# Review of Health and Medical Research

# Joint Submission from Arthritis Australia and the Australian Rheumatology Association

## About Arthritis Australia

Arthritis Australia is the peak arthritis organisation in Australia and is supported by affiliate offices in every state and territory.

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.

## About the Australian Rheumatology Association

The Australian Rheumatology Association (ARA) is the Special Society within the Royal Australasian College of Physicians (RACP) that represents Rheumatologists. The ARA supports and educates members and other practitioners in the musculoskeletal field to enable provision of best possible management for patients. It fosters excellence in the diagnosis and management of musculoskeletal and inflammatory conditions through training, professional development, research and advocacy.

The ARA has long recognised the importance of medical research in delivering excellence in clinical care and has strongly supported and promoted research activities. The ARA Annual Scientific Meeting (ASM) is the key event on the rheumatology calendar providing an important forum for education and dissemination of research findings. The ASM profits go directly to the ARA Research Trust to support rheumatology research through fellowships, scholarships and grants administered by Arthritis Australia and the RACP.

# Contents

## Summary and Key Recommendations

Arthritis Australia and the Australian Rheumatology Association welcome the opportunity to provide a submission to the Strategic Review of Health and Medical Research in Australia.

In this submission we highlight the importance of health and medical research to Australia's long term health and prosperity and make a number of recommendations that we consider will ensure that health and medical research is well placed to deliver future benefits in terms of reduced burden of disease and a more efficient and cost-effective health system.

We also highlight specific issues relating to research into arthritis and musculoskeletal conditions which is chronically underfunded in Australia relative to the burden of disease and disability and the cost burden to the health, disability and aged care systems that these conditions cause.

Our key recommendations include:

- Research funding through the NHMRC should be set at a real rate of growth of 5% pa
- Research funding should align with National Health Priority Areas (NHPAs). Allocated levels of funding should give appropriate weight to the burden of disease associated with the NHPA, its cost burden to the health, disability and aged care systems and the need to build and sustain research capacity in the sector to respond to future needs.
- Identified national health priority areas, including arthritis and musculoskeletal diseases, should be supported by clearly articulated research funding mechanisms including a dedicated Centre of Research Excellence, dedicated funding streams and targeted calls for research by the NHMRC. The competitive grants process should also give additional weight to applications which address priority areas.
- An immediate additional injection of $6 million of research funding for the arthritis NHPA is required to restore parity with recent average increases in funding for other NHPAs. In addition future research funding levels for the arthritis NHPA should be reviewed to more appropriately reflect its associated current and future social and economic burden.
- In underfunded priority areas such as arthritis and musculoskeletal conditions, the government, either through the NHMRC or through a separate funding stream, should boost research funding to more appropriate levels by matching funds provided from other research funders in the area, such as Arthritis Australia and the ARA Research Trust.
- Increased support should be provided to clinician researchers in the health system through increased funding for clinical research fellowships and more supportive hospital and institutional arrangements which provide protected funding, time and resources for clinicians to conduct research and training.
- Targeted support should be provided to build clinical research capacity in areas of need such as arthritis and musculoskeletal research where current low levels of research funding are undermining the clinical research workforce. Joint State-Commonwealth funding of research training fellowships within hospital-based Rheumatology and Orthopaedic Departments is recommended.
- In addition to designated health priority areas, targeted research funding should be provided for clinical and translational research, health systems and policy research and comparative effectiveness research.

- A range of mechanisms should be put in place to enhance the translation of research into practice including: increased support for clinical research and for collaborative partnerships between researchers and health care providers; active consumer input to the development of research priorities and proposals; greater use of technology to transform the way new clinical evidence is synthesised and disseminated and initiatives to encourage researchers to address translational aspects of their research.

**Box 1: About Arthritis**

Arthritis is often referred to as a single disease but is in fact an umbrella term for more than 100 medical conditions that affect the musculoskeletal system, specifically the joints. Arthritis and musculoskeletal conditions were designated a National Health Priority Area (NHPA) in 2002.

Arthritis is very common with over 3.1 million Australians affected. The most common form, osteoarthritis, affects 1.6 million people.[1] More Australians suffer from arthritis than any other national health priority condition.[2]

Arthritis and musculoskeletal conditions cost at least $9 billion annually through the health,[3] welfare[4] and residential aged care systems.[5]

In 2004-05, arthritis and musculoskeletal conditions cost the health system $4 billion in direct expenditure, the third most expensive national health priority disease group after cardiovascular disease ($5.9 billion) and mental disorders ($4.1 billion).[3] The total cost to the economy of arthritis alone, including the cost of lost productivity and wellbeing, was estimated to be $24 billion in 2007.[5]

Arthritis is also a leading cause of disability and chronic pain in Australia. More than one million Australians are estimated to have activity limitations as a result of their arthritis.[1] Nearly one in three people receiving the disability support pension does so as a result of their musculoskeletal condition at an estimated cost of nearly $4 billion in 2011-12.[4]

Arthritis is also a major cause of functional limitations among the elderly. Among residents of aged care facilities, musculoskeletal conditions are the second most common main health condition after circulatory disease (excluding dementias and other mental illness), affecting 18% of residents.[6] Aged care costs associated with arthritis were estimated at close to $1 billion in 2007.[5] Musculoskeletal conditions are also projected to be one of the top three contributors to increases in costs for residential aged care after dementia and circulatory disease with costs expected to increase from $0.7 billion in 2002-03 to $2.7 billion in 2032-33.[7]

By 2050 it is projected there will be 7 million Australians with arthritis, taking into account our aging population and the impact of increasing levels of obesity.[5]

## *1. Why is it in Australia's interest to have a viable, internationally competitive health and medical research sector?*

### *Benefits of health and medical research*

Health and medical research is an important investment which delivers enormous health and economic benefits to society. Net returns from Australian health research between 1992-93 and 2004-05 have been estimated at nearly $30 billion dollars, with an average return in health benefits of $2.17 for every dollar invested. This represents one of the highest returns on investment of any sector of the Australian economy.[8]

Maintaining a well-resourced, internationally competitive health and medical research sector in Australia is essential to allow us to address the challenges posed by our specific population and health system needs, including the impact of our aging population and escalating rates of chronic disease. It is also essential to provide the capacity to respond to major new health challenges that may arise in future.

With health and residential aged care expenditure projected to double over the next two decades,[9] health and medical research will also play a pivotal role in supporting the sustainability of the health system by finding more effective and cost-efficient ways of delivering improved health and healthcare for Australians.

Additional benefits to Australia associated with maintaining a world class health and medical research sector include:

- Increased productivity from reductions in ill-health
- Economic and employment benefits arising from the financial investment in research
- Returns from the commercialisation of research findings
- The potential to leverage research funding from industry and international sources due to the availability of a local cadre of skilled, world class researchers
- Improved quality of health services because it fosters a culture that supports excellence and improving patient care
- Benefits to patients from access to local clinical trials including earlier access to new therapies, better care and outcomes associated with clinical trial participation and faster uptake of proven new therapies as a result of clinician participation in trials.

Australia currently has a comparative advantage internationally in health and medical research, but growing research investment in developing countries such as Brazil, India and China is increasing competition for the international research dollar.[10] In the face of this competition, a "business as usual" approach is likely to result in a decline in future research activity in Australia, with a loss of associated benefits. Greater investment in research and strategies to enhance our international competitiveness are essential if we are to avoid or mitigate this outcome.

***Box 2: Case study - Benefits from arthritis research***

Major advancements in the treatment and prevention of arthritis over the past 10-15 years have transformed people's lives. Research in musculoskeletal diseases has brought about revolutions, such as safer and more effective drugs for rheumatoid arthritis including the new biological disease modifying anti-rheumatic drugs (bDMARDs), new anti-inflammatory drugs, effective treatments for osteoporosis, and improved outcomes for major joint replacements. For example, using current DMARD treatments for rheumatoid arthritis, remission can be achieved in over 50% of patients. Many patients with spondyloarthritis rate the effects of bDMARDs as 'life-changing' and 'miracle drugs'. These treatments give those affected a fair chance to enjoy a meaningful life that include living independently, remaining in the workforce, and reducing demands on the health system. Although taken for granted now, these advances in patient care can be traced directly back to earlier advances in basic and clinical research. Rheumatology research is now among the premier arms of applied biomedical research worldwide.

Australian researchers have contributed to recent successes with many Australian clinician-scientists being prominent members of the international arthritis research community, who regularly publish in premier international journals, and who are invited to present their research in prestigious sessions of international meetings. This high level of achievement has been reached despite significantly lower levels of research funding from Australian sources compared to other national health priority areas (see Box 3).

## *Strategies to attract, develop and retain a skilled research workforce*

The ability to attract, develop and retain a skilled research workforce is the cornerstone of a vibrant and responsive health and medical research sector. It is also essential for attracting research funds from industry and overseas sources to augment research funding provided by government.

While a skilled workforce across the spectrum of health and medical research is important, particular mention should be made of the importance of developing and retaining a skilled workforce of clinician researchers. Clinician researchers play a vital role in supporting clinical excellence because they operate at the interface of research and clinical care and provide training for the next generation of clinicians and researchers. Their work is focussed on improving the health of their patients and they provide a critical conduit for translating the latest breakthroughs into real outcomes in the clinic. Clinician researchers also provide capacity to conduct comparative effectiveness research which assesses health interventions in actual clinical scenarios and is critical to providing cost-effective health care. [11]

Currently, many researchers in Australia are dissatisfied with their career opportunities, with a 2008 survey showing that 73% had considered leaving health and medical research for another career. Reasons for dissatisfaction include a shortage of funding, poor financial rewards, employment insecurity as a result of the short-term nature of research funding grants, poor career development opportunities and better availability of employment elsewhere.[12]

In addition, workforce pressure on the sector will be exacerbated by an aging workforce. More than 6000 health and medical researchers aged over 40 years in 2009 are expected to leave the workforce within the next decade.[13] Clinician researchers are already in limited supply and the time that clinical staff specialists spend on research has eroded over time.[10]

Unless measures are adopted to improve support, remuneration and career structures for health and medical researchers in basic as well as clinical research, the best and brightest in the country are likely to seek a career in other sectors or move overseas to pursue their research careers.

In relation to arthritis research, the number of active clinician researchers is relatively small compared to other research areas: this has disadvantaged the sector with respect to obtaining research funding, and now threatens the viability of maintaining an active arthritis research community.

Strategies to attract and support a skilled research workforce should include:

- Improve the career structure for researchers by fostering long term support for both biomedical and clinical researchers, reducing dependence on short-term funding, providing longer-term funding grants and increasing salaries.
- Foster a culture of research within the health system by including research goals and performance indicators in institutional accreditation processes and strategic plans and providing protected time and resources for staff to conduct research and training. In hospitals, properly conducted clinical research should be recognised and supported as an important standard of care. Dedicated block funding for research should be provided through hospital and other institutional funding agreements.
- Support clinician researchers by providing protected time and resources for research and by expanding NHMRC practitioner fellowships and increasing the availability of clinical research fellowships across hospitals, aged care and primary health care settings.
- Targeted support should be provided to build clinical research capacity in areas of need such as arthritis and musculoskeletal research where current low levels of research funding are undermining the research workforce (see Box 3). Joint State-Commonwealth funding of research training fellowships within Hospital-based Rheumatology and Orthopaedic Departments is recommended.
- Foster research collaboration by supporting research networks and clinical trials groups, including improving access to research support and infrastructure
- Support increased training for clinicians in clinical research methodology.

**Recommendation**

- Increased support should be provided to clinician researchers in the health system through increased funding for clinical research fellowships and more supportive hospital and institutional arrangements which provide protected funding, time and resources for clinicians to conduct research and training.
- Targeted support should be provided to build clinical research capacity in areas of need such as arthritis and musculoskeletal research where current low levels of research funding are undermining the clinical research workforce. Joint State-Commonwealth funding of research training fellowships within hospital-based Rheumatology and Orthopaedic Departments is recommended.

## 2. How might health and medical research be best managed and funded in Australia?

### *Increase funding levels*

Sustained public investment in health and medical research is important to underpin Australia's long-term health and prosperity.

Despite substantial increases in NHMRC funding in recent years, Australia's OECD ranking for investment in health and medical research as a percentage of GDP is declining as other countries also ramp up their investment.[10] In addition, the recommendation of the Grant review that the Australian government increase its investment in medical research to $1.8 billion by 2008-09 has not been met.[14] Recent increases in NHMRC funding are also levelling off [15]at a time when the pressures on our health system and on government expenditure from an aging population and increasing rates of chronic disease make the case for increasing investment in health and medical research more compelling than ever.

To provide certainty for researchers and to maintain adequate growth in research funding, NHMRC funding growth should be set at a real rate of growth of 5% per annum, which is the average increase in health expenditure in real terms for the 10 years to 2009-10.[16]

**Recommendation**:

Research funding through the NHMRC should be set at a real rate of growth of 5% pa.

### *Adopt a more strategic approach to research funding*

An effective research portfolio for the future will require a balance of investigator driven and priority driven strategic research. While investigator driven research is essential to encourage innovation and 'blue sky' thinking, a priority driven, strategic component will help to ensure that research efforts align with areas of national priority and will help to reduce fragmentation, duplication, inefficiencies and gaps in research.[17]

A systematic, consultative approach should be adopted to identify national health and medical research priorities. Identified priority areas, including the designated National Health Priority Areas, should then be the subject of targeted calls for research by the NHMRC, funded by a dedicated funding stream; or competitive funding programs could give additional weight to applications which address these priority areas. Each identified priority area should have a Centre for Research Excellence or Centre for Clinical Research Excellence (CCRE/CRE) supported by the NHMRC to enhance basic and applied research and assist in translating research findings into improved patient outcomes. Notably arthritis and musculoskeletal conditions have never received a CCRE/CRE award in the history of this scheme, despite being a National Health Priority Area

In addition to a broad national approach to setting research priorities, support should be provided for researchers and funders to work together to identify national research priorities and strategies in particular areas, such as the National Health Priority Areas, or primary care. Consumer input to this process is essential as this will improve the relevance of research to the consumer experience and support the translation of research findings into positive health outcomes.[18] Arthritis Research UK has adopted this approach, establishing a number of clinical study groups to identify national clinical research priorities in different disease areas through consultation and consensus.[19] In

Australia, the leading non-government funders of cancer research in Australia are in the process of developing a national cancer research plan.[17]

A strategic approach would also address the balance of funding to be provided across different types of research eg basic, clinical, translational, health systems and policy research (see section 3 below).

### *Improve institutional arrangements and governance*

Despite ongoing efforts to streamline ethics and governance processes for clinical trials through the NHMRC's Harmonisation of Multi-centre Ethical Review program, this remains a difficult area. Clinical trials conducted across jurisdictional borders still usually require separate approvals for each site participating in a trial. Streamlining governance and ethics review processes should be a national priority as it is critical to improving clinical trials efficiency, encouraging collaboration across centres and maintaining Australia's international competitiveness as a location for clinical trials.

NHMRC should review its policies and processes relating to the composition of grant review panels and the allocation of grant applications to panels for review. This review should aim to ensure that grant applications are reviewed by panels with the appropriate expertise to make a balanced and informed assessment.

### *Fund Indirect research costs*

Funding for indirect research costs such as laboratory equipment, operating costs and administrative support is not covered by NHMRC project funding grants but can be as much as sixty cents per dollar of research funding.[20] Some hospitals provide funding support for certain clinical trial costs but many do not and may charge for associated services such as ethical review. This creates difficulties for researchers who need to find supplementary sources of funding to cover these costs.

While there are some programs for funding indirect research costs, funding arrangements vary across jurisdictions and sectors, creating inequities and favouring research in some sectors at the expense of others. A more consistent and equitable basis for funding the full costs of research, including indirect research costs, should be developed and implemented.

### *Fund research infrastructure*

Research infrastructure provides essential support for the conduct of health and medical research.

In addition to buildings and laboratories, databanks, bio-banks and data linkage capability are important infrastructure resources which provide valuable information to assist in identifying disease causes, developing new treatments and interventions and evaluating their effectiveness in practice. For example, improved data linkage across health data collections such as the MBS, PBS and hospital data collections for example would provide a rich research resource that would assist in identifying and assessing existing clinical issues so they can be addressed , as well as assessing the effectiveness of new treatments in real life (as opposed to clinical trial) conditions.

Arthritis Research in the UK has begun to roll out its plans for INBANK, a centralised, disease-based resource linking clinician and patient reported data with biological samples and routinely collected patient outcome data from the National Health Service and related sources. INBANK will provide a national platform of clinical data which will provide access for recruitment to studies, access to

samples to test and develop biomarkers and data linkage to follow up morbidity data and clinical benefit/adverse events.[21]

In Australia, the Australian Rheumatology Association maintains the Australian Rheumatology Association Database (ARAD) which collects important health information from individuals with inflammatory arthritis that provides an important resource for researchers and policy makers. [22] However future funding for this resource is uncertain. (See Box 3)

**Box 3: Case study – Australian Rheumatology Association Database**

In Australia, the Australian Rheumatology Association maintains the Australian Rheumatology Association Database (ARAD) which collects important health information from individuals with inflammatory arthritis. The aim of ARAD is to determine the effectiveness and safety of new biological drugs used to treat different forms of inflammatory arthritis. In addition to monitoring individual patient outcomes and adverse events, de-identified data is provided to researchers as new questions arise and also for government policy decision-making.

Data from ARAD was vital for the PBAC review of real-world effectiveness of biologic therapies in Australia and was the only source of data that could show sustained improvement in quality of life over the first five years following the introduction of these revolutionary treatments for arthritis. These therapies cost many thousands of dollars per patient per year and having long-term information on comparative effectiveness is very important to ensuring cost-effective use.

ARAD also supports data linkage with other data collections to help determine important risks associated with biological agents such as malignancies. Australian patients differ in important ways from other regions given our higher background skin cancer and melanoma risks and our stringent requirements for very active disease to be treated. Analyses supported by the ARAD data linkage capability have shown associations with smoking and poorer health outcomes in inflammatory arthritis patients and preliminary analyses are showing a slight increase in non-melanoma skin cancers in Australian men and women and possibly prostate cancers in men in patients taking certain types of arthritis drugs.

Despite ARAD being a vital resource for quality and safety information for patients, in addition to being a valuable resource for research, this registry does not have secure or sustainable funding but relies on a mixed source of funding from government, through an NHMRC enabling grant, and pharmaceutical companies, that is not guaranteed. This in stark contrast to other national registries such as the United Kingdom, Germany and Spain where governments have seen the value in sustaining these registries. The full potential of ARAD as an important research resource in Australia is not being realised due to lack of funding. The enabling grant funding come to an end in 2010-11 with maintenance of the resource now reliant on pharmaceutical funding. However, there are concerns that sole reliance on pharmaceutical funding for ARAD in the future may create a potential conflict.

### *Increase consumer participation*

Actively seeking consumer views on health research can improve relevance and translation of research into practice and is essential to align research with end-user needs.[23] Consumers should be involved in all areas of research development including setting of research priorities and questions, development of research proposals and translational aspects.

Mechanisms to enhance active participation by consumers in health and medical research should be implemented in consultation with consumer groups.

### *Encourage private sector support and philanthropy*

At present philanthropic donations from the community and the corporate sector to medical research are mainly disease or cause related and the level of funding provided can reflect the profile of individual conditions and the marketing strategies and resources of individual charities, while less visible conditions or causes remain under-funded. The lack of a large fund that supports general medical research, along the lines of the Wellcome Trust in the UK for example, means aspiring donors usually need to choose between competing causes or divide their donations between a range of different organisations

Without detracting from worthy causes, there could be scope to establish an independently run general medical research charity fund to which individuals and corporations could contribute that could be used to supplement government research funding through the NHMRC. Dollar for dollar matching by the government of donated funds, together with attractive tax concessions, would provide incentives to attract donations to the fund.

## *3. What are the health and medical research strategic directions and priorities and how might we meet them?*

### *Align research funding with identified national priority areas*

Research priorities should align with the designated National Health Priority Areas (NHPAs), the burden of disease, the need to support healthy aging and the need to address the social determinants of health. Research funding should support identified priorities. Grant applications that address priority areas should be given a higher weighting in grant assessment procedures.

Government funding for research to support health policy and improved delivery of health services, particularly for chronic disease prevention and management, will also help to ensure a responsive and efficient health system for the future.

With respect to allocating research funds, the government must consider not only the estimated burden of disease for each NHPA condition, but also the costs associated with these conditions through the health, welfare and residential aged care sectors. With government expenditure on health and aging expected to increase to an unsustainable level of around half of total expenditure by 2050 it is essential that the government supports research into innovative, cost-effective solutions for high cost conditions to help maintain future expenditure at sustainable levels.

For example, arthritis and musculoskeletal conditions account for 4% of the burden of disease and injury in Australia compared to 19% for cancer,[24] but the annual costs to the health system of each condition are comparable at around $4 billion.[3] In addition, arthritis and musculoskeletal conditions cost nearly $4 billion in payments annually for the disability support pension, over five times more than circulatory system disorders and cancers combined,[4] as well as nearly $1 billion in aged care costs.[5] These costs will only grow as the prevalence of musculoskeletal conditions increases due to an aging population and the impact of obesity.

Despite the social and economic costs of arthritis and musculoskeletal conditions, research in this area is chronically underfunded and falling relative to other NHPAs (see Box 4). NHMRC funding allocated to the arthritis NHPA was just $30 million in 2011, a level unchanged since 2008, while total NHMRC research funding for NHPAs increased by 19% over the same period.[15] If this average increase in NHPA research funding had applied to the arthritis NHPA, funding should have been $36 million in 2011.

**Recommendation**

- Research funding should align with National Health Priority Areas (NHPAs). Allocated levels of funding should give appropriate weight to the burden of disease associated with the NHPA, its cost burden to the health, disability and aged care systems and the need to build and sustain research capacity in the sector to respond to future needs.
- Identified national health priority areas, including arthritis and musculoskeletal diseases, should be supported by clearly articulated research funding mechanisms including a dedicated Centre of Research Excellence, dedicated funding streams and targeted calls for research by the NHMRC. The competitive grants process should also give additional weight to applications which address priority areas.
- The arthritis NHPA is chronically underfunded relative to its social and economic burden and relative to other NHPAs. An immediate additional injection of $6 million of research funding for the arthritis NHPA is required just to restore parity with recent average increases in funding for other NHPAs. In addition future research funding levels for the arthritis NHPA should be reviewed to more appropriately reflect its associated current and future social and economic burden.

### *Boost research funding in underfunded priority areas*

Some priority areas may have greater difficulty in securing adequate private or philanthropic support for research funding because of limited commercial scope or competition for the charity dollar with more emotive, high profile causes. In these cases, market forces may lead to underinvestment in research in these areas, providing a strong rationale for increased government support. This applies to systems based research such as comparative effectiveness research and also to certain National Health Priority Areas, such as arthritis and musculoskeletal conditions.

For example, funding for cancer research from government and non-government organisations totalled $300 million in 2011[25] (excluding industry funding which is also substantial), an additional $125 million above the NHMRC allocation. By comparison, the annual national research budget of Arthritis Australia, the main and largest non-government provider of arthritis research funding is approximately $650,000. This amount includes around $125,000 per annum contributed from the ARA Research Trust which was established in 2000 to fund medical research into arthritic diseases.

In National Health Priority Areas where current research funding availability is relatively low, such as arthritis and musculoskeletal conditions (see also Box 4), the Australian Government either through the NHMRC or through a separate funding stream should boost funding. This could be done by matching funds provided from other research funders in the area, such as Arthritis Australia and the ARA Research Trust, in order to build, support and retain research capacity to address the high personal, social and economic costs of these conditions. This arrangement would also provide an incentive for encouraging corporate and philanthropic donations in these areas, knowing that monies donated would be matched by government funds.

**Recommendation**

- In underfunded priority areas such as arthritis and musculoskeletal conditions, the government, either through the NHMRC or through a separate funding stream, should boost research funding to more appropriate levels by matching funds provided from other research funders in the area, such as Arthritis Australia and the ARA Research Trust.

***Box 4: Case Study - Underfunding of research into arthritis and musculoskeletal conditions***

Arthritis and musculoskeletal conditions were designated a National Health Priority Area (NHPA) in 2002. They are highly prevalent, a leading cause of disability and a major and growing expense to the health, welfare and residential aged care systems (see Box 1).

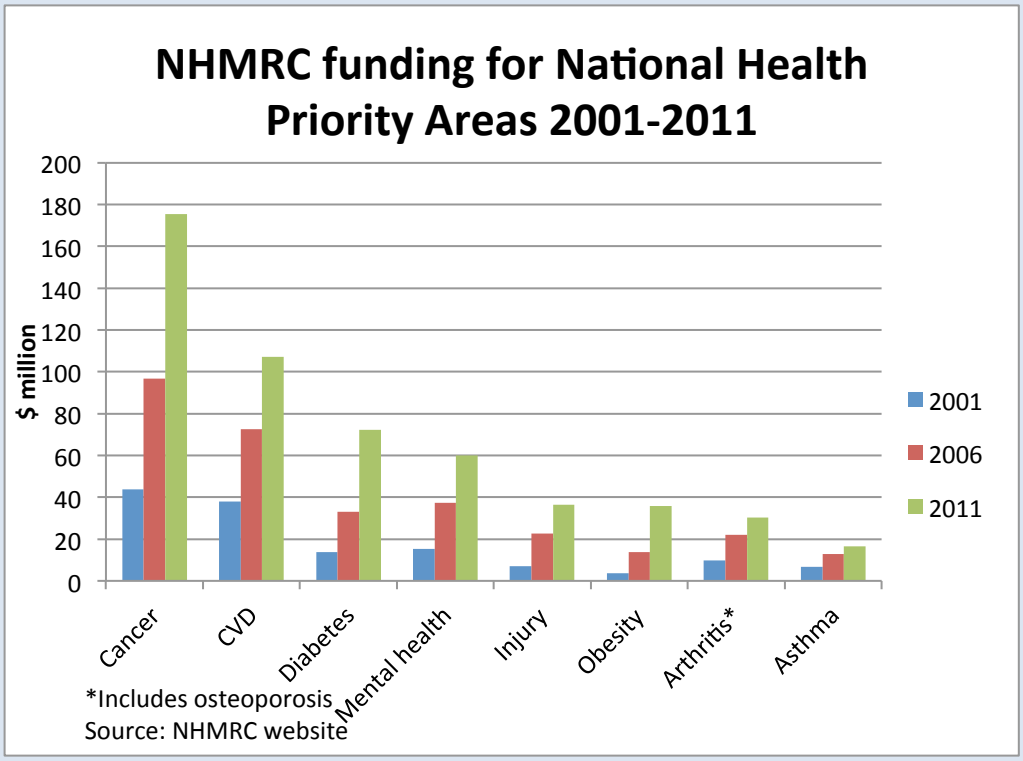
Arthritis and musculoskeletal conditions represent an enormous direct cost of at least $9 billion annually, comprising $4 billion in costs to the health system,[3] nearly $4 billion in costs for the Disability Support Pension (this excludes carer payment and carer allowance costs)[4] and nearly $1 billion in aged care costs.[5] These costs will only grow as the prevalence of these conditions increases due to an aging population and the impact of obesity.

The current estimate of the burden of disease in Australia due to musculoskeletal conditions (4%) may also underestimate the true social and economic impact of these conditions. This view is supported by preliminary advice from researchers undertaking the Global Burden of Diseases, Injuries and Risk Factors Study (www.gbd.org) who have found that the relative burden of disease due to musculoskeletal conditions has increased substantially since the late 1990s.[26]

Despite these facts, arthritis research is chronically underfunded compared to the personal, social and economic impact it has on the Australian community and compared to research funding available for other NHPAs.

Both total research funding and the growth in research funding from the NHMRC for arthritis and osteoporosis which are the focus of the musculoskeletal NHPA are low relative to the other NHPAs (see figure 1). NHMRC funding for arthritis and osteoporosis totalled just $30 million in 2011, the lowest level of all the NHPAs except asthma, accounting for less than 6% of total NHMRC funding allocated to NHPAs. NHMRC funding for research grew by nearly $500 million to $755 million in the ten years to 2011. Over this time, the annual funds allocated to arthritis and osteoporosis research have grown by only $20 million, compared to an increase of $131 million for cancer and $69 million for cardiovascular disease research.

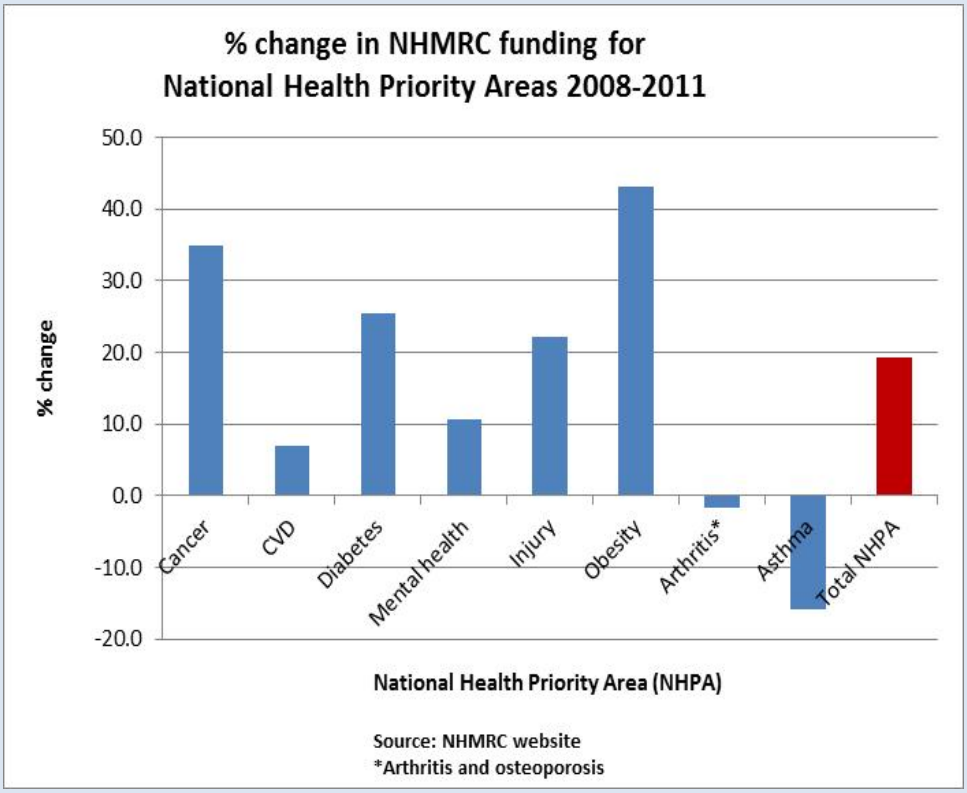
***Figure 1***



***(Box 4 Continued)***

This trend to underfunding of arthritis research relative to other NHPAs has exacerbated in recent years. Since 2008, NHMRC funding for arthritis/osteoporosis research has remained around $30 million while total NHMRC funding for NHPAs increased by 19%. (See figure 2)

***Figure 2***




Underfunding of arthritis research relative to other NHPAs is especially pronounced when you consider the total pool of research funding available, including funding from other sources for those conditions. Funding for cancer research from government and non-government organisations for example totalled $300 million in 2011[17] (excluding industry funding which is also substantial), $125 million on top of the NHMRC allocation. The same year, the National Heart Foundation invested $13 million in cardiovascular research.[27] In comparison, Arthritis Australia, the largest non-government provider of arthritis research funding in Australia, was able to allocate only A$650,000 to arthritis research in 2011.

These low levels of research funding are severely undermining research capacity in the area of arthritis and musculoskeletal conditions, with serious implications for the future of arthritis research in Australia and for the ability to sustain clinical excellence in the field.

This is unacceptable given the burden and costs of arthritis. Increased investment in research into arthritis and musculoskeletal conditions, in line with their health and economic impact and their status as a national health priority area is essential.

An immediate additional injection of $6 million of research funding for the arthritis NHPA is required to restore parity with recent average increases in funding for other NHPAs. In addition future research funding levels for the arthritis NHPA should be reviewed to more appropriately reflect its associated current and future social and economic burden.

### *Chronic disease prevention and management*

Research into how to prevent, manage and reduce the progression of chronic disease in Australia must be the key priority for health and medical research into the future. Chronic disease accounts for 80% of the disease burden in Australia[28] and, coupled with an ageing population and the increasing prevalence of risk factors such as obesity, will be a key driver of health costs in the future.

The proportion of government expenditure allocated to health and ageing is projected to double from around one quarter of total expenditure currently to an unsustainable level of around half of total expenditure by 2050.[29] Consequently, governments have a vested interest in sponsoring and supporting research into the most effective and cost-effective ways to prevent and manage chronic disease and particularly into those conditions that have a significant impact on government health, aged care and welfare expenditure.

Research into chronic disease prevention and management is highly relevant to improving global health, including in developing countries where the burden of chronic disease is escalating.[30]

### *Clinical and translational research*

Priority should be given to greater support for clinical and translational research to ensure that research findings are implemented as quickly as possible into clinical practice. At present the time lag between health research and its eventual health benefits has been estimated to be 17 years, but if this time lag could be shortened rates of return on research would increase.[31]

As mentioned previously increased support for clinician researchers is an important way to foster faster translation of research into clinical practice. This can be achieved by providing protected time and resources for clinician researchers to conduct research, supporting clinical research networks and clinical trials groups, and building a research culture in all sectors of health care from hospitals to primary care.

There is also scope to increase government support for clinical research into therapies such as lifestyle modification that do not involve expensive new drugs or devices and hence are unlikely to attract industry sponsorship because of their limited commercial potential.

### *Health systems and policy research*

An important component of a national research agenda must be research into how best to deliver health care to optimise outcomes for consumers.

Recent decades have seen a major shift in the burden of disease from infectious to chronic disease, yet the health system and health services have yet to adjust to this shift in the predominant modality of ill-health. Hence an important focus of research into chronic disease is systems based research to examine the best ways to deliver chronic disease prevention and management programs and services.

### *Comparative effectiveness research*

Comparative effectiveness research assesses the relevance and effectiveness of health interventions in actual clinical situations.[32]

Comparative effectiveness research is important to assess the best use of existing treatments to achieve optimal outcomes for patients, such as more informed use of expensive treatments or the

effectiveness of medication versus non-drug therapies. This research is critical to providing cost-effective health care.

Funding for comparative effectiveness research should be a priority for governments which, as the major funders of health care stand to reap the greatest benefits from its findings. Industry has little interest in supporting comparative effectiveness research as its findings may undermine their commercial returns.

An example of the potential cost savings that could result from comparative effectiveness research is provided by studies in advanced breast cancer that found the use of high-dose chemotherapy was no better than standard dose chemotherapy, resulting in estimated savings to the Australian health system of $50 million per annum.[33] In rheumatology, with ongoing medical advances there is a clear need for comparative effectiveness research in a number of areas. A good example is rheumatoid arthritis drugs where comparative-effectiveness studies of older treatments versus newer more expensive treatments could yield substantial cost savings. Newer approaches to conservative management of knee osteoarthritis may also prove cost-effective compared to current conservative and surgical treatments.

Proposals to establish a separate funding stream through NHMRC dedicated to comparative effectiveness research should be supported. [32]

### *Non-commercial research*

While it is Important to support and encourage privately funded research and encourage increased investment in medical research by industry, it is important to recognise that industry research will always pursue avenues which promise the greatest commercial gain. This may not always represent the best value or outcomes for the health system or patients, or for the government as the predominant funder of health services and pharmaceuticals. Over-reliance on commercially focussed research has the potential to raise health care costs and lead to under-investment in research in areas which offer less potential for commercial returns but may offer equivalent or better outcomes, such as lifestyle modification for chronic disease management.

Hence it is important to foster independent research which addresses clinically important questions regardless of the prospect of a commercial return. Comparative effectiveness research, support for independent clinical research networks and clinical trials groups and health systems research are all areas which should be funded primarily by government.

**Recommendation**

- In addition to designated health priority areas, targeted research funding should be provided for clinical and translational research, health systems and policy research and comparative effectiveness research.

## *4. How can we optimise translation of health and medical research into better health and wellbeing*

Translation of research findings into practice is the ultimate goal of health and medical research and allows the full benefits of research investment to be realised. Translating the vast quantity of research findings into formats that can easily be applied in practice, however, remains challenging.

Translation of health and medical research findings can be enhanced in the following ways:

- Increase support for clinician researchers, clinical research networks and clinical trials groups (see section 1.2), thereby creating a pool of local expertise in developing, testing and implementing new therapies focussed on improving patient outcomes which will speed the uptake of new proven therapies in practice.
- Adopt measures to support increased clinical trial activity in Australia, including improving governance and ethics approval processes to reduce start up times and maintain our competitiveness as a clinical trial location in the face of increasing competition from developing countries such as China, India and Brazil.
- Increase support for collaborative partnerships between researchers and health care providers to align research questions with clinical need, such as the NHMRC's centres of research excellence and partnership programs, or give higher weighting for projects that are collaborative and interdisciplinary. Collaborations should bring together hospitals, medical research institutes, universities and health care providers.
- Increase consumer input to the development of research priorities and proposals to improve the relevance of research to the consumer experience and support the translation of research findings into positive health outcomes.[34]
- Establish research translation networks in priority areas to promote and support a greater focus on improving the uptake of research findings. Networks could be established in each priority area to assist in synthesising evidence and adapting it for use at the point of care.
- Harness the power of technology to transform the way clinical evidence is synthesised and disseminated to enhance timely access to new clinical evidence. Wiki platforms for the development of clinical practice guidelines that are continuously updated and online resources such as eviQ Cancer Treatments which provides evidence based information tailored for use at the point of care, illustrate the potential of this approach.
- Require open access to publications arising from research funded through the NHMRC.
- Harness new structures created through the government's health reform agenda, such as the Health and Hospitals networks, Medicare Locals and lead clinician groups to assist in conducting research, synthesising and disseminating research results and encouraging uptake into clinical practice.
- Introduce initiatives to encourage researchers to address translational aspects of their research. The Canadian Institutes of Health Research support a range of knowledge translation initiatives including providing funding for translational research, training and capacity building in knowledge translation, funding for knowledge synthesis such as Cochrane reviews and funding for end of grant knowledge translation and dissemination.[35]
- Allow data linkage across health data collections such as the MBS, PBS and hospital data collections, and also the soon-to-be-introduced e-health records. This will provide a rich research resource that will assist in identifying and assessing existing clinical issues so they can be addressed , as well as allowing the uptake and effectiveness of new treatments ( in real life as opposed to clinical trial conditions) to be assessed.
- Support post-marketing research to evaluate the effectiveness of drugs, devices and procedures approved for MBS or PBS subsidy in achieving improved patient outcomes, to ensure that only effective procedures and drugs continue to be used and subsidised. This

research could be supported by adding an evaluation component to fees paid for PBAC or MSAC assessment.

**Recommendation**

- A range of mechanisms should be put in place to enhance the translation of research into practice including: increased support for clinical research; increased support for collaborative partnerships between researchers and health care providers; active consumer input to the development of research priorities and proposals; greater use of technology to transform the way new clinical evidence is synthesised and disseminated and initiatives to encourage researchers to address translational aspects of their research.

For further information contact:

Franca Marine
National Policy and Government Relations Manager
Arthritis Australia
Level 2, 255 Broadway, Glebe NSW 2037
PO Box 550, Broadway NSW 2007
p- 02 9518 4441
f- 02 9518 4011
m- 0432 567 413
e- fmarine@arthritisaustralia.com.au

*References*

[1] Australian Institute of Health and Welfare 2010. *A snapshot of arthritis in Australia 2010*. Arthritis series no. 13. Cat. no. PHE 126. Canberra: AIHW.
[2] Australian Bureau of Statistics 2010. *National Health Survey: Summary of Results, 2007-08*
[3] AIHW 2010. *Health system expenditure on disease and injury in Australia, 2004-05*. Health and welfare expenditure series no 36. Cat. No. HSE 87. Canberra: AIHW
[4] Department of Families, Housing, Community Services and Indigenous Affairs 2011. Characteristics of Disability Support Pension Recipients. June 2011 and Treasury estimates for DSP expenditure for 2011-12 from http://www.budget.gov.au/2011-12/content/bp1/html/bp1_bst6-02.htm. Estimate of $4 billion derived by applying the proportion of recipients of the Disability Support Pension (DSP) who nominated a musculoskeletal condition as their primary condition (28.2%) to the estimated cost of the DSP in 2011-12 ($13.8 billion)
[5] Access Economics 2007. *Painful Realities: The economic impact of arthritis in Australia in 2007*
[6] Australian Institute of Health and Welfare 2010. *Australia's health 2010*. Australia's health series no. 12. Cat. no. AUS 122. Canberra: AIHW.
[7] Goss J 2008. *Projection of Australian health care expenditure by disease, 2003 to 2033*. Cat. no. HWE 43.Canberra: AIHW
[8] Access Economics 2008. *Exceptional returns: the value of investing in health R&D in Australia II*.
[9] Goss J 2008. *Projection of Australian health care expenditure by disease, 2003 to 2033*. Cat. no. HWE 43.Canberra: AIHW.
[10] Research Australia *2011 Shaping Up: Trends and Statistics in Funding Health and Medical Research*
[11] Zalcberg JR 2012. Comparative effectiveness research for a new NHMRC funding stream. *MJA* 196 (1): 22-23
[12] Kavallaris M et al. 2008 Perceptions in health and medical research careers: the Australian Society for Medical Research Workforce Survey. *MJA* 188:520-524.
[13] Schofield DJ et al. 2011 A crisis in the making? Education, ageing populations and the future of the medical research workforce *Med.Edu*.45:200-7.

[14] Investment Review of Health and Medical Research Committee 2004. *Sustaining the virtuous cycle for a healthy, competitive Australia*. Final Report Dec 2004. Commonwealth of Australia 2004.
[15] NHMRC Research funding statistics and data from http://www.nhmrc.gov.au/grants/research-funding-statistics-and-data viewed 20/3/2012
[16] Australian Institute of Health and Welfare 2011. *Health expenditure Australia 2009-10*. Health and welfare expenditure series no. 46. Cat. No. HWE 55. Canberra: AIHW
[17] Cancer Research Leadership Forum 2012. *Towards a national cancer research plan*. February 2012.
[18] Saunders C, Crossing S, Girgis A, Butow P, Penman A, 2007. Operationalising a model framework for consumer participation in health and medical research. *ANZ Health Policy* 2007, 4:13
[19] http://www.arthritisresearchuk.org/research/funding-of-clinical-studies/national-prioritisation-of-clinical-research.aspx Viewed 27/3/2012
[20] LEK Consulting 2009. *Costing medical research to reform health outcomes*, Sydney
[21] Arthritis Research UK http://www.arthritisresearchuk.org/research/inbank.aspx Viewed 23/3/2012
[22] http://www.rheumatology.org.au/rheumatologists/aradatabase.asp
[23] Saunders C, Crossing S, Girgis A, Butow P, Penman A, 2007. Operationalising a model framework for consumer participation in health and medical research. *ANZ Health Policy* 2007, 4:13
[24] Begg S, Vos T, Barker B, Stevenson C, Stanley L, Lopez AD, 2007. *The burden of disease and injury in Australia 2003*. PHE 82. Canberra: AIHW
[25] Cancer Research Leadership Forum 2012. *Towards a national cancer research plan*. February 2012
[26] Personal communication; Professor Lyn March, Royal North Shore Hospital
[27] http://www.heartfoundation.org.au/research/news/Pages/default.aspx Viewed 15 March 2012.
[28] Australian Institute of Health and Welfare, 2006. *Chronic diseases and associated risk factors in Australia,* AIHW cat. no. PHE 81, AIHW, Canberra, p. 96.
[29] Australian Government, The Treasury 2010. *Australia to 2050: future challenges: The 2010 Intergenerational Report*
[30] Australians for Global Action on NCDs 2011. Time for global action on chronic disease. *MJA* 194 (4): 158-159
[31] Wellcome Trust 2008. *Medical Research: What's it worth?*
[32] Zalcberg JR 2012. Comparative effectiveness research for a new NHMRC funding stream. *MJA* 196 (1): 22-23
[33] Clinical Oncological Society of Australia and Cancer Council Australia 2009. Joint submission to the Clinical Trials Action Group:
[34] Saunders C, Crossing S, Girgis A, Butow P, Penman A, 2007. Operationalising a model framework for consumer participation in health and medical research. *ANZ Health Policy* 2007, 4:13
[35] Canadian Institutes of Health Research http://www.cihr-irsc.gc.ca/e/38924.html Viewed 20/3/2012