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## 2018 Pre-budget submission

# Arthritis: Providing better care at less cost

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## **About Arthritis Australia**

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

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

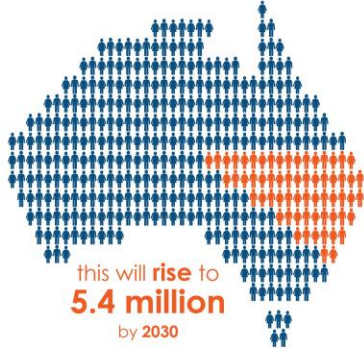
## Arthritis: Providing better care at less cost

### Key messages

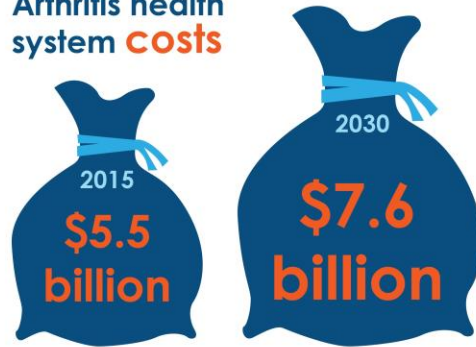
- Much can be done to prevent and provide better care at less cost for people with arthritis.
- Arthritis is one of the most common, costly and disabling chronic conditions in Australia.
- There are more than 100 different forms of arthritis affecting nearly four million Australians of all ages at a cost to the health system of at least \$5.5 billion a year.<sup>1</sup>
- Arthritis is also the second most common cause of disability<sup>2</sup> 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.<sup>3</sup>
- Arthritis and musculoskeletal conditions account for 12% of the total Australian disease burden, equal to mental health conditions. Arthritis alone accounts for 8% of the total burden.<sup>4</sup>
- Arthritis tends to be poorly managed in Australia.<sup>5</sup> Much money is spent on inappropriate, unnecessary and ineffective care, at great expense to both governments and individuals, while proven, effective care strategies go unfunded.
- For example, more than **\$100 million** a year is spent on knee arthroscopies for osteoarthritis, including around \$10 million in Medicare rebates alone<sup>6</sup> despite the fact that strong evidence shows the procedure is of limited value for this condition and may cause harm.<sup>7 8</sup>
- We propose that the Federal Government remove the Medicare rebate for arthroscopies for osteoarthritis and **re-allocate the \$10 million annual saving** to the proposals outlined in this submission to support better care for people with arthritis.
- The proposals outlined in this submission represent key priorities drawn from the [Time to Move: Arthritis](#) strategy and align with key actions identified at a recent roundtable discussion to inform the development of a National Arthritis Action Plan, as directed by the Minister for Health, the Hon Greg Hunt.
- These proposals represent a modest investment which offers the potential to **unlock savings of hundreds of millions of dollars a year in reduced health and welfare costs** and generate major economic benefits through **increased productivity**.
  - \$1.8 million over three years to develop new information resources and tools to help people with arthritis to better manage their condition.
  - \$8.4 million over two years to roll out a national program to support better management of osteoarthritis in primary care, based on a model of care developed and tested by the Agency for Clinical Innovation in NSW. This program has the potential to save \$170 million a year in reduced knee joint replacement surgeries.
  - \$1.2 million over two years to provide scholarships to upskill nurses in rheumatology and to undertake a proof-of-concept study to provide rheumatology nursing services attached to a Primary Health Network or Local Hospital District.
  - \$60m over four years to boost research funding for arthritis and musculoskeletal conditions. These funds could be sourced from the Medical Research Future Fund. Hundreds of millions of dollars a year in savings to the health system could be achieved by improving the evidence base for treatment and management of people with arthritis and musculoskeletal conditions.

# Arthritis is one of the most common, costly and disabling chronic conditions

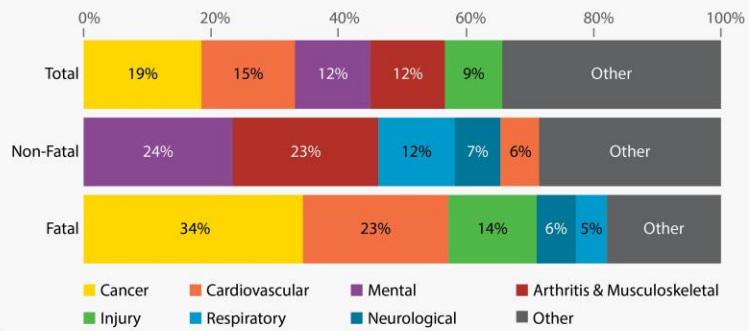
**4 million** Australians currently live with arthritis



Arthritis health system costs

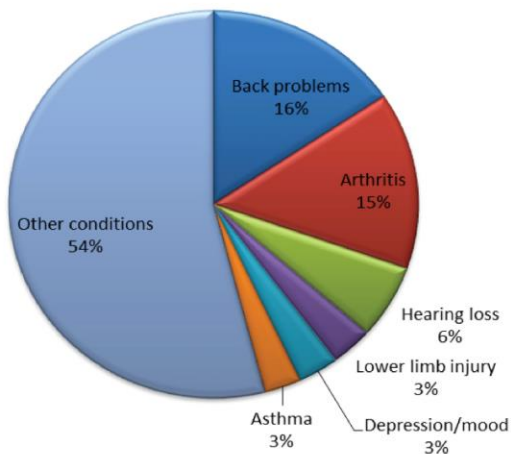


Proportion (%) of total, fatal and non-fatal burden by disease group, Australia 2011



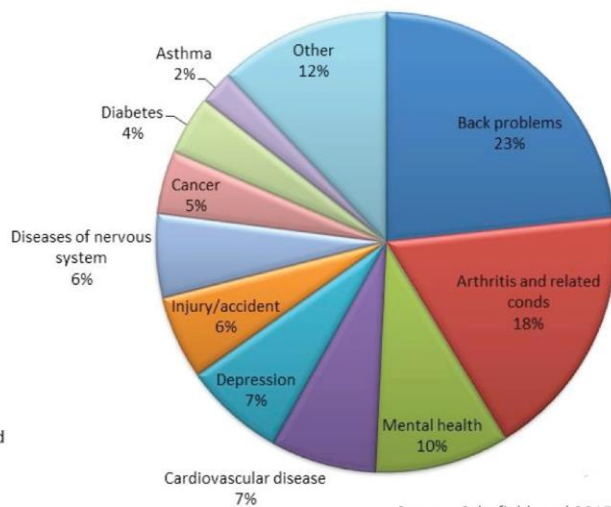
Source: AIHW 2016 Burden of Disease Study

Proportion of all disability by main disabling condition, Australia 2009



Source: ABS Survey of Disability, Ageing and Carers, 2009

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



Source: Schofield et al 2015

# 1) Support the development of new information and support tools and resources for people with arthritis

## Proposal

Provide funding of \$1.785 million to Arthritis Australia over three years to develop additional consumer information, education and support tools and resources to provide more tailored information to better meet the needs of people with different types of arthritis and of different ages, life stages and cultural backgrounds.

## Background and rationale

Arthritis Australia currently offers 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 condition 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 for as long as possible.

However, there are more than 100 different types of arthritis affecting people of all ages and people's information, education and support needs vary depending on the type of arthritis they have, their age at diagnosis, their personal 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 new platforms for communication, and to ensure the information and support provided is age and culturally appropriate.

Additional funding will allow Arthritis Australia to develop new and innovative resources and to expand and improve existing resources to better meet the needs of people with arthritis.

Arthritis Australia has a strong track record of developing world class, innovative consumer resources. For example, our osteoarthritis specific website, MyJointPain.org.au is a world- first, algorithm-based, tailored management tool which has been independently evaluated and shown to be effective in supporting people to better manage their condition. A similar website is being developed to support people with back pain.

## Proposed resources

Funding is sought to support the development of the following new and expanded resources and tools:

- **Develop new online resources to support children and families living with juvenile arthritis** including video interviews with a range of healthcare professionals as well as children and families living with the condition. The new resources would utilise the existing platform of our Empowered website which currently includes resources for people with rheumatoid arthritis, ankylosing spondylitis and psoriatic arthritis.

Cost: \$160,000, comprising \$150,000 for video production and content development and \$10,000 for website enhancements.

- **Expand and enhance the existing Arthritis Infoline support service** to create a more comprehensive, multi-format, nationally consistent information hub, supported by accredited healthcare professionals. The current Infoline service has limited operating hours and is manned mainly by trained volunteers and the scope of services provided varies across the country.

The new information hub would offer personalised email, telephone and online support (eg webchat) and a moderated community forum to meet increasing consumer demand for more varied and flexible modes of engagement and information delivery.

Cost: \$850,000 comprising: \$750,000 over three years to employ two full time equivalent rheumatology nurses or similarly qualified healthcare professionals to enhance the existing services provided by trained volunteers and to moderate the community forum; \$100,000 for software costs to set up and maintain the community forum.

- **Expand and develop new CALD and ATSI resources.** Arthritis Australia currently offers a suite of information resources in 10 different languages. However, there is a need to review and update existing multicultural resources and translate additional resources, especially medicines information which is only available in English, into different languages. In addition, there is a need to develop culturally appropriate resources for Aboriginal and Torres Strait Islander people.

Cost: \$300,000 comprising \$200,000 to cover the cost of translating 10 additional information sheets into each of 10 languages (100 in total) and \$100,000 to develop a new range of ATSI resources.

- **Develop and distribute new resources in identified areas of need** including a booklet on fibromyalgia, new resources for pain and fatigue management and a bespoke guide to disability support services for people with musculoskeletal conditions, including printable and video resources for online and social media platforms.

Cost \$125,000 for the development of five new resources in both printable and video formats.

- **Campaign to raise awareness of new resources and services.** \$350,000 over three years to run a promotional campaign to raise awareness of the expanded information and support service and new resources.

## Cost

<i>Development of new arthritis resources - Budget</i>	
<i>Item</i>	<i>Cost</i>
Develop new online resources for children and families living with juvenile arthritis.	\$160,000
Expand and enhance the Arthritis Infoline service to create a more comprehensive information and support hub, including a moderated community forum, supported by accredited healthcare professionals	\$850,000
Expand CALD and develop ATSI resources	\$300,000
Develop new resources in identified areas of need	\$125,000
Campaign to raise awareness of new resources and services	\$350,000
<b>Total</b>	<b>\$1,785,000</b>

## 2) Roll out a program to improve management of osteoarthritis in primary care

### Proposal

Roll out a model of care for people with osteoarthritis (OA) of the hip and/or knee and other musculoskeletal conditions across all Primary Health Networks (PHNs) in Australia, based on the successful model currently being rolled out across NSW by the Agency for Clinical Innovation within Local Health Districts in close collaboration with their partner PHNs.

### Benefits

- Health system savings of \$170 million a year due to reduced demand for joint replacements for OA of the knee.
- Better health and reduced disability for people with OA of the hip and/or knee. This will allow people with the condition to remain in the workforce longer, will reduce welfare costs and may delay the need to enter residential aged care facilities.
- More appropriate and earlier access to elective surgery in public hospitals for hip or knee joint replacements for people with severe OA that is no longer responding to conservative management options.

### Background

Osteoarthritis (OA) is the most common form of arthritis in Australia, affecting 2 million people.<sup>9</sup> OA of the hip and/or knee costs the health system over \$2 billion a year in elective joint replacements alone<sup>10</sup> and is also a leading cause of chronic pain, disability, early retirement and lost productivity.

Most people with OA of the hip and/or knee in Australia do not receive appropriate care.<sup>11</sup> Current care is mostly palliative, with a focus on advanced disease, medication and surgery. Typically, treatment is limited to the use of paracetamol, non-steroidal anti-inflammatory medication, or opioids, to reduce symptoms until the condition worsens, at which point the patient is referred for a joint replacement.<sup>12</sup> One in 10 opioid scripts in Australia is for OA, and an opioid is prescribed at one in five medical encounters for this condition, at a cost of \$25 million in 2015/16.<sup>13</sup>

Appropriate non-surgical care entails the provision of patient education and self-management support, including guidance on weight loss measures, exercise and physical therapy, as well as support to address psychosocial issues and better manage common co-morbidities such as type 2 diabetes and heart disease. In combination these strategies help to delay OA disease progression, reduce pain and disability associated with the condition and reduce demand for expensive joint replacement surgery.

We spend more on joint replacements for OA of the hip and knee than on any other hospital procedure, at a cost to the health system of over \$2 billion a year.<sup>14</sup> However, a significant portion of this expense is avoidable through better non-surgical care. Modelling indicates that better non-surgical care for people with knee OA could save the health system \$170 million a year in reduced numbers of knee joint replacements alone.<sup>15</sup>

Effective treatment and management of OA of the hip and/or knee will also make an important contribution to preserving independence and wellbeing among older Australians and may delay the need to enter residential aged care facilities.

The Agency for Clinical Innovation (ACI) in NSW has been working to develop a Local Musculoskeletal Service (LMS) model of care to improve the management of OA and osteoporosis in primary care.

The LMS model of care is based on using local co-ordinators linked to a Primary Health Network and Local Hospital District to engage with local health care providers to establish multidisciplinary care teams and referral pathways to deliver effective care for people with these conditions. A significant advantage of this approach is that it enables the delivery of the model to be adapted in line with local needs and resources.

The current LMS model of care builds on and incorporates learnings from an initial proof of concept trial run in four Primary Health Networks in NSW from July 2014 to June 2016, called the Musculoskeletal Primary Health Care Initiative. This initiative was designed to test whether successful hospital outpatient based chronic care programs developed by ACI for OA of the hip and/or knee and osteoporosis re-fracture prevention could be adapted to the primary care environment.

Although a formal evaluation of the Musculoskeletal Primary Health Care Initiative has yet to be completed the initial findings have been positive enough for the ACI to select the model for roll out as part of its [Leading Better Value Care](#) initiative. So far, six Local Hospital Districts/PHNs in NSW have agreed to implement the LMS model, with more making plans to implement this method of care delivery within the next twelve months.

## Cost

\$8.4 million over two years, to achieve estimated health system cost savings of \$170 million a year.

The cost of implementing the LMS model of care is around \$300,000 per PHN over two years to fund the activities of the local care co-ordinator. In addition, a project management team of three people would be required to manage and co-ordinate the national roll-out and support change management activities.

A national program to roll out the LMS in all the remaining 25 PHNs in Australia would cost \$8.4 million over two years, including the cost of a local care co-ordinator in each PHN and national project management. These costs would be easily offset by the savings from avoided elective knee joint replacement surgery, estimated at \$170 million a year.



### 3) Upskill nurses in rheumatology to improve care for people with inflammatory arthritis

#### Proposal

Provide funding of \$1.235 million over three years to:

- Provide scholarships to support nurses to undertake further study to become specialist rheumatology nurses
- Undertake a proof-of-concept trial to test the effectiveness of a model whereby a rheumatology nurse attached to a Primary Health Network or local hospital district provides patient education and support services to people with severe or inflammatory arthritis being managed by private rheumatologists in the local area.

#### Background

There is a severe shortage of rheumatology nurses in Australia to help care for people with complex and debilitating forms of autoimmune and inflammatory arthritis. These conditions affect around 1.7 million Australians and cost the health system over \$2.8 billion a year.<sup>1</sup> They also account for 6% of the total burden of disease in Australia and are the leading cause of disease burden in women.<sup>4i</sup>

Internationally, models of care involving rheumatology nurses for people with these conditions are considered best practice. Currently however there are only 39 full time equivalent rheumatology nurses in Australia, or only one nurse for every 45,000 people living with these conditions.<sup>16</sup>

Examples of autoimmune and inflammatory forms of arthritis include rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis, gout, juvenile arthritis, lupus and scleroderma. Nearly one million of those affected are of working age (15-64 years).<sup>1</sup> These conditions cause pain, fatigue, stiffness, reduced mobility, joint damage and deformity. Early diagnosis and urgent access to specialist rheumatologists for treatment (ideally within 12 weeks of symptom onset) are critical to avoid or delay irreversible joint damage, deformity and disability and to achieve the best health outcomes.

However, most people with these conditions do not receive adequate supportive care to help them deal with their condition and its often complex management. Delays in diagnosis and treatment are common and access to rheumatologists is limited in many parts of Australia, especially in rural and remote areas, with lengthy waiting lists for appointments.

Increasing utilisation of rheumatology nurses can help to address these issues and support improved care and better outcomes for people living with severe and inflammatory arthritis. A recent report found that access to a rheumatology nurse leads to better health outcomes, reduced delays in access to specialist care, higher patient satisfaction with care, improved patient knowledge of their condition, better support for patients' emotional wellbeing and improved coordination of care.<sup>16</sup>

Modelling for the report also estimated that adding a rheumatology nurse to a public rheumatology clinic in Australia would:

- improve access to specialist care and reduce delays in treatment. As a result the number of patients able to be seen would increase by up to 47%

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<sup>i</sup> Includes rheumatoid arthritis and 'other musculoskeletal conditions', a category which predominantly covers autoimmune and inflammatory forms of arthritis and related conditions.

- result in 32% of patients achieving remission at four years compared to 23% in a rheumatologist only clinic
- reduce the average cost of care by \$890 per patient.<sup>16</sup>

### ***Case study***

Royal Hobart Hospital employed a rheumatology nurse in 2010.

This role provides education and psychosocial support for patients with arthritis and rheumatic conditions, supports multidisciplinary care and compliance with therapy and helps people to manage the ups and downs associated with their condition. Patients and their families are educated on self-management and are cared for in a multi-disciplinary model of care which encourages involvement of their GP. Patients are encouraged to contact the rheumatology specialist nurse should they have queries about their disease or medication or be experiencing a disease flare.

The rheumatology nurse also liaises with local GPs about diagnosis and appropriate management of their patients with these conditions and triages cases so that only the most appropriate are referred to the specialist rheumatologist. This frees up the rheumatologists' time to concentrate on more complex aspects of patient care and reduces clinic waiting lists. In these ways, the role supports early diagnosis and treatment for these conditions which are crucial to prevent irreversible joint damage, delay disease progression and reduce disease severity and disability.

Following the creation of this position, presentations of people with inflammatory arthritis to the emergency department dropped significantly as patients were more appropriately managed for flares of diseases as a result of this liaison service. Patients are encouraged to phone the nurse if they are having a disease flare and in conjunction with a rheumatologist and/or the patient's GP she can triage patients and either help to manage the patient remotely or book them in as an emergency in outpatient clinics.

## **The proposal**

Arthritis Australia is seeking support for the following three-part program to build the rheumatology nurse workforce in Australia:

- Convene a working group of experts to define the roles and associated competencies and training pathways for rheumatology nurses.
- Provide scholarships to assist nurses to undertake further education as specialist rheumatology nurses or rheumatology nurse practitioners.
- Undertake a proof of concept trial to test the effectiveness of a model whereby a rheumatology nurse attached to a Primary Health Network or local hospital district provides patient education and support services to people with severe or inflammatory arthritis being managed by private rheumatologists providing resident or outreach services in the local area. The rheumatology nurse would practise in collaboration with the patients' treating physicians and GPs. This trial would be run across three PHNs/LHDs in different geographic areas, including metropolitan, regional and rural areas. An independent evaluation of the costs and effectiveness of the trial would be commissioned to inform future implementation.

## Cost

<b>Build the rheumatology nurse workforce - budget</b>	
Working group to define role, competencies and training pathways (over one year)	\$50,000
Scholarships to upskill nurses (over three years) <ul style="list-style-type: none"> <li>• 10x \$9,000 scholarships to complete the Graduate Certificate in Rheumatology Nursing</li> <li>• 5x \$30,000 scholarships for nurses to complete a Master's degree to qualify as a rheumatology nurse practitioner.</li> </ul>	\$240,000
Proof of concept trial including <ul style="list-style-type: none"> <li>• Employment and associated costs for three nurses over 2 years \$750,000</li> <li>• Project management and administration costs \$150,000</li> <li>• Evaluation costs \$45,000</li> </ul>	\$945,000
<b>Total</b>	<b>\$1,235,000</b>

## 4) Boost research funding for arthritis and musculoskeletal conditions

### Proposal

Provide a dedicated, additional allocation of \$60 million over four years from the Medical Research Future Fund and/or NHMRC to double research funding for arthritis and musculoskeletal conditions.

### Benefits

- Hundreds of millions of dollars a year in savings to the health system from improving the evidence base for treatment and management of people with arthritis and musculoskeletal conditions.
- Improved health outcomes, improved workforce retention and reduced disability for people with these conditions, leading to a reduction in government expenditure on welfare and residential aged care.
- Flow on benefits to other auto-immune conditions which share similar development pathways. For example, current research into a vaccine for rheumatoid arthritis may also yield benefits for people with Type 1 diabetes.

### Background

Much money is spent on care for people with arthritis and musculoskeletal conditions which is inappropriate, unnecessary or has an inadequate evidence base. Billions of dollars are spent each year on surgical interventions but the rate of these interventions differs across the country and outcomes vary, for reasons which are currently unclear.

The return on investment for clinical trials investigating gaps in medical evidence is six to one, with the savings due to improvements in patient health and direct savings to the health system and wider economy.<sup>17</sup>

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

- **\$1.2 billion** a year spent on knee replacements for osteoarthritis.<sup>18</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>19</sup> In addition the rate of knee replacement by population varies fourfold across the country<sup>20</sup> and 20-40% of people who have this surgery achieve little clinical benefit<sup>21</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.
- **\$400 million** a year spent on biological drugs for rheumatoid arthritis,<sup>22</sup> which could be spent more effectively with research to improve drug targeting (personalised medicine).
- **\$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>23</sup> which may be mostly unnecessary<sup>24</sup> and which could be addressed by a modest investment in research into better models of care.
- **\$100 million** a year on knee arthroscopies for osteoarthritis, despite strong evidence showing that the procedure is of no benefit for this condition and may cause harm.<sup>25 26</sup> Again research into more efficient models of care can reduce unnecessary surgeries like this.

## Why do we need a dedicated funding allocation?

Limited research capacity in the area of arthritis and musculoskeletal conditions is a significant issue in Australia, driven mainly by ongoing low levels of research funding. Strategic and dedicated investment is required to address this issue.

Research funding for musculoskeletal conditions is disproportionately low relative to the disease burden and cost of these conditions.

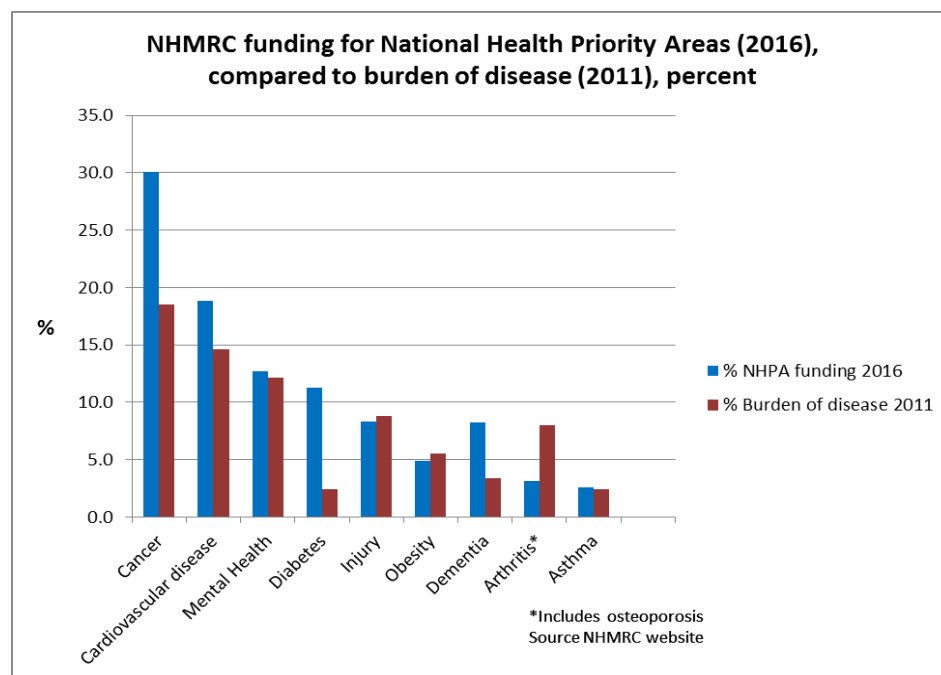
Arthritis and musculoskeletal conditions account for 12% of the total disease burden, and 8% of disease expenditure, and are the leading cause of disability, chronic pain and early retirement due to ill-health in Australia. Population ageing, growing obesity levels and increasing rates of autoimmune conditions will see a substantial increase in this burden and cost in future.

Yet this National Health Priority Area (NHPA) received just 3.1% (\$17.6 m) of NHMRC NHPA research funding in 2016 (Figure 1) and funding has declined by 33% over the last five years. In comparison, mental health conditions which also account for 12% of the total disease burden in Australia, received \$71.6m.<sup>27</sup>

Ongoing low levels of research funding have severely undermined research capacity in the area of arthritis and musculoskeletal conditions, with serious implications for our capacity to undertake future research and sustain clinical excellence in the field.

Other NHPAs have received dedicated and significant allocations of research funding in recent years to enhance research capacity, eg the Boost Dementia Research initiative (\$200 million over five years) and the Strategic Investment in Mental Health Research priorities through the NHMRC (\$26.2 million over five years).

**Figure 1**



Sources: NHMRC website; AIHW 2016 Burden of Disease

## Programs

The targeted funding allocation would be allocated to the following programs

- \$3.5 million over five years to support the national rollout of the Australian Arthritis and Autoimmune Biobanking Collaborative (A3BC), which is currently being established with seed funding from a philanthropic grant.

This collaborative endeavour will support research into personalised medicine and provide an invaluable resource for researchers in the field. It will collect biospecimens and use genomic and other 'omic' analyses, data linkage to other health data sets and big data and machine learning methods to identify and understand disease biomarkers related to the onset and progression of these conditions.

- Establishment of a national research institute to provide leadership and support strategic expansion of research into arthritis and musculoskeletal conditions
- Support for Centres of Research Excellence
- Infrastructure funding to support clinical trials groups
- Research fellowships to boost research workforce capacity in the field
- Project funding for research projects in priority areas.

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