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Arthritis Australia

2023 Budget submission

Better consumer centred care for one of Australia's most common and costly health conditions

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Better consumer centred care for one of Australia's most common and costly health conditions

Arthritis and musculoskeletal conditions affect people of all ages, including children and young adults, and are the most common, costly and disabling chronic conditions in Australia. There are over 100 types of arthritis, ranging from osteoarthritis to severe autoimmune conditions, and arthritis and musculoskeletal conditions cost the health system an estimated $14 billion in 2019-20 – much of which could be avoided with better access to evidence based care and prevention and a more equitable investment in research that addresses consumer priorities.

In 2021, NHMRC funding for research in arthritis and musculoskeletal conditions, which at 13% represents one of the largest burden of disease groups, was less than half of what went to disease groups with a similar burden of disease such as cardiovascular disease and mental illness (see Table 1 below).

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, 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.

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.

Arthritis, as one of our most common and costly conditions, could be an exemplar for how implementing better preventative management in the community and investing in consumer driven research can lead to better outcomes for consumers and cost savings for the health system and broader economy.

Key priorities for action

Arthritis Australia has consulted consumers and a multidisciplinary group of experts, as well as our network of community based affiliates across Australia, to identify the top three priorities for implementation of the Action Plan moving forward:

- Addressing the disproportionately low investment in consumer driven arthritis research to improve outcomes for children and adults with arthritis and unlock health system cost savings
- Providing support for people with arthritis to undertake physical activity and exercise safely to improve their condition
- More affordable access to evidence based, multidisciplinary care

Funding proposals

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

- Investment in consumer driven arthritis and musculoskeletal research to improve outcomes for children and adults with arthritis and unlock major health system cost savings
- 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
- Fund an evaluated national arthritis exercise program
- Expand access to group allied health services to people with arthritis under existing Chronic Disease Management Plan items
- Fund community-based arthritis educators to deliver much-needed information and support for children and adults with arthritis

Investing in consumer driven 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 $25 million in 2023 and per year until the disparity has been addressed, 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.
- Funding for Arthritis Australia to develop and pilot a national model for consumer engagement in arthritis research, to support and connect consumers and researchers

Background and rationale

Research funding for arthritis and musculoskeletal conditions in Australia is 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 and 24% of the non-fatal burden, incur the highest health system spending’, and are a leading cause of disability, chronic pain and early retirement due to ill-health in Australia. 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.[1]

Australia has many of the world’s top researchers in the field of arthritis, yet arthritis research has been chronically underfunded. For every person living with arthritis or a musculoskeletal condition, the government spent less than $3 on research through the NHMRC in 2021. This compares to $147 per person living with dementia, and $85 per person with a cardiovascular condition.

Consumers are calling for funding of 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. But currently there is no national program to train and support consumers and consumer organisations, and their input is expected to be free, with no grant budget line item required. Arthritis researchers would benefit from a national approach to arthritis consumer involvement in research.

As the only arthritis advocacy group to represent all forms of arthritis, Arthritis Australia intends to build on its convening role by bringing partnerships together to invest in research driven by consumer priorities and with meaningful consumer codesign at every stage. 72% of researchers surveyed by Research Australia had, at one point, received funding for their research through Arthritis Australia’s National Research Program[2].

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 (2018)	18%	13%	13%	13%	2.9%
Health system cost (2018-19) $bn	$11.7	$11.8	$13.9	$9.6	$5.4*
NHMRC funding (2021) $m	$153.7	$102.5	$41.7	$102.3	$55.3
Medical Research Future Fund Missions $m	$135 (brain cancer)	$220	Nil	$125	$185

NHMRC funding statistics/website accessed 10 November 2022

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

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.

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. 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.[3] At least **$200 million** of this cost could be avoided by delivering better management and lifestyle modifications for people at risk of knee replacement.[4]
- **$540 million** a year spent on biological drugs for rheumatoid and other inflammatory forms of arthritis, which could be spent more effectively with research to improve drug targeting (personalised medicine).
- ***$220 million*** a year on imaging for low back pain,[5] which may be mostly unnecessary[6] and which could be addressed by a modest investment in research into better models of care.

A new consumer driven agenda for arthritis research

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 driven priority areas for research investment:

- 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

A model for consumer engagement in arthritis research

Arthritis Australia is ideally placed to be a 'connector' for arthritis researchers and people living with arthritis, leveraging our online platforms and consumer databases to enable researchers to match with consumers willing to participate in their work, and outlining research opportunities for people with arthritis to assist in designing and/or participating in.

A pilot program would build consumer co-design into our National Research Program, build on work conducted to date to better understand what research to fund, and to more clearly articulate how consumers should be involved in decisions about the design, conduct and dissemination of research projects. It would include training for researchers on how to meaningfully engage and collaborate with consumers, as well as training for consumers on how to participate in the research process and meaningfully share their lived experience of and expertise in arthritis.

Cost

$200 million over 10 years for an MRFF Mission

$25 million in 2023 for targeted calls for research on arthritis and musculoskeletal conditions

$0.5 million to develop and pilot a national model for consumer engagement in arthritis research

National leadership to improve outcomes for children with severe arthritis

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
- 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. There must be a review of 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.[7]

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 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."

"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 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."

Fund community based arthritis exercise programs

Objective

Increase access to community arthritis-appropriate exercise programs to help people with arthritis undertake more physical activity to better manage their condition and to reduce demand for medicines and surgery.

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.

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 people under 65 who could have benefited had to be turned away, and were often not comfortable seeking an alternative such as attending a gym.

This proposal aligns with recommendation 2.2.4 of the *National Strategic Action Plan for Arthritis* which includes providing funding for people with arthritis to access arthritis-appropriate evidence-informed exercise programs.

This proposal also aligns with the National Preventative Health Strategy's emphasis on encouraging and helping people, include older people, to take part in physical activity.

Background and rationale

Benefits of physical activity and exercise

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[8] 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.[9]

A landmark study found that two-thirds of patients with moderate to severe knee osteoarthritis eligible for joint replacement surgery delayed surgery for at least 2 years following appropriate non-surgical treatment, comprising patient education, exercise therapy and weight control .[18]

Hip and knee replacements for osteoarthritis cost the health system around $2.3 billion in 2012/13[10] and this cost is projected to rise to $5.3 billion by 2030.[11] Widely implementing non-surgical management strategies for osteoarthritis has been estimated to save more than $200 million a year in reduced knee replacements alone. [12]

In the wake of the impact of covid and lockdowns on mental health and wellbeing, it is more important than ever to support community activities that contribute to health and social wellbeing.

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. 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"*.
>
> *"I was aware of being stronger while cooking, gardening and lifting"*
>
> *"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"*
>
> *"I was motivated to do the program as it was so easy to log in and join the class. I never missed a session and enjoyed it immensely"*

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!*

The Joint Movement program guidelines will be reviewed and updated to incorporate learnings from the evaluation.

A randomised control trial of a similar program in Canada showed significant improvements in self-reported pain, physical function, and fear of movement in the training group compared to the control group.[13]

Cost

$1.7 million over two years for national delivery and promotion of the program.

Access to group allied health services for people with arthritis through existing MBS chronic disease management items

The investment needed:

- Expand access to group allied health services to people with arthritis under GP Chronic Disease Management Plans

Background and rationale

> *"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."*

Arthritis is one of the most common comorbid conditions. Three out of four people with arthritis have at least one other chronic condition, and arthritis increases the risk of developing other chronic conditions. 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.[14] 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.[15]

Currently, as part of General Practitioner Management Plans (GPMP), people with chronic disease can access only five MBS subsidised individual allied health services per year, which unfortunately often falls far short of the support that is required to support behaviour change leading to more physical activity and weight management, which can reduce pain and disability, and may reduce the need for expensive joint replacement surgery. However, 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, 58,000 of these services were claimed at a cost of $1.6 million. The expansion of this access to people with arthritis would make such support more affordable and accessible.

Consumers in Arthritis Australia's 2018 survey reported that they faced high out-of-pocket costs for their care, which was mostly undertaken in the private sector. In particular, people reported extremely high cumulative costs associated with private specialist visits, imaging, allied health professional services (especially for exercise therapy), medicines and surgery. The high cost of accessing care was the most commonly cited concern among survey respondents, mentioned by one in three people. Given arthritis and musculoskeletal conditions are a leading cause of early retirement and loss of work hours, consumers face a double financial hit.

A major concern raised by those consulted (59%) was limited patient access to multidisciplinary care in both the public and the private sector. The cost to patients of accessing allied health professionals was identified as a major barrier to improving arthritis management. Typically, a series of allied health visits are required to achieve improvement or behaviour change.

Benefits:

- Reduced out of pocket costs to consumers and better 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.

Cost

$5.8 million per year to expand group allied health services under GPMP to people with arthritis.

Fund arthritis educators to provide community based support

Objective

Improve health outcomes for children and adults with arthritis by improving access to community-based information, education and support.

The investment needed:

Fund a proof of concept trial of arthritis educators linked to arthritis organisations around Australia to increase the capacity of these organisations to deliver information, education and support for children and adults with arthritis.

Educators would be health promotion or community educators with appropriate skills to educate and motivate behaviour change. Roles would include:

- Provide tailored information, education and support to children and adults living with arthritis to assist them to understand their condition and its management.
- Assist people to navigate the health system to access appropriate services and supports, potentially avoiding unnecessarily presenting to emergency departments.
- Refer people to appropriate exercise programs and other community based supports (eg peer support groups) to help them to self-manage and cope with their condition.
- Undertake group-based patient education and support sessions for people who are newly diagnosed, on referral from local health professionals.
- Deliver education sessions in underserviced areas eg rural and regional areas.
- Liaise with and educate health professionals.
- Provide a nurse support line for children and adults with arthritis.

An evaluation to assess the benefits and cost-effectiveness of the service would also be completed.

Background and rationale

Access to information, education and support from health professionals and other sources is important to equip people with chronic conditions such as arthritis with the knowledge and skills to self-manage their condition and to participate in decisions about their care. It is also an important contributor to psychological wellbeing and an individual's ability to cope with their condition.

However, access to information and support within the health system for adults and children with arthritis is limited:

- People with arthritis commonly report that they are advised to 'put up with' their condition and offered few options for their treatment.[16] [17] [18] Lack of information and advice from GPs is a major concern.[19] In particular, people are rarely advised to exercise or lose weight for osteoarthritis, even though these strategies are recommended in all clinical guidelines, have been shown to be as effective as non-steroidal anti-inflammatory medicines and can avoid or delay joint replacement surgery. [20]
- A recent survey found that only half of people receiving care for their arthritis were satisfied with the information and support they received for their condition and only 30% were satisfied with the support they received for their emotional and mental wellbeing.[21]

- Two out of three people with arthritis report that they are faring badly with their condition. People who report poor access to information and support from health care professionals are two to three times more likely to report that they are faring badly with their arthritis. [22]

This proposal aligns with recommendation 1.3.1 of the *National Strategic Action Plan for Arthritis* which is 'Fund arthritis educators to provide education and support to children and adults with arthritis.' Consultations during the development of the Action Plan highlighted this action as one of the top priorities for consumers.

Benefits

Funding community-based arthritis educators to provide education and support for people with arthritis will help to fill current gaps in the provision of care and support within the health system, leading to improved health outcomes and quality of life.

Access to appropriately qualified educators is associated with better health outcomes, higher patient satisfaction, improved patient knowledge of their condition and better support for patients' emotional wellbeing. [23] [24]

Access to educators will also help to increase referral to evidence-based non-surgical management strategies, such as exercise and weight loss. These non-surgical strategies have been shown to improve symptoms in people with osteoarthritis by one third and to substantially reduce demand for expensive joint replacement surgery.[25] [26]

Cost

$2.3 million over two years for a proof-of-concept trial and evaluation.

This would cover eight full-time-equivalent health educators across Australia over two years, promotion of the service and an evaluation of the benefits and cost-effectiveness of the service.

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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