Time to Move: Arthritis

A national strategy to reduce a costly burden

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Arthritis Australia March 2014

TIME TO MOVE: ARTHRITIS

The Time to Move strategy outlined in this document provides a road map for improving care across Australia for people with arthritis.

The strategy is supported by three additional documents which respectively address the care of people with osteoarthritis, rheumatoid arthritis and juvenile idiopathic arthritis:

Time to Move: Osteoarthritis;

Time to Move: Rheumatoid Arthritis; and

Time to Move: Juvenile Idiopathic Arthritis.

These documents are available at www.arthritisaustralia.com.au

What is arthritis?

Arthritis is an umbrella term for a range of conditions that affects the joints.

There are over 100 different types of arthritis affecting people of all ages including children. The most common types are osteoarthritis (OA), rheumatoid arthritis (RA) and, in children, juvenile idiopathic arthritis (JIA).

Osteoarthritis

OA is a degenerative joint disease that affects 1.9 million Australians. Although often referred to as "wear and tear" arthritis, OA is a disease and not an inevitable part of the ageing process.

Rheumatoid arthritis

RA is a serious, chronic, inflammatory autoimmune condition that can occur at any age. Early diagnosis and appropriate treatment can prevent much of the joint damage, deformity and disability associated with RA.

Juvenile idiopathic arthritis

JIA is an inflammatory autoimmune condition that affects around 5000 Australian children. If not treated quickly and appropriately, it can seriously affect the growth and development of a child, causing severe joint damage, growth abnormalities and permanent disability.

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Executive Summary

Arthritis is one of the most common, disabling and costly chronic diseases in Australia. It affects more than three million people of all ages with more than half of those affected being of working age.¹

Arthritis costs the health and welfare systems more than \$5.6 billion annually.^{1,2}

The loss to the Australian workforce is highly significant. More than 80,000 people aged 45 to 64 years can't work because of their arthritis, at an estimated loss to GDP of \$9.4 billion a year³ and a cost of about \$1.3 billion annually for the Disability Support Pension.²

As the population ages, the number of people with arthritis is expected to reach seven million by 2050.⁴

Yet the management of arthritis in Australia falls well short of best practice. Two thirds of people with arthritis say they are faring badly,⁵ over half of people with the most common form of arthritis in Australia (osteoarthritis) don't receive care in accordance with current guidelines,⁶ and most general practitioners are dissatisfied with the care they are able to provide.⁷

Many people with arthritis face limited services, inequity of access, delays in diagnosis and treatment, fragmented care that is rarely multidisciplinary, inadequate support for self-management, a lack of psychosocial support and a heavy financial burden.

But much can be done to reduce the impact and severity of arthritis.

The Time to Move strategy provides a road map for improving care across Australia for people with arthritis, addressing the spectrum of intervention from prevention to advanced disease. It is supported by three additional documents which respectively address the care of people with osteoarthritis (OA), rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA). These documents are available at <u>www.arthritisaustralia.com.au</u>.

The principles of the Time to Move strategy are that it is patient centred and based on the patient experience, addresses prevention to reduce the number of people developing arthritis, supports early diagnosis and promotes best practice evidence based care, and is focussed on good outcomes for patients. The key components are:

- awareness raising campaigns and strategies
- health promotion and primary prevention strategies
- enhanced education and self-management support for people with arthritis
- community based multidisciplinary arthritis clinics and teams
- workforce capacity building, including enhancing support for primary care to provide effective management of people with arthritis
- research.

If this strategy is implemented, it will:

- reduce the pain and disability associated with arthritis, helping people maintain their independence and quality of life, and maximise their ability to work and participate fully in society
- save more than \$150 million in the first year due to a reduction in inappropriate referrals for surgery and better triage and management of people before surgery⁸
- improve workforce participation and workforce retention for people with arthritis
- reduce arthritis-related disability and reduce welfare payments
- slow the demand for joint replacement surgery in the medium to long term as a result of the better management of earlier stage disease.

It's time to move on arthritis.

1. The case for change

"Although the diseases that kill attract much of the public's attention, musculoskeletal conditions are the major cause of morbidity throughout the world, having a substantial influence on health and quality of life, and inflicting an enormous burden of cost on health systems"

Dr. Gro Harlem Brundtland, Director-General of the WHO, January 2000⁹

Arthritis is one of the most prevalent, disabling and costly chronic diseases in Australia, affecting more than 3 million people of all ages and costing the health system well over \$4.3 billion annually.¹

In addition, arthritis is a leading cause of disability and early retirement, costing \$1.3 billion annually in Disability Support Pension payments² and \$9.4 billion in lost GDP due to early retirement.³ The personal, social and economic cost of arthritis including lost wellbeing and reduced productivity was estimated to be \$24 billion in 2007.⁴

Taking steps now to reduce the impact and severity of arthritis is critical. Improvements in longevity in recent decades mean that not only are more people developing arthritis, they are living longer with the condition and because arthritis is mostly progressive, the longer people live with the condition, the more severe it is likely to become.

A substantial proportion of the cost and burden of arthritis could be reduced by adopting prevention strategies and improving the care we provide for people with arthritis. Providing best practice care for people with arthritis prevents or slows disease progression, reduces the pain and immobility caused by arthritis and helps to preserve independence and quality of life.

Yet evidence indicates that current management of arthritis in Australia falls well short of best practice. Two thirds of people with arthritis report that they are faring badly with their condition,⁵ over half of people with the most common form of arthritis in Australia (osteoarthritis) do not receive appropriate care⁶ and most GPs report dissatisfaction with the care they are able to provide to people with arthritis.⁷

Limited services, inequity of access, delays in diagnosis and treatment, limited access to multidisciplinary care, fragmented care, inadequate information and support for self-management, lack of psychosocial support and a heavy financial burden are common problems reported by people with arthritis.

With the prevalence and severity of arthritis set to increase exponentially in coming decades due to an ageing and increasingly obese population, it is imperative that we improve the management of arthritis in Australia if we are to alleviate the personal, social and economic burden of the condition. The Time to Move strategy outlined in this document provides a road map for improving care across Australia for people with arthritis. Although this document and the disease specific documents which accompany it focus on osteoarthritis (OA), rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA), people with other forms of arthritis will also benefit from implementation of the strategy.

The strategy outlines a best practice model of care for these conditions which addresses the spectrum of intervention from prevention to advanced disease and identifies key recommendations to support the implementation of the model. Disease specific aspects of the model and more detailed information and recommendations are provided in the accompanying documents, which are available at www.arthritisaustralia.com.au

The Time to Move strategy outlined in this document provides a road map for improving care across Australia for people with arthritis.

1. The case for change

1.1 Osteoarthritis

OA is highly prevalent, costly and disabling.

- OA is the most common form of arthritis affecting 1.9 million Australians.
- Although often referred to as "wear and tear" arthritis, OA is a disease and not an inevitable part of the ageing process 58% of people with OA are of working age.¹
- OA costs the health system \$3.75 billion a year¹, of which \$2 billion is due to joint replacements. The cost of joint replacements is increasing by \$80 million a year.¹⁰
- OA is one of the leading causes of chronic pain,¹¹ disability, early retirement and lost productivity in Australia.³
- The burden of OA is expected to increase exponentially in coming decades due to an ageing and increasingly obese population, with prevalence expected to reach three million Australians by 2032.¹

Current management of OA in Australia is inadequate. Over half of people with OA do not receive appropriate care according to current guidelines.⁶

Much can be done to improve prevention and treatment of OA, resulting in substantial savings to the health system.

- Up to 70 per cent of OA of the knee is preventable by avoiding excess weight gain and joint injuries.^{13,14}
- Implementing a sports injury prevention program could save the health system \$98 million a year in the short term through reduced sports injuries while substantially reducing the incidence of OA in the longer term.¹⁵
- Better management of OA in the earlier stages, including support for self management, weight loss and exercise, can improve symptoms and delay disease progression.¹⁶
- Reducing inappropriate referrals for joint replacement surgery and adopting better triage and management of people before surgery could save at least \$156 million in the first year due to reduced demand, shorter waiting lists and better outcomes for elective joint replacement surgery.¹⁷

For further information, see *Time to Move: Osteoarthritis* at <u>http://www.arthritisaustralia.com.au/images/stories/documents/reports/Time_to_move_osteoarthritis.pdf</u>

1.2 Rheumatoid arthritis

RA is a serious, chronic, autoimmune condition affecting around half a million Australians.¹

- In RA the body's immune system attacks the joints, causing pain, fatigue, joint swelling and stiffness.
- Inflammation also affects other organs, reducing life expectancy by six to seven years in those affected.¹⁸
- If poorly treated, RA can be highly disabling because it causes progressive and irreversible joint damage and loss of function.

RA can occur at any age but is most commonly diagnosed between the ages of 35 and 55 years,¹⁹ affecting people in the prime of their working lives.

• Up to one in five Australians diagnosed with RA is likely to be out of the workforce within five years because of their condition.²⁰

There is no cure for RA but dramatic advances in treatment over the past decade have resulted in major improvements to short-, medium- and long-term outcomes for those affected.

Early diagnosis and treatment of people with RA, ideally within 12 weeks of symptom onset, is crucial.

- There is a window of opportunity early in the disease during which aggressive treatment can alter the course of the disease, prevent or delay joint damage, increase the chance of disease remission and improve long-term outcomes, including reduced disability.^{21,22,23}
- Early diagnosis and appropriate treatment can prevent much of the joint damage, deformity and disability associated with RA.

Delays in diagnosing and treating people with RA and inequitable access to services, especially public services, impede care for people with RA in Australia and need to be urgently addressed.

- A recent study found that the median time between symptom onset and initiation of treatment was 173 days, with some patients experiencing delays of up to a year.²⁴
- The waiting time for the most urgent cases seen in public rheumatology outpatients clinics in Queensland was 111 days in the December 2013 quarter, while the waiting times for the next most urgent category was three years.²⁵

Multidisciplinary team care is also critical for effective management of people with RA but is not widely available in Australia, particularly in rural and remote areas and in the private sector, in which the majority of rheumatology practice takes place.

For further information, see *Time to Move: Rheumatoid Arthritis* at <u>http://www.arthritisaustralia.com.au/images/stories/documents/reports/Time_to_move_rheumatoid_arthritis.pdf</u>

1.3 Juvenile idiopathic arthritis

JIA is an inflammatory autoimmune condition that affects around 5000 Australian children.²⁶

- It causes stiff, painful and swollen joints, and some forms also affect other organs, such as the skin and eyes.
- If not treated quickly and appropriately, JIA can seriously affect the growth and development of a child, causing severe joint damage, growth abnormalities and permanent disability.²⁷
- Around 50 per cent of those diagnosed will continue to have ongoing active disease into adulthood. In these cases, the
 prolonged disease course and exposure to treatment increases the risk of disability, complications and other morbidities
 associated with the condition.²⁸

Early diagnosis and treatment of JIA are critical in preventing irreversible joint damage and achieving good long-term outcomes. The sooner an accurate diagnosis is made and appropriate treatment initiated, the better outcomes are likely to be.²⁹

Yet delays in diagnosing JIA in Australia are common.

- Up to 41 per cent of children in some areas experience delays of more than six months from symptom onset to diagnosis.³⁰
- Inadequate public and health practitioner awareness of the condition and limited access to specialist paediatric rheumatologists for diagnosis appear to be key factors leading to these delays.^{31,32}

The most significant barrier to best-practice treatment of JIA in Australia is the shortage of specialist paediatric rheumatologists and appropriately skilled allied health professionals to support multidisciplinary care. Some states/ territories have no paediatric rheumatologists.³³

For further information, see *Time to Move: Juvenile Idiopathic Arthritis* at http://www.arthritisaustralia.com.au/images/stories/documents/reports/Time_to_move_juvenile_idiopathic_arthritis.pdf

2. Methodology

Arthritis Australia convened a multidisciplinary steering committee to review current health service delivery in Australia for people with OA, RA and JIA and to recommend a model of care to support appropriate and timely diagnosis and treatment for these conditions. The committee included experts from rheumatology, general practice, pharmacy, patient advocacy, allied health and key services. A list of members of the steering committee is provided at Appendix 1, and the terms of reference is found in Appendix 2.

Core principles adopted by the committee in developing the model of care included identifying patient centred, evidence based, practical solutions that could be implemented and were sustainable. A summary of the core principles adopted is provided at Appendix 3.

The committee assessed existing care against local and international literature, guidelines, standards and models of care in developing its recommendations. In addition the committee identified priority areas which offer the greatest scope to reduce the burden of OA and are the most feasible to implement in the short term (See Priority areas).

A series of stakeholder consultations was also held across Australia to identify key issues and priorities to be addressed in the Time to Move strategy. These consultations were held in all capital cities and were hosted by the local arthritis organisation. Participants in these consultations included people with arthritis, carers, medical practitioners, nurses, allied health workers, pharmacists and researchers (see Appendix 4). The draft model of care was subsequently distributed to participants in the consultations for additional comment.

3. The Model

The intention of the proposed model of care is to identify key elements of best practice treatment and support for people with arthritis and their carers, recognising that local delivery models will vary across Australia, due to their dependence on existing systems, networks and resources.

A patient journey framework was used to develop the model and is also used to illustrate how the model will work. Examining the patient journey across the continuum of care from wellness through to advanced disease provides an accepted framework for considering how clinical and support services can be reorganised and improved to achieve high quality patient centred care.

In proposing this model, elements have been distilled from the range of models, standards and guidelines reviewed. However the current recommendations draw most heavily from the following models:

- Service Model For Community-Based Musculoskeletal Health In Western Australia. Department of Health, Western Australia, 2013;³⁴
- NSW Agency for Clinical Innovation. Model of Care for the NSW Paediatric Rheumatology Network, 2013; ³¹
- Osteoarthritis Chronic Care Program Model of Care, NSW³⁵; and
- UK Department of Health Musculoskeletal Services Framework (2006).³⁶

3.1 Key elements of care

The model of care aims to deliver the following key elements of care for people with or at risk of arthritis:

- increased community, health care provider and policy maker awareness and understanding of the personal, social and economic burden of arthritis;
- health promotion and primary prevention strategies to reduce the risk of developing arthritis;
- early diagnosis and appropriate intervention to prevent or delay disease progression and reduce future disability;
- accurate and accessible information, education and support for self-management that is age and culturally appropriate, both on diagnosis and as the condition progresses;
- equitable and appropriate access to primary, specialist and multidisciplinary care, including care coordination for more complex cases;
- access to appropriate evidence based pharmacological and non-pharmacological therapies in line with individual needs;

- effective ongoing management, including management of complications and co-morbidities;
- timely and equitable access to appropriate surgery;
- access to programs and services in the home, community, school and work environments to support independence and participation; and
- planned and managed transition services for adolescents moving from paediatric to adult health services.

3.2 Key components

The proposed strategy and model of care is based on the following key components:

- awareness raising campaigns and strategies;
- health promotion and primary prevention strategies;
- enhanced education and self-management support for people with arthritis;
- community based multidisciplinary arthritis clinics and teams;
- workforce capacity building, including enhanced support for primary care to provide effective management of people with arthritis; and
- research.

3.2.1 Awareness raising campaigns and strategies

The primary aim of awareness raising campaigns and strategies will be to support prevention, early detection, diagnosis and intervention in arthritis. Awareness raising campaigns will aim to:

- break down community misconceptions that arthritis is an old person's disease, and an inevitable part of ageing about which nothing can be done;
- increase public awareness of the signs and symptoms of arthritis and the importance of early diagnosis and intervention to encourage people to seek prompt attention, especially for symptoms of inflammatory arthritis.

A range of awareness raising strategies and campaigns are currently delivered by Arthritis Australia and state and territory arthritis organisations, but the scope and reach of these activities is constrained by limited resources.

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A more targeted and strategic approach could assist in enhancing the impact of existing awareness raising activities. Developing campaigns in partnership with other organisations, including associations of health professionals involved in the care of people with or at risk of arthritis, also offers scope to extend the reach and impact of awareness raising activities.

3.2.2 Health promotion and primary prevention

Up to 70% of OA is preventable by reducing overweight and obesity and preventing joint injuries, while smoking is a major risk factor for developing $RA.^{37}$

In addition to reducing the risk of developing arthritis, adopting a healthy lifestyle is important in managing most forms of arthritis and reduces the risk of associated co-morbidities, especially cardiovascular disease. This includes maintaining a healthy weight, participating in physical activity and exercise, avoiding or quitting smoking, and avoiding misuse of alcohol.

Public awareness of the increased risk of arthritis associated with overweight and obesity, joint injuries and smoking, however, is limited. There is an urgent need to support and include arthritis messaging in population based health promotion and obesity control strategies and to increase access to safe and effective healthy lifestyle and exercise programs for those with, or at risk of, arthritis. A range of commercial and government funded programs already exists to support physical activity and healthy lifestyles, including those funded by government through the Healthy Communities Initiative.³⁸ Working with organisations that deliver existing programs, to incorporate elements which address the needs of people with or at risk of arthritis, would provide a cost-effective means of enhancing arthritis prevention and management.

Increased support for GPs and other primary care health practitioners to provide healthy lifestyle advice and counselling and referrals to appropriate programs is also required, eg by developing local referral pathways and by accrediting programs offering safe and effective lifestyle interventions Medicare Locals have a role in building local workforce capacity and developing local referral pathways for access to effective community-based lifestyle counselling, exercise and weight loss programs.

In addition, there is scope to enhance the knowledge and skills of exercise professionals, and others delivering healthy lifestyle services, to ensure that they can develop programs that minimise the risk of joint injuries and are appropriate for people with or at risk of arthritis.

Implementation of a national sports injury prevention program is also an important preventive strategy that will both reduce the incidence of OA in the longer term and result in substantial savings to the health system, including in the short term.

3.2.3 Education and support for self-management

Self-management has been identified as a key strategy for managing chronic disease. Effective self-management requires access to information, education and support from health professionals and carers.³⁹

An evaluation of a range of self-management interventions in Australia across a number of chronic conditions found that these interventions reduced the use of health services, as well as improving health outcomes and quality of life. This evaluation also highlighted the importance of nurses, allied health and Aboriginal health workers in supporting self-management within the health system.⁴⁰

Few people with arthritis receive appropriate education and support to self-manage their condition.⁴¹ Arthritis organisations across Australia deliver a range of information and support services for people with arthritis, including self-management education programs. GPs, however, infrequently refer people with arthritis to these organisations⁴² and only one third of people with arthritis discusses self-management with their GP or specialist.⁴³

A more systematic and integrated approach to supporting patient education and self-management at the primary and secondary care levels is urgently required. Greater utilisation of health practitioners, such as nurses, physiotherapists and pharmacists, can provide more structured ongoing support for self-management for people with arthritis. In particular, increased utilisation for this purpose of nurses in general practice and rheumatology nurses, is recommended as a priority.

3.2.4 Multidisciplinary arthritis clinics

Multidisciplinary team care is consistently recommended in local and international guidelines and standards of care for people with most forms of arthritis but is not widely available in Australia. A key element of the proposed new model of care is to deliver multidisciplinary team care for people with arthritis who require complex care, through the establishment of community based multidisciplinary arthritis clinics. The clinics will deliver care for people with RA, JIA and other forms of inflammatory arthritis as well as more complex and advanced cases of OA.

These clinics will operate as a one-stop shop for diagnosis, assessment, triage, treatment and/or referral to other specialists and services. They may be located in a variety of different settings, including Medicare Locals, GP clinics, non-tertiary hospitals and community based clinics and health centres (as per the WA community services model).

Ideally the services provided by these clinics would be co-located to maximise convenience for the person with arthritis and to support integrated and coordinated care. Some services (e.g. diagnostic imaging, pathology or some allied health) may be available through referral to other providers nearby. In some areas, multidisciplinary team care may be delivered through partnerships between practitioners, linked by clear referral, management and communication protocols. In rural and regional areas and for more specialised care such as paediatric rheumatology, services may be provided through the clinics via outreach with telehealth follow-up, or via referral to other clinics where these services are available.

The clinics would also facilitate access to other specialist services such as orthopaedics, ophthalmology (for JIA) or cardiology through linkages, partnerships and referral pathways or through interdisciplinary clinics.

A guide to the components of a comprehensive service is provided in the WA Service Model for Community-Based Musculoskeletal Health³⁴ and the Osteoarthritis Chronic Care Program³⁵. However, the format, composition and location of these teams and clinics will vary according to local needs and available facilities, practitioners and resources. Nonetheless, core elements and features should include:

- access to an appropriately skilled multidisciplinary team, core members of which should include a rheumatologist, a rheumatology nurse, a physiotherapist, an occupational therapist, a psychologist and a social worker;
- care coordination and case management services provided by an appropriately qualified practitioner such as a GP, a nurse/nurse practitioner or allied health professional;
- assessment of a person's needs and the development of an individualised care plan;
- disease management education and support for self-management;
- triage and timely referral for services including other specialist services such as orthopaedic surgery; and
- engagement with the person's GP.

Establishment of these clinics could be facilitated by Medicare Locals in collaboration with local stakeholders and providers, including existing state musculoskeletal health networks. Local Hospital Networks are also likely to have an interest in establishing these clinics as an important outcome will be to streamline and reduce referrals to hospital outpatient clinics for elective joint replacement surgery.

3.2.5 Workforce capacity building

Rheumatologists

There is a need to address shortages and maldistribution in the rheumatology and paediatric rheumatology workforces to improve access to specialist diagnosis and care for people with arthritis, especially those with inflammatory arthritis. This is particularly important as rheumatologists are the only medical practitioners that can prescribe biologic disease-modifying anti-rheumatic drugs (bDMARDs) which are used to treat inflammatory forms of arthritis such as RA and JIA.

An expansion of training for adult rheumatologists under the Specialist Training Program in areas of significant shortfall (e.g. Queensland) and dedicated funding for a training position in paediatric rheumatology are required to improve access. Also, incentives to establish practice in currently underserviced areas should be explored.

Nurses

Internationally nurses, including advanced practice nurses and nurse practitioners, play an increasing role in delivering rheumatology care and services.^{44,45} Specialist nurses in rheumatology have been found to improve patient outcomes and reduce costs in both primary and specialist care.⁴⁶

There is substantial scope to develop a rheumatology nursing workforce in Australia to provide improved and cost-effective specialised supportive care for people with arthritis. The availability of an appropriately skilled nursing workforce could also support service delivery in currently underserviced areas, especially in rural and remote areas. At present however, it is estimated that there are only 30 to 50 rheumatology nurses in Australia. The recent development of an online Graduate Certificate in Musculoskeletal and Rheumatology Nursing, which has been available through the Australian College of Nursing since 2012, will assist in building this workforce.

Nurses in primary and secondary care can also play an important role in delivering disease management education, support for self-management and care coordination. Medicare Benefits Schedule items already

3. The model

allow remuneration for nurses in general practice providing monitoring and support for a person with chronic disease, although the uptake for arthritis to date is limited. There is no similar funding mechanism, however, to support increased utilisation of nurses in secondary care.

General practitioners

Evidence suggests that targeted information and education campaigns in easily accessible formats are required to improve diagnosis and management of people with arthritis by GPs and other health practitioners⁴⁷.

There is substantial scope to use internet-based programs and tools to provide accessible information to GPs and allied health practitioners on diagnosis and management of different forms of arthritis, including information on local services and referral pathways. Existing tools being implemented by some Medicare Locals, such as Health Pathwaysⁱ or Map of Medicine,ⁱⁱ could be used or new resources could be developed.

Models of care for other chronic conditions using upskilled GPs to provide specialist level care in a multidisciplinary primary care based clinic in collaboration with specialists, have also shown success (e.g. the Inala Chronic Disease Management Service). This could provide an effective model for outreach rheumatology services.

Allied health professionals

Shortfalls in confidence and skills among allied health professionals in the management of arthritis, and inflammatory arthritis in particular, have been demonstrated in Australia. Information and education programs targeting each of the allied health professional groups involved in arthritis care is required to upskill them to provide best practice care for people with arthritis.

There may also be scope to enhance the role of allied health professionals to support better care for people with arthritis. In a number of local and international models, physiotherapists act as case managers and take a leading role in the multidisciplinary management of both OA and inflammatory arthritis. Evidence also indicates that pharmacists could play an enhanced role in supporting multidisciplinary care for people with OA.⁴⁸ In a pilot study in South Australia, selected pharmacies are being provided with training, resources and an in-store health service to support people with arthritis and osteoporosis.⁴⁹

3.2.6 Research

Research into better ways to prevent and treat arthritis in Australia is currently constrained by limited capacity and funding.

Research into arthritis and musculoskeletal conditions in Australia is chronically underfunded relative to the personal, social and economic burden of these conditions and relative to other National Health Priority Areas (NHPAs). Total research funding for the arthritis and osteoporosis NHPA in 2013 was \$24m, lower than all the NHPAs except asthma, and has fallen over the five years to 2013, despite substantial increases in research funding overall.⁵⁰

There is a need to increase strategic investment in research funding for arthritis in order to support improvements in prevention, diagnosis and care. In particular there is a critical need to enhance translational research in musculoskeletal health and to undertake priority setting to identify the most important research questions that should be pursued.⁵¹

3.3 The ideal patient journey

The operation of the model is illustrated through outlining the ideal patient journey.

Stage 1: Arthritis prevention

Health promotion

People at the population level are encouraged to maintain healthy lifestyles including a healthy diet, physical activity, a healthy weight and avoidance or cessation of smoking.

People are aware that obesity, inactivity, joint injury and smoking can increase their risk of developing arthritis and are encouraged to adopt preventive strategies.

ⁱ Health Pathways provides an online health information portal for primary care clinicians to use at the point of care which also includes a guide to local resources

ⁱⁱ Map of Medicine is a collection of evidence-based, practice-informed care maps which connect knowledge and services around a clinical condition and can be customised to reflect local needs and practices

Those at risk of developing arthritis (and other chronic diseases) have access to advice and information to help them reduce their risk. They have access to information about local programs and resources and can access affordable community based programs (or other easily accessible programs e.g. internet) to support them to lose weight, be physically active and stop smoking. Health practitioners, including GPs, nurses, physiotherapists and pharmacists, are able to provide support and referral to effective programs to help people to reduce their risk.

Physical activity and sporting program service providers are aware of the need to protect joints from injury to prevent arthritis and have the skills to instruct their clients on how to reduce their risk of injury.

People who participate in fitness activities and sports are instructed and trained to avoid joint injuries.

People in occupations which are associated with an increased risk of OA are provided with advice and work practices designed to reduce the risk of developing OA.

Arthritis awareness

People are aware of the signs and symptoms of arthritis and that it can occur at any age, including childhood. They understand that effective treatment and management strategies exist and that early intervention is important. They are aware that symptoms of inflammatory arthritis - joint swelling, redness and prolonged stiffness - especially require prompt medical attention if they persist beyond 4-6 weeks.

Information on symptoms of arthritis and its management and sources of additional information, such as pamphlets and posters, are available in appropriate locations such as community health services, doctor's waiting rooms and pharmacies, as well as through reputable websites and social media sources.

Stage 2: Early diagnosis

People with symptoms of arthritis are able to find reputable sources of information in an easily accessible format (e.g. Arthritis Australia website, MyJointPain.org.au) that will help them to understand their symptoms and know when to seek professional help. People know that a telephone helpline is available and this helpline is widely promoted through pamphlets in pharmacies, GP waiting rooms, community health centres etc, as well as online sources.

For some people with mild OA, available information and resources may be enough to help them self-manage their condition.

People with symptoms may also choose to consult their GP, pharmacist, physiotherapist, nurse practitioner, paediatrician or orthopaedic surgeon. These health care professionals are trained to be knowledgeable about arthritis and its diagnosis and management and have easy access to resources, guidelines and local services. They are especially aware that symptoms indicative of inflammatory arthritis require urgent attention and referral to rheumatologists for specialist advice.

Making a diagnosis

People with symptoms of arthritis have access to health care professionals competent to make a diagnosis or to refer appropriately. These health care professionals are aware of (or have easy access to tools and resources providing detailed information on) diagnostic criteria for OA, RA and JIA, and appropriate imaging and tests required to assist in confirming a diagnosis.

For people with early OA, the diagnosis is confirmed by their primary care practitioner.

Adults and children with suspected inflammatory arthritis are referred promptly to local multidisciplinary arthritis clinics/teams for confirmation of diagnosis. These clinics/ teams are facilitated by Medicare Locals or other local health services and are available in most areas. People are seen within six weeks of referral. Both public and private services are available. People living in rural and remote areas have access to outreach services close to home, with local care and support provided by appropriately skilled practitioners, such as GPs and rheumatology nurses.

The clinics provide access to rheumatologists, and, wherever possible paediatric rheumatologists and are supported by triage services and/or early arthritis clinics to ensure timely access for the most urgent cases. Triage and assessment services may be conducted by appropriately trained health care professionals including GPs, rheumatology nurses and physiotherapists. Specialist services available through these clinics may be provided by local specialists or through outreach clinics and telehealth services, depending on local needs and resources.

People living in rural and remote areas have access to outreach services close to home, with local care and support provided by appropriately skilled practitioners, such as GPs and rheumatology nurses.

3. The model

Stage 3: Early treatment

Osteoarthritis

People diagnosed with mild to moderate OA are appropriately managed in primary care, by their GP or by a physiotherapist or an appropriately trained or credentialed pharmacist working in consultation with the person's GP. The person's health care practitioner is knowledgeable about best practice management for OA and about the role of other health care providers and has easy access to resources, guidelines and local services.

On diagnosis, the primary care practitioner assesses the person with OA for pain, function, physical activity levels, weight and general health, including any co-morbidities. An individualised management plan is developed in collaboration with the person with OA. The management plan includes:

- advice on appropriate physical activity and exercise;
- information on weight loss/management if required;
- information on nutrition;
- information on the role of other practitioners such as physiotherapists, occupational therapists, pharmacists, psychologists, exercise physiologists and weight management service providers;
- referral to these services, if appropriate;
- information and advice on medications, if required; and
- a strategy to support self-management including a designated primary contact for support and advice (e.g. a nurse in general practice), a schedule for reviewing progress, and options to escalate selfmanagement support (e.g. telephone coaching, CBT approaches) if required.

At diagnosis the person with OA is also provided with information and education about their condition and its management and support to help them to self-manage their condition. In a general practice, this information, education and support is most likely to be provided by an appropriately trained nurse.

The person with OA is advised about tools and additional resources to help them self-manage their condition including telephone coaching services, MyJointPain.org.au and local arthritis organisations which can provide services including self-management education, support groups and exercise programs.

Regular reviews are scheduled to monitor how well the person is coping with their condition.

Rheumatoid arthritis and juvenile idiopathic arthritis

People and children with early/suspected inflammatory arthritis are referred promptly to local multidisciplinary arthritis clinics/teams for confirmation of diagnosis, assessment and treatment. Referrals to the clinics are triaged to ensure the most urgent cases are seen promptly.

For children and young people with JIA, referrals should be to the closest clinic at which paediatric rheumatology services are available, although shared care arrangements may be put in place for ongoing care.

On diagnosis, people and children with inflammatory arthritis receive a comprehensive assessment of their disease, general health and psychosocial needs and an individualised multidisciplinary care plan is developed. The plan includes evidence based pharmacological and non-pharmacological treatments, patient set goals and targets and school and vocational support as necessary. Family and carers are involved in care planning as appropriate. For children and young people with JIA, the plan also addresses the support needs of family members.

People with arthritis have a nominated case coordinator and educator, usually a rheumatology nurse, who provides them with tailored information and education on the disease and its management and provides ongoing psychosocial support and support for self-management. The case coordinator also maintains communication with the person's GP or local health care provider. People are also advised about other resources and supports available to them including age and culturally appropriate resources and services offered by state and territory arthritis organisations such as self-management education programs, exercise programs and support groups. A comprehensive information pack and tools to help people to monitor and manage their own condition is provided to the person in either a hard copy or online format, in line with patient preferences.

Appropriate therapy with disease modifying anti-rheumatic drugs (DMARDs) is initiated promptly by the rheumatologist with frequent monitoring of treatment response and reviews of therapy until remission or low disease activity is achieved.

Appointments with members of the multidisciplinary team for assessment and treatment are coordinated so that they can be completed on the one day. If people need to travel a long distance to access the specialised multidisciplinary team and would prefer to receive treatment closer to home, arrangements are made with local health professionals located nearer to the person's home to deliver appropriate therapy and support.

People have the choice of accessing either public or private services for their treatment. If they elect to receive private services, adequate funding for these services, especially allied health services, is available through Medicare.

Stage 4: Ongoing management

As OA progresses, the level of functional decline, disability and the number of co-morbidities tends to rise, increasing the complexity of care and the level of support required to achieve best outcomes. More intensive, coordinated multidisciplinary care is usually required to achieve best outcomes and to support people to manage their condition.

At this stage, people with OA will be referred to their local multidisciplinary arthritis clinics for assessment and for the provision of more intensive coordinated care, including appropriate management of co-morbidities.

For people with RA and children with JIA whose disease is well controlled, ongoing management is provided by their GP in a shared care arrangement with the multidisciplinary team, which reviews the person every six months. However if the person experiences a disease flare or if they are no longer responding to treatment, they are able to access specialist advice urgently.

The GP has access to information and resources to assist in managing the person and their condition, including algorithms to support disease monitoring, screening for complications and co-morbidities and referral back to the multidisciplinary clinic if required.

Support is provided at all stages and across all health service providers to encourage children, young people and adults with arthritis to adopt healthy lifestyles including maintaining a healthy weight, physical activity and exercise, good nutrition, smoking avoidance/ cessation and avoidance of alcohol misuse.

People with arthritis who are struggling to retain employment due to their condition have access to advice and programs to assist them to remain in the workforce.

Stage 5: Advanced stage care and surgery

People with arthritis who may require more advanced care or surgery are referred to the multidisciplinary clinic for triage, management and referral.

Protocol driven triage arrangements ensure that people who require and are suitable for surgery, including

joint replacement surgery, receive timely referral to an orthopaedic consultant and are seen within clinically recommended times. They are provided with clear information about the procedure and the risks and benefits of joint replacement surgery, effective preparation for surgery to ensure best outcomes (e.g. weight loss) and arrangements for rehabilitation after surgery. If the person decides to proceed they are put on the elective joint replacement waiting list or are offered the option of having the procedure in a private facility. Surgery in both sectors takes place within clinically recommended times.

Those awaiting surgery or who are not yet ready for surgery, or for whom surgery is not indicated, receive appropriate care to minimise pain and maximise function and independence.

Access to necessary home modifications, community services and aids and equipment to support independence and mobility is facilitated through the multidisciplinary team members.

4. Benefits of implementing the model

The key benefit of adopting this model will be to improve the management and support of people with arthritis. This will provide significant benefits to individuals by reducing the pain and disability associated with arthritis, helping them to maintain their independence and quality of life and maximising their ability to work and participate in social activities.

Significant benefits will also accrue to the health system, society and the economy from better management of these highly prevalent and disabling conditions. These benefits include:

- a reduction in direct health system costs of around \$98 million per year due to a reduction in sports injuries that could be realised within a year of implementing a comprehensive national sports injury prevention program, with further long term savings due to reduced OA prevalence and severity;⁵²
- savings of at least \$156 million in the first year due to reduced demand, shorter waiting lists and better outcomes for elective joint replacement surgery due to a reduction in inappropriate referrals for surgery and better triage and management of people before surgery;⁵³
- reduced demand for joint replacement surgery in the medium to long term relative to current trends as a result of the better management of earlier stage disease;
- higher rates of workforce participation and workforce retention for people with arthritis;
- reductions in the prevalence and severity of arthritis-related disability and a reduction in welfare payments including the Disability Support Pension; and
- improved management of co-morbidities including cardiovascular disease and diabetes for people with arthritis.

5. Recommendations

Many of the recommendations to improve care for people with RA, OA and JIA are similar and these recommendations are drawn together thematically below. Some additional recommendations specific to each condition can be found in the accompanying disease specific papers.

- 1. Increase public, health practitioner and policymaker awareness and understanding of arthritis and opportunities for prevention and improved management
- 2. Prevent arthritis and support lifestyle modification to help people with arthritis to manage their condition
 - 2.1 Work with organisations active in obesity, smoking, and chronic disease prevention and those delivering healthy lifestyle, physical activity and sporting programs to incorporate messaging and programs relating to arthritis prevention and management
 - 2.2 Work with sporting organisations and the fitness industry to implement a national sports injury prevention program

3. Support early diagnosis and intervention

- 3.1 Utilise existing telephone hotlines/website booking services (eg HealthDirect, HealthEngine) to facilitate urgent referrals to a rheumatologist for early diagnosis and treatment for children and adults with suspected JIA or RA
- 3.2 Support improved education of primary health care professionals to promote early diagnosis and intervention
- 3.3 Conduct early arthritis clinics in underserviced areas to provide triage to improve early access to specialist care

4. Improve information, education and support for people to self-manage their condition

- 4.1 Increase utilisation of practice and rheumatology nurses and/or other allied health professionals, including pharmacists and physiotherapists, to provide patient information, education, and selfmanagement support, psychosocial support and for more complex cases, care co-ordination
- 4.2 Develop national comprehensive disease specific information packages and tools for people diagnosed with arthritis to help them understand their condition and its treatment, navigate their way around available services and supports, set and monitor individual treatment goals and manage their own care
- 4.3 Refer those newly diagnosed to arthritis state and territory organisations for access to information resources, self-management education and support groups

5. Provide equitable and timely access to multidisciplinary care for people with severe or inflammatory arthritis

- 5.1 Establish community based multidisciplinary arthritis clinics/teams providing both public and private services, in collaboration with Medicare Locals and other stakeholders
- 5.2 Develop system incentives/funding models to support the delivery of multidisciplinary care in the private sector, including increasing access to Medicare subsidised allied health visits under Chronic Disease Management plans, in line with clinical requirements
- 5.3 Provide services in rural/underserviced areas through specialist and multidisciplinary outreach clinics, with additional support through telehealth services

6. Support best practice treatment and care specific to each form of arthritis including

- 6.1 Support the adoption of a target based treatment approach for people with RA which aims for clinical remission or low disease activity based on systematic measurement of treatment outcomes
- 6.2 Improve transition planning and care for young people with JIA moving to adult services
- 6.3 Develop and implement strategies to promote conservative management of OA in primary care, especially exercise and weight loss
- 6.4 Develop and implement strategies to improve access to timely, appropriate joint replacement surgery

7. Build health workforce capacity to better manage people with arthritis

- 7.1 Develop information and education materials, programs and tools (including for eg shared care protocols) for GPs, specialists and allied health practitioners, to support early diagnosis and appropriate treatment for people with arthritis
- 7.2 Upskill nurses in general practice and build a cadre of rheumatology nurses to provide care and support for people with arthritis
- 7.3 Increase the number of rheumatologists and paediatric rheumatologists in underserviced areas by providing dedicated funding for paediatric rheumatology training and expanding the existing Specialist Training Program in areas of need

8. Support quality improvement in arthritis care

- 8.1 Develop a quality indicator framework and data sources to monitor management and quality of arthritis care in Australia
- 8.2 Increase strategic investment in research funding for arthritis in order to support improvements in prevention and care.

6. Priorities and implementation

The following priority areas for implementation have been identified by the steering committee as offering the greatest scope for reducing the burden of arthritis and being the most feasible in the short term:

- strategies to support early diagnosis and urgent referral to rheumatologists for people with RA, and to paediatric rheumatologists for children with JIA;
- providing equitable access to specialist services and multidisciplinary care for people with severe or more complex disease;
- adopting a target based treatment approach for RA;
- increasing utilisation of nurses in general practice and rheumatology nurses to provide patient information, education, and self-management support, psychosocial support and for more complex cases, care co-ordination;
- providing dedicated funding for paediatric rheumatology training;
- improving transition planning and care for young people with JIA moving to adult health services;
- implementing a national sports injury prevention program;
- optimising patient selection and timing for joint replacement surgery; and
- developing a joint position statement on arthroscopies for OA.

Implementation of the strategy will require collaboration between stakeholders across all sectors of the health system, as well as the health promotion sector. Arthritis Australia will work with relevant staeholders to encourage and support the implementation of the Time to Move strategy.

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Models of care steering committee

Name	Organisation/Background
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Mr Jeff Cheverton	Metro North Brisbane Medicare Local
Prof Peter Choong	Orthopaedic surgeon
Ms Anne Develin	The Pharmacy Guild of Australia
Ms Wendy Favorito	Consumer director, Arthritis Australia
Dr Stan Goldstein	Bupa Australia
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Prof Danny Liew	Epidemiologist
Dr Mona Marabani	Rheumatologist (RA)
Ms Franca Marine	Arthritis Australia
Ms Maree Raymer	Physiotherapist
Ms Jennie Roe	Consumer representative
Dr Norman Swan	General practitioner and media commentator
Dr Rob Walters	General practitioner

Appendix 2

Steering committee terms of reference

- 1. Examine and document the patient journey and current model of care for rheumatoid, osteo and juvenile idiopathic arthritis patients (and any other patients deemed appropriate by the steering committee) within the Australian context.
- 2. Identify, within the current patient journey and against existing models of care, any facilitators or barriers to appropriate and timely diagnosis and treatment of these conditions. Identify if there is a preventable burden of disease that is being created through system/model of care barriers.
- 3. Critically review both the patient journey and any identified model of care issues against both local guidelines and system requirements for the treatment of these conditions.
- 4. Examine Australian Government policy and research activities in arthritis compared to other chronic conditions. Identify additional activities that should be undertaken by Government to adequately address, from a policy and practice perspective, the treatment of patients with these conditions.
- 5. Examine international models of care and review against the Australian system. Identify any measures that could reasonably lead to improving patient outcomes if adopted in Australia.
- 6. Develop, with supporting evidence, a model of care that ensures appropriate and timely diagnosis and treatment of these conditions. Include within this model the role of general practice, specialists and allied health professionals.
- 7. Develop a policy white paper outlining a new model of care that adequately takes into account existing health care structures and budget requirements.
- 8. Based on options in the white paper, develop a clear and implementable plan for both a proof of concept test phase and implementation of the developed model of care. This plan should take into account operation of the model within the current system and any changes in policy or system structure required by Government for its full implementation.
- 9. Develop a communication plan that advocates for the implementation of the white paper in both policy and practice.

Core principles for developing the model of care

The Steering Committee adopted the following core principles for developing the model of care:

- follow the patient journey;
- use best practice evidence based care;
- be patient centred and outcomes focussed;
- use a systems approach;
- be integrated with other services;
- provide practical solutions and is implementable;
- support primary prevention;
- support early diagnosis and management; and
- be sustainable.

Participants in stakeholder consultations

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ACT		
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