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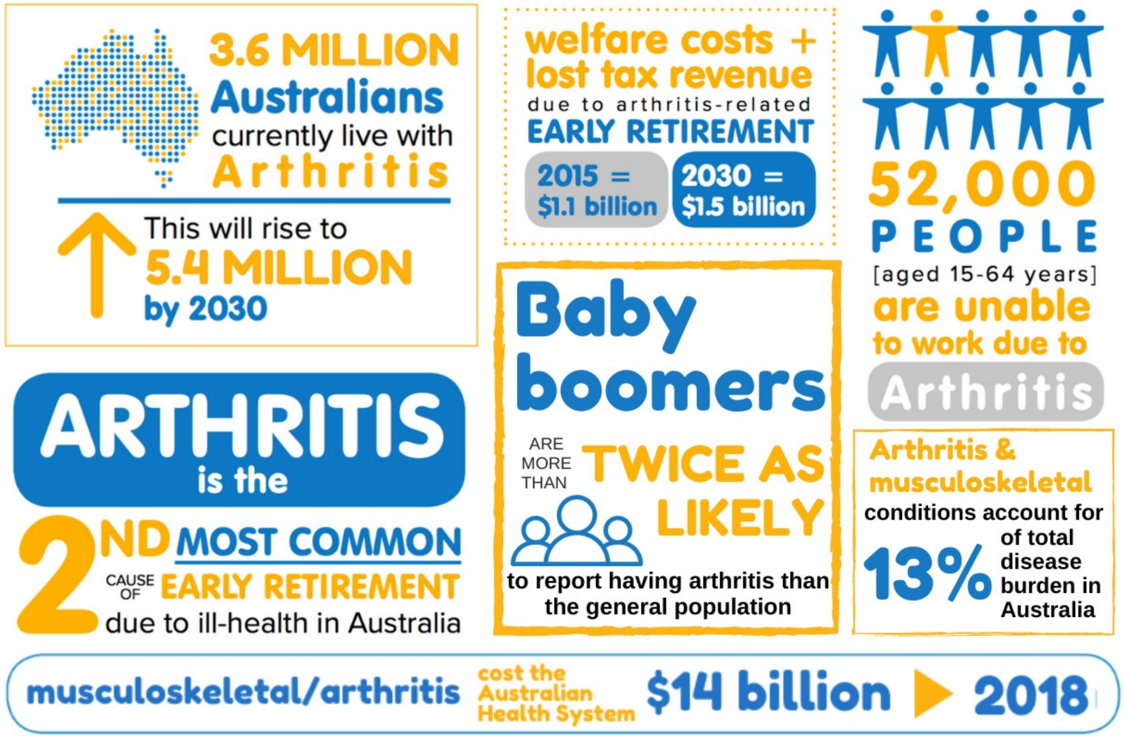
Arthritis Australia 2024 Budget submission

Equitable and affordable support for one of Australia's most common and costly health conditions



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The impact of arthritis and musculoskeletal conditions on the health system and economy

Arthritis and musculoskeletal conditions affect people of all ages, including children and young adults, and are some of the most common, costly and disabling chronic conditions in Australia. This disease group is the third leading cause of burden of disease[1], and a leading cause of disability and early retirement due to ill health, costing $1.1 billion a year in extra welfare payments and lost taxation revenue, as well as $7.2 billion in lost GDP[2].

There are over 100 types of arthritis, ranging from osteoarthritis (affecting 2.2 million or 9.3% of Australians[3]) to severe autoimmune conditions such as rheumatoid arthritis (affecting 456,000 or almost 2% of Australians[4]), and they are some of the most commonly comorbid chronic conditions. The impact of arthritis due to restricted mobility and the side effects of some medicines makes it difficult for people to maintain a healthy weight and can therefore increase the risk and complicate the management of other chronic conditions.

Arthritis and musculoskeletal conditions is the highest cost disease group, costing the health system almost $15 billion in 2020-21[5]. However, reimbursement is skewed towards expensive late stage interventions such as joint replacements, and does not incentivise evidence based care according to guidelines. More than $1.4 billion a year is spent on knee replacements for osteoarthritis[6], but at least $200 million of this cost could be avoided by delivering better management and lifestyle modifications for people at risk of knee replacement[7]. Biologics used for inflammatory arthritis are some of the highest cost medicines on the Pharmaceutical Benefits Scheme, with the potential for research to unlock major savings through improving treatment targeting and down-titration, and new treatment breakthroughs.

There is the opportunity for major cost savings both through reducing low value care and better access to evidence based care and prevention, and by addressing the chronic underinvestment in research to support the work of Australia's world-leading researchers. In 2020-21, arthritis and musculoskeletal conditions ranked 14th in NHMRC funding by Disease, research and health area, and has been trending down from $50.7m in 2018-19 to $43.9m in 2020-21[8]. This is less than a quarter of the funding directed to neurological conditions (representing 8% of the disease burden).

Table 1: Cost, burden and research funding for the four leading causes of disease burden by disease group, plus dementia.

Impact	Cancer	CVD	Arthritis & MSK	Mental health	Dementia
Burden of disease (2023)	17%	12%	13%	15%	4.4%
Health system cost (2020-21) $bn	$11.7	$11.8	$14.7	$9.6	$5.4*
NHMRC funding (2021) $m	$161.5	$104.8	$43.9	$101.1	$55.3
Medical Research Future Fund Missions $m	$135 (brain cancer)	$220	Nil	$125	$185

**NATSEM 2017 Economic cost of dementia in Australia 2016-2056. Includes costs for residential aged care*

Out of pocket healthcare costs

People with arthritis carry a heavy burden of pain and disability that is often trivialised, and face a double financial hit – arthritis is a leading cause of early retirement and loss of work hours and income[9], and consumers face high out of pocket costs from the accumulated costs of care including general practice, specialist and allied health appointments, diagnostics and medicines. These conditions disproportionately affect women, particularly older women who often have low financial assets.

A recent study of younger people living with arthritis in Australia found median per person out of pocket expenditure of $1,635 in just six weeks[10]. Another recent study estimated the total out-of-pocket expenditure on osteoarthritis treatment for Australian women aged 50 years and over to be approximately $873 million annually[11].

The Australian Government's Measuring What Matters framework includes key metrics around the proportion of people delaying or missing out on healthcare due to cost and delays accessing appointments. Arthritis Australia polled Australians living with fibromyalgia (which affects up to 1 million Australians) in late 2023, and found half (50%) of respondents were cutting back on basics – food, toiletries, clothing, school supplies, petrol and power – to pay for critical healthcare including specialist appointments, physiotherapy and medication. Two-thirds (67%) reported they could not afford many of the health appointments and the medications they need. Of these, 83% had stopped using allied health support or were reducing the number of visits; 48% had cut back on seeing their specialist; 37% on GP appointments; and 28% on medications[12].

Funding proposals

In the setting of a cost of living crisis and a severe rheumatology workforce shortage[13], it is more important than ever to provide equitable and affordable access to key health services, upskill health professionals in primary care, and support consumers to self-manage their condition in the community.

The proposals outlined in this submission address key priorities for action that have emerged from consultation with consumers and the sector:

Priority area	Initiatives	Budget impact
1. Equitable access to arthritis information and support including for priority populations	Funding to continue the enhancement and expand the reach of the National Arthritis Infoline service	$180,000 over 1 year
	Funding to create tailored, culturally appropriate programs, in collaboration with Aboriginal and Torres Strait Islander peoples to ensure equitable access to information, health services and support	$900,000 over 2 years
2. Affordable access to allied health and support for behaviour	Provide funding for the national delivery over 2 years of The Joint Movement program, an	$1.7 million over two years

and lifestyle change	evidence-based, evaluated group exercise program designed to improve health outcomes for people with arthritis and musculoskeletal conditions	
	Expand group allied health services under MBS Chronic Disease Management Plan items to people with musculoskeletal conditions	$5.5 million per year
	Increasing the number of allied health services available under existing MBS Chronic Disease Management Plan items to an additional five services per calendar year	In the last financial year, individual allied health services under the CDMP items cost $482 million. If the number of services were expanded, not all patients would go on to claim an additional five sessions per year as this would be dependent on stratification of those with more complex care requirements who would benefit.
3. Upskilling health professionals in best practice arthritis management	Implementing the ATLAS health professional training program	$100,000 over 1 year
4. National leadership to improve outcomes for children with arthritis	Establishing an eight-year program of secure funding to provide fellowships or training programs with the aim of tripling the number of paediatric rheumatology specialists by 2030	$6 million
	Funding positions in the largest states of Australia, and in particular New South Wales, so that several accredited sites are available for training and there is less need to obtain training overseas	To be costed
	Establishment of multidisciplinary centres in major capitals through joint state and federal collaboration A ‘hub and spoke’ model with	To be costed

	outreach clinics in outer metropolitan, rural and regional areas so that equitable care can be provided to all Australian children	
	Ongoing PBS changes to ensure all Australian children with arthritis can access the medicines they need	Low impact
5. Unlocking health system savings by investing in arthritis and musculoskeletal research	The establishment of an MRFF Arthritis and Musculoskeletal Mission as recommended in the National Strategic Action Plan for Arthritis, to increase strategic investment in research and research capacity, building the evidence base to support high-value care	$100m
	Explicit prioritisation of arthritis and musculoskeletal conditions and additional investment of **$50 million in 2024** and per year, under relevant MRFF initiatives, including targeted calls for research in identified consumer priority areas from the MRFF and the NHMRC.	$50m per year

Arthritis Australia also strongly supports the budget proposals of the Australian Rheumatology Association to address the rheumatology workforce crisis, including for the Commonwealth to increase funding of rheumatology training positions in private, rural and remote settings through the Specialist Training Program, and to expand the ‘Other Medical Practitioner’ program to rheumatology registrars.

1. Equitable access to arthritis information and support, including for priority populations

Objective

- To bridge the funding shortfall occasioned by the end of the National Strategic Action Plan for Arthritis implementation grants to:
    - Ensure that consumers continue to have access to the national arthritis Infoline and continue to enhance the quality and reach of the service
    - Ensure that priority populations including Aboriginal and Torres Strait Islanders and Culturally and Linguistically Diverse communities have equitable access to consumer information resources so they are empowered with the knowledge to actively manage their arthritis.

The investment needed:

- Funding to continue the enhancement and expand the reach of the National Arthritis Infoline service - **$180,000 over 1 year**
- Funding to create tailored, culturally appropriate programs, in collaboration with Aboriginal and Torres Strait Islander peoples to ensure equitable access to information, health services and support - **$900,000 over 2 years**

Benefits:

- Connect people with arthritis with a locally operated but nationally consistent and high quality Infoline service, taking pressure off the health system by providing a first port of call for common issues, and connecting people with community services
- Improved self-management of arthritis will contribute to better health outcomes for the most costly disease group in the health system
- Expanded and more equitable access to arthritis information resources for priority populations

Background and rationale

Arthritis Australia and our state and territory affiliate organisations are a key and trusted source of information and support for consumers nationally, and Commonwealth funding for the implementation of the National Strategic Action Plan for Arthritis, which expired at the end of 2023, was critical to the development of new and culturally appropriate resources, as well as the ongoing development and enhancement of the National Arthritis Infoline.

While we understand the refresh of the Chronic Disease Framework will set the policy and funding direction moving forward, this has not yet been completed, leaving a gap.

The National Strategic Action Plan for Arthritis is an evidence based blueprint to improve health and quality of life for people living with arthritis, reduce the cost and prevalence of the condition, and reduce the impact on individuals, their carers and the community. It is the result of extensive consultation with consumers, clinicians and health system stakeholders, including Steering Group representation from key medical and allied health peaks.

Consumer education and information resources was an implementation priority for the Action Plan. These aim to support people to self-manage their arthritis, may include resources and phone advice, are recommended in clinical guidelines for many types of arthritis, and can improve outcomes and reduce use of health services.

However, consumer consultation for the development of the National Strategic Action Plan for Arthritis identified poor access to information and support to self-manage their condition. [14] Priority populations such as Aboriginal and Torres Strait Islanders and Culturally and Linguistically Diverse groups face inequitable access to culturally appropriate and translated resources.

Enhancing and increasing the reach of the national Arthritis Infoline

The National Arthritis Infoline received a record 10,779 calls in 2023, supporting people with arthritis to self-manage their condition, return to work, reconnect with loved ones, and develop healthier eating and exercise habits. It is a free and trusted place for people to turn in moments of crisis, particularly in the current setting of the high cost of living and difficulty accessing primary care. The Infoline links people to a range of other services and resources in their local area to help them manage their condition more effectively, including self-management courses, community education programs, and seminars and support groups.

The Commonwealth provided funding to enhance and promote the Infoline from 2020-2023. This resulted in an enhanced service, including a nationally consistent framework for service delivery, training and continuous improvement. We have been able to achieve an over 50% increase in calls, making a much larger community of people with arthritis aware of the service and able to access it for the first time, as well as rolling out new options such as webchat and peer support which have had significant uptake.

However, the end of this funding will impact our affiliate organisations' ability to maintain the enhancement and promotion of the Infoline in addition to fielding calls. As a result, resources will have to be diverted away from service development and reaching new people who would have benefited from the service.

Bridging funding for Infoline enhancement and promotion would enable initiatives such as:

- Upskilling of operators in supporting priority populations, people in crisis and navigating primary care services including Chronic Disease Management Plans, MyMedicare and Urgent Care Clinics as well as specialist services.
- Ongoing promotion, including strategies to target priority populations such as culturally and linguistically diverse people
- Update key information sheets including tailoring content to people with lower health literacy and translating into community languages
- Rollout of webchat in additional states and territories

Equitable access to arthritis information and support for Aboriginal and Torres Strait Islander peoples

Aboriginal and Torres Strait Islander peoples face higher rates of arthritis and autoimmune conditions. The prevalence of arthritis conditions among Aboriginal and Torres Strait Islander peoples is 17%, compared to 13% among non-Indigenous Australians[15]. They also experience poorer access to healthcare, with Aboriginal and Torres Strait Islander peoples half as likely to access primary care or to receive hip or knee replacement surgery to address osteoarthritis than non-Indigenous Australians[16]. Culturally appropriate information, communication and healthcare delivery are essential to improving health and wellbeing outcomes.

The Staying Moving Staying Strong project, funded by the Commonwealth via an Action Plan grant, developed Australia's first culturally appropriate resources for osteoarthritis, rheumatoid arthritis, lupus and gout for Aboriginal and Torres Strait Islander peoples. The project involved strong engagement with Aboriginal community members and a rigorous review of clinical practice guidelines, resulting in several academic publications[17]. The Staying Moving Staying Strong project team is a national inter-professional team of Aboriginal and non-Aboriginal health practitioners, health service staff, and research leaders, working in partnership with Aboriginal Communities, Arthritis and Osteoporosis Western Australia, and Arthritis Australia.

The Staying Moving Staying Strong project identified the need to further support Aboriginal and Torres Strait Islander peoples living with arthritis in the community via yarning circles (involving psychosocial support, peer to peer learning, and self-management information) delivered in-person and/or online by Aboriginal and Torres Strait Islander peoples in partnership with Aboriginal Community Controlled Organisations, Aboriginal Medical Services, and other arthritis health care providers.

$900,000 investment over a two-year period would produce the following outcomes:

- Development of strong partnerships with Aboriginal Community Controlled Organisations and Aboriginal Medical Services across Australia (specifically, Victoria, Western Australia and Queensland)
- An arthritis e-learning training program (including audio-visual learning material and consumer stories with the potential for in-person training support from the project team at the pilot sites) for Aboriginal and Torres Strait Islander community facilitators, Aboriginal and Torres Strait Islander health professionals and/or non-Indigenous health professionals caring for Aboriginal and Torres Strait Islander people with arthritis.
- Toolkit with resources to implement arthritis community yarning circles in Aboriginal Community Controlled Organisations and Aboriginal Medical Services (including for example, a running sheet, PowerPoint slides, yarning guide, Staying Moving Staying Strong brochures, audio-visual materials).
- Trial and evaluation of arthritis yarning circles in diverse locations (regional/rural/metropolitan, Victoria, Western Australia and Queensland) to produce recommendations for future upscale and sustainability of implementation.

2. Affordable access to allied health and support for behaviour and lifestyle change

Objectives

- Increase access to community arthritis exercise programs to help people with arthritis undertake more physical activity to better manage their condition and to reduce demand for medicines and surgery.
- Increase the affordability of allied health services to support people with arthritis to manage their condition and make behaviour and lifestyle changes.

The investment needed:

- Provide funding for the national delivery over 2 years of The Joint Movement program, an evidence-based, evaluated group exercise program designed to improve health outcomes for people with arthritis and musculoskeletal conditions - **$1.7 million over two years for national delivery and promotion of the program.**
- $5.5 million per year to expand group allied health services under CDMP to people with musculoskeletal conditions
- In the last financial year, 8.5 million individual allied health services were claimed under the CDMP items at a cost of $482 million. If the number of services were expanded, not all patients would go on to claim an additional five sessions per year as this would be dependent on stratification of those with more complex care requirements who would benefit.

Benefits:

- Reduced out of pocket costs to consumers and more affordable access to multidisciplinary care, leading to improved quality of life, delayed disease progression, reduced disability and improved workforce retention for people with severe arthritis
- Potential savings in reduced costs for joint replacements
- Reduced costs to the health, welfare and aged care systems as a result of improved management of arthritis which preserves function and mobility and supports independence.

Fund community based arthritis exercise programs

Exercise is one of the most effective management strategies for arthritis and can also delay or avoid expensive joint replacement surgery.

However only 25% of Australians with arthritis report that they exercise most days and 14% do strength training to manage their condition. On the other hand, 83% report taking medication[18] and arthritis is one of the most common conditions for which opioids are prescribed, despite limited clinical benefit and a high risk of adverse events.[19]

The Joint Movement was developed by Arthritis Australia with the support of leading health and fitness experts. It offers both warm-water and land-based strength exercise programs which are led by trained and accredited exercise professionals. During the covid pandemic, we pivoted to offer online classes, providing consumers with better access and choice.

The Joint Movement was delivered from 2019-2021 in some states and territories with funding from Sport Australia's Better Ageing program. Participants either responded to local advertising or were referred by their GP. However, initial funding expired in 2021 and was restricted to participants aged 65 years or more, which meant that younger people who could have benefited had to be turned away.

This proposal aligns with recommendation 2.2.4 of the *National Strategic Action Plan for Arthritis* as well as the National Preventative Health Strategy's emphasis on encouraging and helping people, include older people, to take part in physical activity.

The Joint Movement evaluation

An evaluation of The Joint Movement Program found statistically significant changes, including a reduction of pain and stiffness and improvements in functional outcomes. Qualitative survey responses indicated that increases in physical activity had positive effects on participants' daily activities and mental and social wellbeing.

The Joint Movement program will be reviewed and updated to incorporate recommendations from the evaluation, including:

- Increase in number of available sessions per week to improve the chance of greater improvements in symptoms, as well as health and wellbeing
- Opening up the program to younger age groups
- Provide opportunities to re-enrol into the program so participants can maintain their progress
- A nationally agreed evaluation plan and data audit

In the words of participants:

> *"[The program] convinced me how much exercises help me mentally and physically everyday"*
>
> *"I have been given some exercises by an Exercise Physiologist but as I found it wasn't as good as our group sessions as the socialising was missing which I found by doing it online with other people"*.
>
> *"It gave me confidence to restart an exercise program as it catered for my current low fitness levels and arthritic knee and shoulder problems"*.

The pivot to offering online classes due to covid was highly beneficial:

> *"I love the fact that I can exercise in the home without having to go out to a gym ... which I would not do"*.
>
> *"As a pensioner, I cannot afford to attend exercise classes and these taught me what I can do to help my arthritis safely during Covid"*
>
> *"I like the fact that I am booked to zoom the class, it makes me do it, as I'm not good at motivating myself for exercise"*

There were some striking examples of the potential of the program to benefit and link to services for consumers with complex needs - in a case study from one provider:

> *We have one particular Torres Strait Islander woman who found our program when it was advertised in the free local press. She could barely move and was very much housebound.*

> *We started working with her, but also assisted her to link up with services such as My Aged Care which then allowed her to get community transport so she could come to classes two times a week. She is now much more independent, has a program of exercise she undertakes every day at home, she has lost 20 kgs, her cardiac health is better than it was, her diabetes no longer needs medication and she has made friends!*

Improve affordable access to allied health through existing MBS chronic disease management items

Proposal

- Expand access to group allied health services to people with musculoskeletal conditions under Chronic Disease Management Plans, to support behaviour and lifestyle change
- Increase the number of individual allied health services available under MBS Chronic Disease Management Plans. Based on an assessment of need and evidence of benefit, people should be able to receive an additional five services per calendar year

"Last financial year I spent over $6,500 on medication alone!!! This doesn't take into account the many doctor visits, physiotherapy, podiatry and specialised exercise programs that I require."

Consumers with arthritis report that they face high out-of-pocket costs for their care, which is mostly undertaken in the private sector. 59% of consumers surveyed by Arthritis Australia cited limited patient access to multidisciplinary care in both the public and the private sector[20]. The cost to patients of accessing allied health professionals was identified as a major barrier to improving arthritis management.

Multidisciplinary team care is consistently recommended in local and international guidelines and standards of care for people with most forms of arthritis, but is not widely available in Australia. There is an over-reliance on medications and surgery for management of arthritis. More than $1.4 billion was spent on knee replacements for osteoarthritis in 2016.[21] At least $200 million of this cost could be avoided by delivering better management and lifestyle modifications for people at risk of requiring a knee replacement.[22]

The cost of accessing private allied health services, which are inadequately covered by Medicare and private health insurance, forms a significant barrier to optimal access to multidisciplinary care.

Only five subsidised individual allied health visits are available to consumers with a chronic condition under Medicare chronic disease management items, and these may be needed for a range of allied health services needed, such as physiotherapy, exercise physiology, dietician, podiatry, Occupational Therapy etc. Typically, a series of allied health visits are required to achieve improvement or behaviour change.

The National Strategic Action Plan for Arthritis recommends that individual allied health services under Chronic Disease Management Plans should be extended along the lines of the psychology model – a review by the GP, who can recommend a further five sessions if needed. Not all patients would receive additional sessions. In 2019, the MBS Review Taskforce's Allied Health Reference

Group recommended increasing the number of allied health appointments under GP Management Plans (GPMPs) and team care arrangements (TCAs) by stratifying patients to identify those with more complex care requirements[23.]

People with type 2 diabetes can access additional Medicare-subsidised care for group allied health treatment services, including diabetes education services, exercise physiology and dietetics. In the last financial year, 66,471 of these services were claimed at a cost of $1.8 million. The expansion of this access to people with arthritis would make such support more affordable and accessible.

3. Upskilling health professionals

Objectives

- Maximise the impact of ATLAS health professional training program to upskill health professionals in best practice management of arthritis

The investment needed:

- ATLAS training program implementation - $100,000 over 1 year

Implementing ATLAS: driving sustainability and scalability of an Australian digital platform to improve arthritis care

The Arthritis Training, Learning and Upskilling (ATLAS) platform is a flexible and accessible digital learning resource for health professionals to improve their competencies in arthritis care. ATLAS was developed by a consortium of organisations over 2022-2024, supported by the Australian Government as a key implementation strategy of the National Strategic Action Plan for Arthritis

Despite the high burden and costs of arthritis, health professionals across disciplines report a lack of confidence in their knowledge and skills of best-practice care. For busy health professionals, clinical education needs to be accessible, flexible, modular and appealing. ATLAS was created as a digital solution that embodies these criteria by a consortium of organisations bringing internationally-regarded expertise in clinical care, research, education and lived experience (including Arthritis and Osteoporosis WA, Curtin University, The University of Sydney and The University of Melbourne), as well as industry partners Go1, Arthritis Australia and the Australian Rheumatology Association.

ATLAS is due for launch in early 2024 and will be available to health professionals and to training organisations to deliver for curriculum and micro-credentialling. Maximising the impact of ATLAS requires a dedicated, post-development phase of work to develop a sustainability and scalability solution. A sustainability model that enables governance, revenue, maintenance and monitoring is critical to the longevity of the platform and its appeal to stakeholders. Similarly, impact potential is directly influenced by the scalability of ATLAS – ensuring health professionals across Australia and internationally and training organisations are made aware of the platform.

A sustainability solution includes:

- the establishment of a governance model between consortium partners, and a not-for-profit revenue creation and distribution mechanism to support maintenance, curation of content and monitoring uptake
- an ongoing communications and dissemination program to ensure the platform is made available to end users.
- Evaluate and update ATLAS at 12 months powered by use analytics.

4. National leadership to improve outcomes for children with juvenile arthritis

Benefits of action

- Earlier diagnosis and treatment of juvenile arthritis can greatly improve outcomes and the odds of remission, reducing pain and disability and saving health system costs.
- Investment in paediatric rheumatology will bring care for Australia's children up to international standards
- Better access to medicines and multidisciplinary care will improve outcomes and reduce out of pocket costs for families.

The investment needed:

For the Commonwealth government to commit to funding and fully implementing the recommendations of the House of Representatives Standing Committee on Health, Aged Care and Sport inquiry into childhood rheumatic diseases, including:

- Funding a national paediatric rheumatology package to ensure Australian children with arthritis can access the care that they need and avoid preventable pain and disability, including urgently establishing an eight-year program of secure funding to provide fellowships or training programs with the aim of tripling the number of paediatric rheumatology specialists by 2030 – **$6 million.**
- Funding positions in the largest states of Australia, and in particular New South Wales, so that several accredited sites are available for training and there is less need to obtain training overseas
- Establishment of multidisciplinary centres in major capitals through joint state and federal collaboration
- A 'hub and spoke' model with outreach clinics in outer metropolitan, rural and regional areas so that equitable care can be provided to all Australian children
- Ongoing PBS changes to ensure all Australian children with arthritis can access the medicines they need without huge out of pocket costs.

Background and rationale

Juvenile arthritis is poorly recognised by the community and by health professionals, but it is as common as juvenile diabetes. Children live with many debilitating symptoms such as severe pain, fatigue, 'brain fog', mental health impacts, and sometimes permanent damage to joints, eyes and other organs. These symptoms affect kids' ability to participate in school, sports and social activities, and they can face a lack of understanding and empathy from teachers and their peers.

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.

At the moment, access to treatment in Australia falls far short of the international standard. There is a severe shortage of paediatric rheumatologists, and access to best practice multidisciplinary care is variable and often costly. Improved access particularly to pain management, psycho-social support, allied health and medicines is needed.

There are still unnecessary barriers to accessing medicines including Disease Modifying Anti-Rheumatic Drugs and biologics. Progress has been made and must continue in improving paediatric access to these medicines via the Pharmaceutical Benefits Scheme to ensure there is equitable and timely access for all children across Australia.

The Parliamentary Inquiry found that access to diagnosis and treatment in Australia falls well below the standard of other countries such as the UK, and called for urgent leadership and funding from the Commonwealth to ensure these children receive the healthcare they need.[24]

The voices of families living with juvenile arthritis

> *"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."*

> *"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 effect."*

> *"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."*

> *"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."*

5. Unlocking health system savings by investing in arthritis and musculoskeletal research

The investment needed:

- A major and sustained funding boost from the MRFF or other government sources to bring investment in arthritis and musculoskeletal research up to the level of other chronic conditions with a similar burden of disease and impact on the health system and economy. This could include:
    - The establishment of an MRFF Arthritis and Musculoskeletal Mission as recommended in the National Strategic Action Plan for Arthritis, to increase strategic investment in research and research capacity, building the evidence base to support high-value care
    - Explicit prioritisation of arthritis and musculoskeletal conditions and additional investment of **$50 million in 2024** and per year, under relevant MRFF initiatives, including Emerging Priorities and Consumer-Driven Research, Preventive and Public Health Research and Primary Health Care Research initiatives, Clinical Trials Activity, Clinician Researchers, and Early to Mid-Career Researchers initiative.
    - Targeted calls for research in the identified consumer priority areas below from the MRFF and the NHMRC.

Background and rationale

Despite Australia having many of the world's top researchers in the field of arthritis and musculoskeletal conditions, research funding is disproportionately low relative to the disease burden and cost of these conditions. A recent analysis found that the current trend of MRFF distribution suggests targeted, disease-based funding provided through the MRFF tends to go to disease groups with a high death burden and does not target disability burden.[25]

Consumers are calling for a fair share of research funding for arthritis research that responds to their needs and priorities. They want to be more involved in arthritis research – over 90% of our survey respondents said they would be willing to assist in research and its design. Research Australia was commissioned to undertake a detailed review of Australia's arthritis research landscape. Priority areas were identified through dialogues and input with over 100 consumers living with osteoarthritis, rheumatoid arthritis, and juvenile idiopathic arthritis, as well as a research gap analysis. Consumer priority areas were:

- Better Care: coordinated and bundled care with a focus on allied health.
- Basic Research: causes of arthritis, identification of symptoms, prevention.
- Priority Populations
- Cross Cutting Research: research activity whose outputs are potentially applicable across multiple types of arthritis or musculoskeletal conditions

The cost of underinvestment in arthritis research

Ongoing low levels of research funding have severely undermined research capacity for arthritis and musculoskeletal conditions, with serious implications for future research and for sustaining clinical excellence. It also undermines our ability to identify and implement better treatment and management strategies to reduce the personal, social, and economic burden of these conditions.

With the right research infrastructure support, our top researchers can train a greater critical mass that will keep Australia at the forefront of arthritis and musculoskeletal research and better care.

The opportunity

Investing in research into the most effective and affordable strategies to deal with these conditions has the potential to save the health system many hundreds of millions of dollars a year. For example, Australian researchers are currently leading early detection and intervention research for people at high risk for rheumatoid arthritis, the most common form of inflammatory arthritis. Early detection, lifestyle interventions and immunotherapy may lead to a cure[26].

Some areas of expenditure where research could achieve substantial cost savings include:

- **More than $1.4 billion** a year is spent on knee replacements for osteoarthritis.[27] At least **$200 million** of this cost could be avoided by delivering better management and lifestyle modifications for people at risk of knee replacement.[28]
- **$540 million** a year spent on biological drugs for rheumatoid and other inflammatory forms of arthritis[29], which could be spent more effectively with research to improve drug targeting (personalised medicine).
- ***$220 million*** a year on imaging for low back pain,[30] which may be mostly unnecessary[31] and which could be addressed by a modest investment in research into better models of care.

About Arthritis Australia

Arthritis Australia is the peak national arthritis consumer 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 and related musculoskeletal conditions, 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 these conditions.

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