. When he wakes up in a flare he is usually crying out in pain and says "sore leg, see Dr mum". They have said I should speak to physical education teacher this year as he cannot yet communicate particularly well when it starts to hurt, tends to get shy.*

> *The school has been terrible in trying to get them to understand the impact of this disease on our daughter, and trying to get supports in place for her, and even recognising that she even needs help.*
>
> *My daughter does not [tell] anyone about her arthritis because of the misunderstanding around it and being deeply hurt by a casual teacher that thought she was lying about her condition. She missed 50% of school this term. We live 6 hours from Sydney and have to see the rheumy every 3-4 months, this is at least 3 days off and usually exhaustion after we return home so most of a week gone each term. She feels very different to others and social can be really difficult. These kids endure so much that a lot of the school social drama just seems silly to them.*
>
> *Received multiple years of low grades in Physical Education even though we attempted to explain his condition to teachers and the schools. Attitude was he looked fine.*

One respondent provided detailed comments that highlight the need for reasonable adjustments, and the key role of parental advocacy:

> *My daughter's school has many, many stairs. She had 20 days off school in 2021 (plus 4 months in lockdown) when she is too tired to manage the stairs. She has also had four weeks of partial attendance when she was on crutches. In order for new accommodations around stairs and classroom allocation to be made I will be paying close to $800 for colleagues (OT and physio) to complete assessments at school in order for my daughter to have an accessible classroom.*
>
> *We are very fortunate to be part of a school community where teachers genuinely care about the kids. My daughter's teacher has made accommodations for my daughter when asked and with minimal fuss. I know this is largely dependent on the individual teacher and we are unlikely to have a teacher so willingly accommodate my daughter's needs with minimal fuss ever again and she is in year 1. On bad days my daughter is unable to write and needs to type or use voice to text technology to complete work. We have had to provide equipment for this at school.*
>
> *My daughter has at least one day a week where she feels too tired to go to school but becomes very upset as she does not want to miss out on school or seeing her friends.*
>
> *I have had to source information for the school on how to support a child with JIA. I work in the health and disability sector, supporting many children with disabilities at school. I feel that my job gives me an advantage in knowing how to navigate the system, knowing what I can ask for, and how to advocate for any support. It still feels like a constant battle. I cannot imagine what support my daughter would miss out on*

> *without my knowledge and ongoing advocacy. I often feel like I would like to just be her parent and not have to be her advocate in order for her to access support she needs.*

The impacts on schooling for older children is described in several comments:

> *We pulled my daughter from school in year 11. She was missing way too much school to keep up with the demands on the HSC. She did HSC by distance education which was not ideal and likely impacted her scores but it was the only way we could manage her education. We needed to lower expectations in education to make it work. Not ideal outcome but the only way.*
>
> *My son missed most of grade 11 because he couldn't walk around school carrying his books and laptop etc. he also couldn't walk up flights of stairs to get to classes. After going on Humira he didn't miss a day of grade 12. The first year of diagnosis (grade 11) was absolutely heart breaking.*

Social exclusion and a lack of understanding from peers was mentioned by a number of commenters:

> *Because arthritis is "invisible" to the eye people don't understand the level of difficulty normal activities can be. There seems to be a level of mistrust of diagnosis in children from peers sometimes as well.*
>
> *In first class she was in a wheel chair for the first year. Some kids bullied her as they said she was faking, she took lots of mornings off due to pain. For 5 years she had to go to Sydney every 2 weeks for treatment.*
>
> *The impacts are huge as she can't keep up with her friends in the playground and PE classes. She doesn't get picked for teams. She's excluded.*
>
> *Kids are cruel. The torment, teasing and name calling was horrendous in a formal school. Distance education has definitely improved his ability to communicate and to also want to learn again, getting him to engage after a public school was the hardest thing to do.*

Economic impacts

Our survey asked respondents who were adults living with arthritis diagnosed when they were a child, to indicate if they had experienced any of the following economic impacts. 17 responses were received:

- Difficulties with lack of employer understanding (65%)
- Inability to work (59%)

- High absenteeism from work (due to medical management) (53%)
- High absenteeism from work (due to physical or emotional challenges) (47%)
- Only able to work reduced hours (29%)
- Not able to find work in the field in which you are qualified (12%)
- Early retirement due to medical condition (6%)

A number of comments were made to the effect that the respondent had tried different approaches to work due to their condition, including part time work and being self-employed, some of which had worked well for them.

Out of pocket expenses are addressed under ToR three below.

3. Access to medical services, including diagnosis, treatment and ongoing management and support including patient information, with a focus on rural and remote communities

We surveyed consumers on a range of access issues, out of pocket costs, and how well their child's condition is being managed. The key issues identified include:

- Delays in diagnosis, including instances of GPs not recognizing symptoms, misdiagnosis, and emergency department presentations
- Delays in accessing the right treatment for children who don't respond well to the most commonly used medicines
- Lack of access to specialists and other services in rural and regional areas
- Out of pocket costs and the impact of cost on being able to access the services needed for optimal management, particularly for medicines and allied health

Comments received were predominantly negative, describing instances where the health system has not served children and families well.

Diagnosis

A major concern with juvenile arthritis is that delays in diagnosis and appropriate treatment are likely to lead to poorer outcomes and potentially permanent damage and disability. Survey respondents were asked "How long did it take you/your child to be correctly diagnosed after first experiencing symptoms?" 28% of respondents indicated that a correct diagnosis had occurred within three months of experiencing symptoms. However, 49% of respondents waited over six months for a correct diagnosis, 32% waited over a year, and 13% waited over three years. These results align with published research[78].

Seven comments were received which indicated a range of experiences, from those who received the right care quickly - *"Was very lucky. Got to see an amazing specialist on a cancellation"* – to one person who waited 10 years for a diagnosis.

Two commenters indicated that they believed an element of luck had been involved in the diagnosis and did not believe all health professionals would have recognised juvenile arthritis:

> *"My child began experiencing symptoms shortly before her 6th birthday, after a number of ultrasounds and xrays a referral was sent to the paediatrics at Hospital. Unfortunately her pain was not able to be adequately managed with over the counter medication and we attended the emergency department approximately 1 month after symptom onset where we were lucky enough to be seen by a junior doctor who had done a rotation within the rheumatology clinic. This doctor was able to identify the condition and initiate appropriate referrals to ophthalmology and rheumatology and we were seen within 3 days. If we were left to go through the GP > Paediatrician > Rheumatology pathway that is standard the wait would have been significantly longer and result in more severe impacts - even the 1 month delay resulted in slight joint contracture."*
>
> *"We were extremely lucky to have a very experienced GP (who isn't our usual GP) strongly suspect JIA very early on. My regular GP and other GPs at the practice have all admitted they would not know how to recognize JIA."*

Two commenters indicated that there was an initial misdiagnosis:

> *"Whilst initial diagnosis is oligoarticular arthritis, symptoms continued to develop and took a while for it to show up on blood work - once condition worsened we then got adequate assistance. "*
>
> *"Originally misdiagnosed as a sprain. Had to repeatedly present to ED at Children's hospital before it was properly investigated."*

Survey respondents also commented on this issue when asked how they would rate the general level of awareness of health practitioners about juvenile arthritis:

> *Three different GPs couldn't identify my daughter's juvenile arthritis, despite swollen fingers, knees and being unable to walk.*
>
> *It took over 5 years for our GP to think about it possibly being arthritis because his bloods would come back RA negative.*
>
> *We were told 'growing pains' and 'bone bruise' even after MRI by our local GP for around 12 months. He was away one day and I mentioned the sore knees to the young doctor we didn't usually see and she said straight away that she thought it was arthritis. I feel like you have to be 'lucky' to get a GP who understands and has knowledge of JIA. We live 6 hours from Sydney and lack of understanding is an ongoing struggle.*

Access

There are only a small number of paediatric rheumatologists in Australia – the Australian Health Practitioner Regulation Agency reported that 19 were on the national register in 2020-21, and this represents headcount as opposed to FTE, as some may work part time or have non clinical committments. We understand from the APRG that FTE in the public system sits at only 9.89 nationally, and that internationally accepted standards for the provision of comprehensive paediatric rheumatology care include a ratio of 1 paediatric rheumatologist with multidisciplinary team per 200,000 children. Using that standard, Australia needs 30 FTE.

Funding is variable and some jursidictions such as Tasmania and the Northern Territory have no paediatric rheumatologists. Due to the limited number of paediatric rheumatologists consumers,especially those from rural or regional communities have to travel long distances for appointments, and some families move to major centres to be closer to their treating specialist. There are only two training hospitals for paediatric rheumatologists in Australia.

Arthritis Australia's 2017 report, Rheumatology Nurses: Adding Value to Arthritis Care, found that there was just one full-time rheumatology nurse for every 45,000 people living with chronic, inflammatory arthritis conditions. The report found that adding rheumatology nursing to the traditional care model would mean quicker access to specialist care and an earlier start to treatment, an increase in the number of patients going into remission and a decrease in the average cost of care per patient.

In our survey, 90% of respondents indicated that a paediatric rheumatologist was the treating practitioner. Of these, 48% were at a public hospital, and 42% were in the private sector. Six respondents indicated 'other', which could potentially include general paediatricians or adult rheumatologists for those respondents living with juvenile arthritis who are now adults. Two respondents said that their GP was the treating practitioner.

Respondents were asked to rate access to:

- General practitioner
- Rheumatologist
- Allied health
- Diagnostic services
- Medicines
- Patient information and support

Most respondents (85%) rated their access to GPs as good or excellent, with only 7% rating it as poor or very poor, and 7% as neither good nor bad. Access to a rheumatologist was also rated well with 76% selecting good or excellent, and 16% rating it as poor or very poor, with 9% selecting neither good nor bad. Access to medicines (72% good or excellent) and diagnostic services (68% good or excellent) was also rated well.

The rating for access to allied health was lower, with 55% of respondents rating it good or excellent, but 24% rating it as poor, and 21% neither good nor bad.

Only 43% of respondents rated patient information and support as good or excellent, with 28% rating it poor or very poor, and 29% neither good nor bad.

One parent provided a detailed summary of access issues facing their child, and the need for psycho-social support:

> *We have access to a great local physio but see them privately. Desperately need a greater range of biologic or other drugs approved for use in JIA. Most children respond to enbrel, humira or actemra, but for those who don't (like my daughter), access to other drugs is only possible with lots of jumping through hoops and compassionate supply. Also desperately need specially trained psychology/counsellor services as part of the course of diagnosis.*
>
> *Every parent of a JIA child that I have had contact talks of the socio-emotional struggles that their child faces. I would love to see regular check ins with a counsellor of some sort with rheumatology reviews to normalise the mental health aspects of the disease."*

Another respondent commented on the limited choice of specialist:

> *There… needs to be more information in regards to the different practitioners available. I had to go searching for a specialist who would actually listen to me rather that the first one I was sent to. Being able to choose who you see makes a difference.*

Some comments described inadequate care and treatment and its impacts on their children:

> *"Unfunded departments in the hospital [have] left my son with access to a triage style medical system. This means the level of care he has received to date has been superficial and inadequate. This has led to him receiving an acquired disability from hospital staff not doing taking the time to fully investigate what we were presenting with."*

The time to the first appointment with a paediatric rheumatologist was one to four weeks for 28% of respondents, and four to six weeks for 18%. 75% of respondents had gotten the first appointment within 6 months, but 9% of respondents had waited over 6 months.

12 respondents made comments, with some commenting that they went or were advised to go to a private paediatric rheumatologist to be seen more quickly, and others being referred from the emergency department.

Respondents were asked to rate how well their or their child's condition is being managed. 72% of respondents felt their or their child's condition was being managed well or very well, with 19% rating it neither well nor poorly managed, and 10% as poorly or very poorly managed.

16 comments were made on this question, on issues including a lack of effective treatment options:

> *My daughter hasn't responded well to the regular medications and approved biologics. We are now on a trial drug that is working well so far. Our rheumatologist goes above and beyond in his care of our daughter.*
>
> *…no fault of the medical staff. They have tried absolutely everything but nothing is helping.*
>
> *Think it is being managed ok but I am starting to run out of treatment options. My management when I was first diagnosed was very poor and led to long term health problems which have resulted in me being unable to take some first line treatments.*

Commenters mentioned that good management of their child's condition required a lot of effort from them as parents:

> *As I have arthritis myself I have pushed and done all the management with very limited and expensive medical support.*

Comments were made about cost and wait time for treatment:

> *But we have to pay privately for everything. No access to NDIS and no access to timely public services. The chronic disease plan is a waste as it costs more to see the GP!*
>
> *Covid appears to have impacted our access to appointments, which has meant much longer waiting times for appointments and cancelled appointments*
>
> *Up until recently it has been extremely poor. His new specialist is very good, but has too big of a case load.*

Out of pocket costs

Arthritis Australia's survey asked respondents to what degree their family has been impacted by out of pocket costs relating to care and treatment of their child's arthritis (or their arthritis, if the respondent was an adult who had been diagnosed as a child), for the following categories:

- Medicines
- GP appointments
- Specialist appointments
- Allied health appointments (eg physiotherapy, podiatry, psychology, occupational therapy)
- Diagnostics (eg blood tests, scans)

Costs associated with GP appointments had the least impact on survey respondents, with 78% saying this had a low impact or no impact, followed by the costs of diagnostics at 74%. 73% of respondents said that the cost of medicines had a medium or large impact, followed by the cost of specialist appointments at 67%, and costs of allied health at 55%.

31 comments were received which outlined what these respondents considered to be the key issues in relation to costs. Expenses related to travel, including accommodation, fuel, time off work to attend multiple appointments, child care and parking were mentioned by a number of respondents. Some commenters said that out of pocket costs were particularly high at the outset/while seeking a diagnosis. A number of respondents gave a summary of the various out of pocket expenses they incurred, which made clear that the cumulative costs of care and treatment can be very significant:

> *We pay a top level of private insurance which has helped for the hospital visits for corticosteroid injections, anesthetist and hospital day stay. Medications are $40 each one plus general Nurofen and panodol. Physio visits, a little cover from [the insurer]. Doctor appointments bulk billed. Specialist was $400 initial consult and so far three monthly review appointments are $250 each. Counselling is private $130 per session each week. Dealing with being in pain and being different to 'normal kids'.*
>
> *Multiple MRI scans of which none were rebateable so did not even go towards Medicare safety net. Lots of out of pocket expenses - To see rheumatologist and for diagnostics and allied health. At one stage my son was seeing four different allied health people each week to help with speech, writing, physio and podiatry.*
>
> *I have significant allied health professional costs and only get a small amount back from private health insurance. Appointment costs are manageable and I probably spend close to $150 on medication a month.*
>
> *Naproxen at $140 for six weeks supply plus syringes shocked me. Private paediatrician minimum $240 a visit and when flaring we were going every two weeks roughly. Hit Medicare cap pretty quickly luckily which reduced costs, but would be a big burden on some families.*

Some respondents said that they had chosen to pay for a private paediatric rheumatologist as they would be seen more quickly than in the public system. Some respondents had accessed financial support via the healthcare care, NDIS and bulk billing, but there is variable access:

> *There is considerable financial help available, but it isn't always easy to access. I feel for NESB or low literacy families trying to navigate the paperwork in order to access various schemes. Our GP always bulk bills, as does our local radiology and pathology clinics. We were spending a lot on allied health but now have NDIS funding which has*

> *been amazing but was hard to navigate and be approved for. My daughter also has her own health care card for medicines.*
>
> *My daughter is not eligible for NDIS. We currently pay out of pocket for psychology, physiotherapy, OT, GP appointments as well as scans and any adaptive equipment my daughter needs to cope at home and school.*

A member of our Consumer Advisory Panel has raised the issue of barriers to equitable access to the Health Care Card. She is not able to work due to her arthrtiis, and because there is no family income limit for the Disability Support Pension she is not eligible for the DSP and therefore the Health Care Card.

Support available

Respondents were asked to indicate which of the supports listed they had accessed, which are set out from the most commonly accessed to the least accessed below:

- Online peer support group (36%)
- NDIS plan (34%)
- Support from school (34%)
- Other (20%)
- Pharmaceutical company support (17%)
- Disability Support Pension (14%)
- Non-government/community/charity support (12%)
- State government support (12%)
- NDIS Information, Linkages and Support (8%)

The 'other' category included support from schools, Zoe's Angels, Arthritis Queensland, the Juvenile Arthritis Foundation of Australia, kids camps, and carer's allowance.

No respondents indicated that they had received support from their local government.

Supports needed

A number of relevant comments were received in response to questions about supports needed or what changes a national inquiry could recommend that would make the most difference. More affordable access to medicines, specialist care and allied health were commonly mentioned. Easier access to the NDIS was raised by several respondents, including the complexity of applying for support for a condition in which the level of functional impairment fluctuates. Carer's allowance and the health care card were also raised by a number of commenters.

In order to inform service planning by Arthritis Australia and our state and territory affiliates, and advocacy for services, respondents were asked to score a selection of 10 supports proposals presented from 1 = of most benefit to 10 = of least benefit. The most popular proposals included

- Activity day: face to face - to connect with other children/families with JIA and learn more about the condition and self management
- Education program/resources for support at school (e.g. for peers and/or teachers to become educated about the condition)
- Education program for both parents/carers and children to better understand the condition and its management
- Activity day: face to face - seminar or forum for parents/carers
- Activity day: online - seminar or forum for parents/carers
- Pain management techniques – education on chronic pain management

A number of state Arthritis affiliate organisations run kids camps, and Arthritis Australia has been working with them to extend access to the camps including to children from interstate and rural or regional areas – unfortunately, this activity has been impacted by border closures and restrictions on gatherings during the covid pandemic.

Respondents were asked for their suggestions of other supports that would benefit their child, and what changes could be recommended by the Inquiry that would make the biggest difference. These fell into the following themes:

- Social activities – there was strong support for kids camps, modified sports and other activities. Digital ways of connecting children and parents to provide mutual support were suggested
- Community awareness and education of school staff
- There were a number of suggestions to improve healthcare, including:
    - education of GPs, specifically on the issue of improving diagnosis
    - Improved access and affordability of medicines
    - Improved mental health support and counselling
    - better access to multidisciplinary care including pain management
    - better follow up and integration of specialist care from public hospitals
- A need to address out of pocket costs and provide greater financial support
- Easier access to the NDIS
- Research into lifestyle interventions that improve quality of life

4. Best practice quality of care and availability of treatments, including emerging treatments with a focus on equitable access to effective drugs

Arthritis Australia strongly supports the principle that children with juvenile arthritis must have timely and streamlined access to the best quality care and treatment, including the best available medicines. This is particularly important given the risk of permanent damage and disability if these conditions are not effectively treated, and the limited treatment options available, particularly when children do not respond well to the usual treatments.

Currently, there are still unnecessary barriers to accessing medicines including Disease Modifying Anti-Rheumatic Drugs and biologics. There must be a review of paediatric access to these medicines via the Pharmaceutical Benefits Scheme as well as other arrangements to ensure there is equitable and timely access for all children across Australia.

As mentioned above we have focussed our submission primarily on issues of access and impacts on consumers, and refer to the expertise of the ARA and APRG for detailed information on current best practice care and treatment, as well as emerging treatments.

However, we would also like to highlight a few specific issues that have arisen in relation to medicines access during the covid pandemic:

- The worldwide shortage of tocilizumab, as a result of its use in treating severe covid infections, has had serious impacts on access for children with juvenile arthritis in Australia, who have limited alternatives. All possible efforts must be made to avoid this situation in future, and the medicines shortage taskforce should become a permanent feature, in order to manage ongoing and future shortages.
- Generally, consumers have reported increased delays in biologic script approvals during the pandemic, which has resulted at times in patients being without their dose when it is needed. Arthritis Australia is working with Muscoloskeletal Australia on a consumer survey to better understand the issues, but it is clear that there can be real and serious healh impacts if systems and processes for access to biologics result in consumers not being able to access their medicines when they are needed.

5. The adequacy and consistency of professional education, training and awareness amongst healthcare professionals and community awareness of the disease.

A lack of community and health practitioner awareness of arthritis in all its forms is a longstanding issue. In 2016, polling for Arthritis Australia indicated that only 10% of adults thought they knew a lot about arthritis[9].

A 2013 study using focus groups and semi-structured interviews to elicit parental and adolescent perspectives on pediatric rheumatology care and service delivery heard that there was a lack of knowledge and understanding among JIA health care providers, including GPs and paediatricians. A general lack of awareness was also believed by participants to be a major cause of delays in the diagnosis of JIA[10].

Our recent consumer survey reflected this. Survey respondents were asked how they would rate the general level of awareness of health practitioners about juvenile arthritis. The majority of respondents (61%) rated health practitioner awareness about juvenile arthritis as poor or very poor, with 21% rating it neither good nor bad and 18% rating it good or excellent. Nine comments were received which mostly related to GP care. While some described positive experiences, several spoke of delays in diagnosis as outlined under ToR 3.

Comments also described instances of individual GPs being apparently ill-equipped to provide care for flares or symptom control:

> *Many doctors don't know how to treat or help when she has a flare and cannot get into a rheumatologists. We are told for her to breathe through the pain. Even when she is screaming in pain.*
>
> *Anything to do with his arthritis is referred back to his specialist within the public health system and it can take weeks to months to get an appointment outside of his regular appointments.*
>
> *Many GPs… do not know how to manage or recognize flare ups. I am often doing lots of research and my questions lead the GPs down various paths to solve problems. I feel like I am navigating the ship and taking the GP on the journey.*

Overwhelmingly, respondents rated community awareness about juvenile arthritis as poor or very poor (94%, with 60% rating it very poor). Nine comments were made, on issues including poor understanding and support in early childhood and primary school settings, and a perception that arthritis only affects older people:

> *People feel it's an old person's condition. My daughter is often made to feel she's faking her pain or just wanting 'special treatment'.*
>
> *'Really, you are too young to have arthritis?"- I don't know how many times we have heard this statement. My daughter was given detention by a casual teacher at her school for making up arthritis as an excuse to get out of PE.*
>
> *I had never heard about this and my uncle has ankylosing spondylitis and my mum was a nurse. Did not know this condition is as common as diabetes in children which most people have known about for years.*

In response to a question about what changes a national inquiry could recommend, a number of respondents nominated increasing education and awareness of health practitioners, particularly around early diagnosis to prevent permanent damage and disability. The need to raise community and school awareness of arthritis in children was also a common theme.

The National Strategic Action Plan for Arthritis has a number of priority actions in relation to education and awareness. Arthritis Australia is leading a consortium of partners to deliver online health professional education modules on osteoarthritis and rheumatoid arthritis, including a focus on earlier diagnosis. We are working with the Australia and New Zealand Musculoskeletal Clinical Trials Network (ANZMUSC), in collaboration with the Australian

Paediatric Rheumatology Group to develop living guidelines for the treatment of Juvenile Idiopathic Arthritis. These are evidence-based recommendations tailored to the Australian practice context, updated in real-time as new evidence is produced.

For healthcare workers such as GPs, emergency medicine and general paediatrics, as well as students, there should be education on joint pain and stiffness and associated symptoms in children which is more broad and includes differential diagnoses. Information on best-practice management of juvenile arthritis needs to be accessible and regularly updated.

Conclusion

Arthritis Australia thanks the Committee for the opportunity to make a submission to this Inquiry and ensure that the voices of consumers are heard, which we hope will result in better outcomes for children with juvenile arthritis and their families.

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[1] Australian Institute of Health and Welfare 2021. Australian Burden of Disease Study: impact and causes of illness and death in Australia 2018. Australian Burden of Disease Study series no. 23. Cat. no. BOD 29. Canberra: AIHW

[2] Australian Institute of Health and Welfare 2021. Disease expenditure in Australia 2018-19. Cat. no. HWE 81. Canberra: AIHW.

[3] Australian Institute of Health and Welfare (2020) Juvenile arthritis. AIHW, Australian Government, accessed 15 December 2021

[4] Australian Institute of Health and Welfare 2008. Juvenile arthritis in Australia. Arthritis series no. 7. Cat. no. PHE 101. Canberra: AIHW

[5] Gerben Hulsegge, Nicholas Henschke, Damien McKay, Jeffrey Chaitow, Kerry West, Carolyn Broderick, Davinder Singh-Grewal. Fundamental movement skills, physical fitness and physical activity among Australian children with juvenile idiopathic arthritis, Journal of Paediatrics and Child Health, Volume51, Issue 4, April 2015.

[6] Slater H, Jordan JE, Chua J, et al. Young people's experiences of persistent musculoskeletal pain, needs, gaps and perceptions about the role of digital technologies to support their co-care: a qualitative study. BMJ Open 2016;6:e014007. doi: 10.1136/bmjopen-2016-014007.

[7] Foster HE, Eltringham MS, Kay LJ, Friswell M, Abinun M, Myers A. Delay in access to appropriate care for children presenting with musculoskeletal symptoms and ultimately diagnosed with juvenile idiopathic arthritis. *Arthritis Rheum.* 2007;**57**:921–7. doi: 10.1002/art.22882.

[8] Tzaribachev N, Benseler SM, Tyrrell PN, Meyer A, Kuemmerle-Deschner JB. Predictors of delayed referral to a pediatric rheumatology center. *Arthritis Rheum.* 2009;**61**:1367–72. doi: 10.1002/art.2467

[9] 2016 OmniPoll survey of 1319 people age 18+ conducted for Arthritis Australia.

[10] Tong, Allison, Jones, Julie, Speerin, Robyn, Filocamo, Karen, Chaitow, Jeffery, Singh-Grewal, Davinder Consumer Perspectives on Pediatric Rheumatology Care and Service Delivery: A Qualitative Study, JCR: Journal of Clinical Rheumatology. August 2013, Volume 19 (5), p 234–240