

Arthritis Foundation of Australia Level 2, 255 Broadway, Glebe NSW 2037 PO Box 550, Broadway NSW 2007 p: +61 2 9518 4441 f: +61 2 9518 4011 e: info@arthritisaustralia.com.au w: www.arthritisaustralia.com.au

Arthritis Australia 2020 Pre-budget submission

# Improving health outcomes for children and adults with arthritis

For further information on this submission contact:

Franca Marine: Telephone 02 9518 4441 or email: fmarine@arthritisaustralia.com.au

#### About Arthritis Australia

Arthritis Australia is the peak national arthritis consumer organisation in Australia and is supported by affiliate offices 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.

# ARTHRITIS IS ONE OF THE MOST COMMON, COSTLY AND DISABLING CHRONIC CONDITIONS



BURDEN

Proportion (%) of total and non-fatal burden by disease group, Australia 2015





Proportion of all disability by main disabling condition, Australia 2009

WORKFORCE IMPACT



Main chronic conditions of people aged 45-64 years not in the labour force due to ill health, 2010

### Improving support for children and adults with arthritis

#### **Key messages**

- There is a major mismatch between the high burden and cost of arthritis and its low prioritisation in policy and resourcing.
- Arthritis tends to be poorly managed in Australia.<sup>1</sup> Much money is spent on inappropriate, unnecessary, ineffective, or potentially harmful care, at great expense to both governments and individuals, while proven, effective care strategies go unfunded.
- Policies and programs to prevent arthritis and improve its management are urgently needed to deliver better-value care, improved outcomes and increased health related quality of life. The *National Strategic Action Plan for Arthritis* (the Action Plan), prepared by Arthritis Australia for the Department of Health and launched in March 2019, outlines what needs to be done.
- Many of the actions outlined in the Action Plan are likely to be not only cost-effective, but costsaving.

#### **Key statistics**

- Arthritis and musculoskeletal (AMSK) conditions are the most common, costly and disabling chronic conditions in Australia.
- There are more than 100 different forms of arthritis affecting nearly four million Australians of all ages, including children.
- AMSK conditions are the most expensive disease group in Australia, costing the health system around \$12.5 billion in 2015-16. Arthritis alone accounts for around three-quarters of this expenditure, or around \$9.4 billion.<sup>2</sup>
- AMSK conditions are also the third leading cause of total disease burden, accounting for 13% of the total Australian burden of disease, and are the leading cause of non-fatal burden. Arthritis alone accounts for around 9% of the total burden.<sup>3</sup>
- The most common form of arthritis is osteoarthritis, affecting 2.2 million people, followed by rheumatoid arthritis, an inflammatory, auto-immune condition affecting 456,000 people.<sup>4</sup>
- AMSK conditions are the leading cause of disability<sup>5</sup> and early retirement due to ill health, costing an estimated \$18 billion in lost GDP in 2020.<sup>6</sup>
- Two out of three people with arthritis are faring badly with their condition; those who report poor access to information and support are more likely to report that they are faring badly.<sup>7</sup>

#### **Funding proposals**

The proposals outlined in the submission address priority actions from the *National Strategic Action Plan for Arthritis* prepared by Arthritis Australia for the Department of Health and launched in March 2019.

- 1. Fund community-based arthritis educators to deliver much-needed information and support for children and adults with arthritis: *\$4.5 million over four years*.
- 2. Run awareness campaigns to improve public understanding of arthritis and its management and to direct people to reputable information and support services: *\$1.2 million over four years.*
- 3. Develop new information and resources for people with arthritis: \$1 million over 4 years.
- 4. Provide targeted new funding for research into arthritis and musculoskeletal conditions: **\$40** *million over four years.*

# 1) Fund arthritis educators

#### Objective

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

#### Alignment with the National Strategic Action Plan for Arthritis

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.

#### **Proposal**

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 appropriately-skilled specialist nurses, allied health professionals or pharmacists. 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.
- 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**

#### Issue

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 report that they are advised to 'put up with' their condition and offered few options for their treatment.<sup>8 9 10</sup> Lack of information and advice from GPs is a major concern.<sup>11</sup> 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. <sup>12</sup>

- 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.<sup>13</sup>
- 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.<sup>14</sup>

#### **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. <sup>15 16</sup>

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.<sup>17 18</sup> A recent landmark study found that two out of three patients with moderate to severe knee osteoarthritis eligible for joint replacement surgery delayed surgery for at least 2 years following appropriate non-surgical treatment.<sup>18</sup> Widely implementing these strategies has been estimated to save more than \$170 million a year in reduced knee replacements alone.<sup>19</sup>

#### Cost

#### \$4.5 million over four years for a proof-of-concept trial and evaluation.

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

# 2) Fund arthritis awareness campaigns

#### Objective

Improve public awareness and understanding of arthritis and of how it can be prevented and managed.

#### Proposal

Undertake targeted campaigns to raise awareness of the different types of arthritis and how best to prevent and manage them, and to direct people to reputable information and support services.

#### Alignment with National Strategic Action Plan for Arthritis

This proposal aligns with recommendation 1.1.1 of the Action Plan which is 'Develop and deliver education and awareness campaigns tailored to different target audiences, to address identified community knowledge gaps.

#### **Background and rationale**

#### Issue

Although arthritis is very common, it is not well understood. Community misconceptions persist that arthritis is a single condition that only affects old people and that it is an inevitable part of ageing about which nothing can be done. These misconceptions create a sense of futility among consumers, carers and health professionals which can undermine prevention, early diagnosis and effective management.<sup>20</sup>

In addition, confusion and limited awareness of the many different forms of arthritis is common. Limited awareness of rheumatoid arthritis, its potential severity and the importance of early treatment, has been identified as a major impediment to seeking early medical attention.<sup>21</sup> This is a particular concern because early diagnosis and treatment are critical to optimise long term outcomes for people with rheumatoid arthritis. The same is true for juvenile and other inflammatory forms of arthritis.

Awareness-raising campaigns would aim to improve community knowledge of the following:

- The benefits of physical activity, smoking cessation, exercise and healthy weight for managing arthritis symptoms and delaying disease progression.
- The importance of prompt diagnosis and treatment for inflammatory forms of arthritis such as rheumatoid arthritis.
- Arthritis risk factors and prevention including obesity, physical inactivity, smoking and joint injuries.

#### Benefits

Awareness campaigns will help to dispel common myths about arthritis to support prevention, early diagnosis and treatment, and effective self-management of arthritis. This is expected to reduce demand for joint replacement surgery (for osteoarthritis) and for medications such as opioids, while improving health outcomes for people with arthritis.

#### Cost

\$1.2 million over four years.

# 3) Develop new information resources for people with arthritis

#### Objective

Increase available consumer information, tools and resources to address identified gaps and unmet needs for people with arthritis, to assist them to better manage their condition.

#### Proposal

Funding is sought to support the development of the following range of new and expanded resources to address identified gaps and unmet needs:

- Arthritis information resources for Aboriginal and Torres Strait Islander peoples, as there are no culturally appropriate resources currently available.
- A website to provide tailored information and support for people with psoriatic arthritis. This innovative website will provide tailored information, tools and support for people living with this condition that is responsive to their needs, age and stage of life.
- A suite of exercise resources suitable for people with arthritis. Although exercise is one of the most effective treatments for arthritis, many people with the condition are afraid to exercise because of fears that exercise will make their condition worse, or lack of knowledge about what exercises are appropriate.
- An expanded arthritis pain management resource. Arthritis is the leading cause of chronic non-cancer pain in Australia. This resource will provide practical tips and advice to assist people to manage their pain, reducing reliance on medications such as opioids.
- **An expanded information resource on fibromyalgia**. Fibromyalgia is estimated to affect 2-5% of the population, predominantly young to middle-aged women.

#### **Alignment with National Strategic Action Plan for Arthritis**

This proposal aligns with recommendation 1.3.3 of the Action Plan: 'Develop and disseminate new consumer information, tools and resources to address identified gaps and unmet needs.'

#### **Background and rationale**

Arthritis Australia has an extensive range of quality, evidence-based information, education and support tools and resources for people with arthritis in a range of formats. Providing information and support to people with arthritis is essential to help them to learn to manage their conditions and continue to live as normal a life as possible. This includes their ability to continue to work or study, their emotional wellbeing, their social inclusion and their capacity to live independently.

However, there are more than 100 different types of arthritis affecting people of all ages and people's information and support needs vary depending on the type of arthritis they have, their age and life stage, their comorbidities, and the severity and duration of their condition. In addition, there is a need to constantly adapt the format and delivery of resources to better suit target audiences and changing modes of information delivery (eg digital).

#### **Benefits**

These resources will assist people in the target populations to better manage their condition, supporting improved health outcomes.

#### Cost

\$1 million over four years.

# 4) Invest in targeted research for arthritis and musculoskeletal conditions

#### Objective

Escalate research into arthritis and musculoskeletal conditions to strengthen the knowledge base, develop new treatments and provide evidence to support best-practice, high-value prevention, care and support for people living with these conditions.

#### **Proposal**

Invest in targeted research funding for arthritis and musculoskeletal research to build research capacity in the field.

#### **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 (see Table 1). These conditions are the most expensive group of conditions in the health system, costing \$12.5 billion in 2015-16. They are also the third leading cause of disease burden accounting for 13% of the total disease burden<sup>3</sup> and the leading cause of disability,<sup>22</sup> chronic pain<sup>23</sup> and early retirement due to ill-health in Australia.<sup>24</sup>

However, NHMRC funding for research in the field totalled only \$16.4 million in 2018 and has dropped by a third over the last five years. In addition, there has been no specific allocation of research funding from the Medical Research Future Fund to arthritis and musculoskeletal conditions.

Impact	Cancer	CVD	Arthritis and MSK	Mental health	Dementia	Type 2 Diabetes
Burden of disease (2015)	18%	14%	13%	12%	3.8%	3.8%
Health system cost (2015-16) \$bn	\$8.4	\$10.4	\$12.5	\$8.9	\$5.4*	\$2.4
NHMRC funding (2018) \$m	\$177.3	\$96.6	\$16.4	\$71.4	\$61.2 +\$200m/ 5 years	\$49.3
Medical Research Future Fund missions	\$55m (brain cancer)	\$220m	\$0	\$125m	\$185m	\$54.5m (Type 1 diabetes)

#### Table 1: Cost, burden and research funding for the four leading causes of disease burden, Australia, by disease group, plus dementia and diabetes (green).

Source: AIHW Burden of Disease Study, AIHW Health Expenditure by Disease

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

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:

- \$1.4 billion a year is spent on knee replacements for osteoarthritis.<sup>25</sup> At least \$170 million of this cost could be avoided by delivering better management and lifestyle modifications for people at risk of knee replacement.<sup>26</sup> In addition 20-40% of people who have this surgery achieve little clinical benefit<sup>27</sup> for reasons which are unclear. Research into better patient selection for surgery and the delivery of more effective models of care for osteoarthritis would achieve improved outcomes at much lower cost.
- **\$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). A major project, the Australian Arthritis and Autoimmune Biobanking Collaborative, is being established with philanthropic support to provide the infrastructure, biospecimens, data linkage and big data analysis capacity to support research in this area.
- **\$150 million** a year on opioid scripts for musculoskeletal conditions, with the associated costs of adverse events such as addiction and death, which could be reduced by research into the delivery of more effective pain management strategies.
- **\$220 million** a year on imaging for low back pain,<sup>28</sup> which may be mostly unnecessary<sup>29</sup> and which could be addressed by a modest investment in research into better models of care.

#### Cost

\$40 million over four years.

#### References

<sup>1</sup> Runciman WB et al 2012. CareTrack: assessing the appropriateness of health care delivery in Australia. Med J Aust 2012: 197 (2): 100-105.

<sup>2</sup> Australian Institute of Health and Welfare 2019. Disease expenditure by burden of disease groups, 2015-16 <u>https://www.aihw.gov.au/reports/health-welfare-expenditure/disease-expenditure-</u> australia/contents/australian-burden-of-disease-conditions. Cited 17/12/2019

<sup>3</sup> Australian Institute of Health and Welfare 2019. Australian Burden of Disease Study: impact and causes of illness and death in Australia 2015. Australian Burden of Disease series no. 19. Cat. no. BOD 22. Canberra: AIHW

<sup>4</sup> ABS 2018 National Health Survey: First Results 2017-18 - Australia

<sup>5</sup> ABS 2009. *Disability, Ageing and Carers, Australia: Summary of Findings, 2009* 

<sup>6</sup> Schofield DJ et al 2015. Lost productive life years caused by chronic conditions in Australians aged 45-64 years, 2010-2030. *Med J Aust* 203 (6) pp 260.e1-6

<sup>7</sup> Arthritis Australia, 2011. *The Ignored Majority: The Voice of Arthritis 2011* 

<sup>8</sup> Ackerman IN, Livingston JA, Osborne RH. (2016) Personal Perspectives on Enablers and Barriers to Accessing Care for Hip and Knee Osteoarthritis. Physical Therapy. 96(1):26-36.

<sup>9</sup> Nolan G, Koutsimanis H, Page C, Briggs A, Harris B 2016, Consumer feedback on the current and future management of hip and/or knee osteoarthritis in Victoria, MOVE muscle, bone & joint health, Melbourne. MOVE muscle, bone & joint health

<sup>10</sup> Arthritis Australia, 2011. *The Ignored Majority: The Voice of Arthritis 2011* 

<sup>11</sup> Nolan G, Koutsimanis H, Page C, Briggs A, Harris B 2016, Consumer feedback on the current and future management of hip and/or knee osteoarthritis in Victoria, MOVE muscle, bone & joint health, Melbourne. MOVE muscle, bone & joint health

<sup>12</sup> Skou, S.T., et al., Total knee replacement and non-surgical treatment of knee osteoarthritis: 2-year outcome from two parallel randomized controlled trials. Osteoarthritis Cartilage, 2018. 26(9): p. 1170-1180.

<sup>13</sup> Australian Healthcare and Hospitals Association 2017. *Rheumatology nursing: Adding value to arthritis care*. Arthritis Australia 2017

<sup>14</sup> Arthritis Australia, 2011. The Ignored Majority: The Voice of Arthritis 2011

<sup>15</sup> Australian Health and Hospitals Association 2017. *Rheumatology nursing: Adding value to arthritis care*. Arthritis Australia 2017.

<sup>16</sup> van Eijk-Hustings, Y, van Tubergen, A, Boström, C, Braychenko, E, Buss B, Felix, J & EULAR,

2012, 'EULAR recommendations for the role of the nurse in the management of chronic

inflammatory arthritis', Annals of the Rheumatic Diseases, vol. 71, no. 1, pp. 13–19.

<sup>17</sup> Skou, S.T. and E.M. Roos, *Good Life with osteoArthritis in Denmark (GLA:D): evidence-based education and supervised neuromuscular exercise delivered by certified physiotherapists nationwide.* BMC Musculoskelet Disord, 2017. **18**(1): p. 72.

<sup>18</sup> Skou, S.T., et al., Total knee replacement and non-surgical treatment of knee osteoarthritis: 2-year outcome from two parallel randomized controlled trials. Osteoarthritis Cartilage, 2018. 26(9): p. 1170-1180.

<sup>19</sup> Ackerman IN et al 2016. *Counting the Cost: The current and future burden of arthritis. Part 1 Healthcare costs.* 

<sup>20</sup> Egerton T, Diamond L, Buchbinder R et al 2017. A systematic review and evidence synthesis of qualitative studies to identify primary care clinicians' barriers and enablers to the management of osteoarthritis. *Osteoarthritis and Cartilage* 2017 May;25(5):625-638

<sup>21</sup> Stack RJ, Shaw K, Mallen C, Herron-Marx S, Horne R, Raza K, 2012. Delays in help seeking

<sup>22</sup> ABS 2009. *Disability, Ageing and Carers, Australia: Summary of Findings, 2009* 

<sup>23</sup> Henderson JV, Harrison CM, Britt Hc, Bayram CF, Miller GC. Prevalence, causes, severity, impact and management of chronic pain in Australian general practice patients. *Pain Med* 2013 Sep; 14(9): 1346-61

<sup>24</sup> Schofield DJ et al 2015. Lost productive life years caused by chronic conditions in Australians aged 45-64 years, 2010-2030. *MJA* 203 (6) 21 September 2015

<sup>25</sup> The Australian Commission on Safety and Quality in Health Care. *Prioritised list clinical domains for clinical quality registry development*: Final report. Sydney: ACSQHC; 2016

<sup>29</sup> Downie Aron, Williams Christopher M, Henschke Nicholas, Hancock Mark J, Ostelo Raymond W J G, de Vet Henrica C W et al. Red flags to screen for malignancy and fracture in patients with low back pain: systematic review BMJ 2013; 347 :f7095

<sup>&</sup>lt;sup>26</sup> Ackerman IN et al 2016. *Counting the Cost: The current and future burden of arthritis. Part 1 Healthcare costs.* 

<sup>&</sup>lt;sup>27</sup> Choong PF and Dowsey MM 2014. The grand challenge – managing end-staged joint osteoarthritis. *Frontiers in surgery*. doi: 10.3389/fsurg.2014.00009

<sup>&</sup>lt;sup>28</sup> NSW Agency for Clinical Innovation. Management of people with acute low back pain: model of care. Chatswood; NSW Health; 2016. 39 p