EVIDENCE TO SUPPORT THE NATIONAL STRATEGIC ACTION PLAN FOR ARTHRITIS

Arthritis Australia 2019

Contents

1 Burden and cost of arthritis

Arthritis is one of the most common, costly and disabling chronic conditions in Australia. Key indicators of the cost and burden of arthritis include:

- Arthritis affects 3.9 million Australians of all ages, including 2 million people of working age and 6000 children [1].
- There are more than 100 different types of arthritis. The most common forms are osteoarthritis, which affects 2 million people, and rheumatoid arthritis, a serious autoimmune condition affecting nearly half a million people [1].
- Inflammatory forms of arthritis, including rheumatoid and juvenile arthritis and related conditions affect 1.7 million Australians [1].
- Arthritis cost the health system $5.5 billion in 2015 [1].
- Hip and knee replacements for osteoarthritis cost the health system around $2.3 billion in 2012/13 [2] and this cost is projected to rise to $5.3 billion by 2030 [3].
- Arthritis and musculoskeletal conditions account for 12% of the total burden of disease and injury in Australia, equivalent to mental health conditions. Arthritis alone accounts for 8% of the total burden of disease. [4]
- Arthritis is the leading cause of chronic pain [5] and the second most common cause of disability in Australia[6].
- Arthritis is one of the most common comorbid conditions. Three out of four people with arthritis have at least one other chronic condition while 52% of people with COPD, 41% of people with diabetes and 41% of people with cardiovascular disease report that they also have arthritis [7].
- Arthritis increases the risk of developing other chronic conditions, and subsequently complicates their management, due to its treatment (e.g. with non-steroidal anti-inflammatory drugs or corticosteroids) and impact on mobility and systemic inflammation [8].
- Arthritis is the second leading cause of early retirement due to ill health, costing $1.1 billion in extra welfare payments and lost taxation revenue and $7.2 billion in lost GDP in 2015 [9]. Arthritis also accounts for nearly half (40%) of the loss in full-time employment and 42% of the loss in part-time employment due to chronic disease [10].
- One in four people with arthritis experiences mental health issues. People with mental health conditions are also around 50% more likely to have arthritis than the general population [11].
- By 2030, 5.4 million Australians will have arthritis, costing the health system more than $7.6 billion unless more is done to prevent and improve the management of the condition [1].

2 Arthritis awareness

Although arthritis is very common, it is not well understood. Many in the community incorrectly believe that arthritis is an old person's disease, an inevitable part of ageing, for which nothing can be done. These misconceptions create a sense of futility among consumers, carers and health care professionals which can undermine prevention, early diagnosis and effective management of the condition in its many forms [12, 13].

Recent polling for Arthritis Australia indicates that only 10% of adults report that they know a lot about arthritis. Even among people with arthritis, only one in three reports that they know a lot about the condition [14].

Limited public awareness of rheumatoid arthritis, its potential severity and the importance of early treatment, has been identified as a major impediment to seeking early medical attention [15]. Poor symptom recognition among the community and health professionals has also been highlighted as a major contributing factor in diagnostic delays for ankylosing spondylitis, which have been shown to be up to 11 years [16].

People living with arthritis also report that poor public awareness of arthritis is a major issue for them because there is limited understanding of the impact that severe arthritis can have on a person's life, including their ability to socialise, study or work [17]. In addition to limited general community awareness, people with arthritis often report that their health care professionals, even specialists, do not understand the impact that a person's arthritis can have on their daily lives, especially pain and fatigue [18].

Awareness raising campaigns may help to address these issues. There are, however, very few published studies on the benefits and cost effectiveness of arthritis awareness campaigns. New Zealand successfully implemented television public awareness campaigns that were associated with significant increases in referrals to rheumatology services for suspected ankylosing spondylitis [19]. In the US, a rural health communications campaign was implemented to promote awareness about arthritis and the beneficial effects of physical activity [20]. The campaign was implemented through radio, print and distribution of brochures and flyers. However, while 86% of respondents reported having seen or heard the messaging, only 11% recalled the messages [20].

In the United Kingdom, the *S Factor* campaign was run from early 2011 to raise public awareness of the symptoms of rheumatoid arthritis and to encourage people with these symptoms to see their doctor promptly. However, due to resource constraints, no formal evaluation of the campaign was undertaken [21].

In a related area, a mass-media campaign conducted in Victoria, Australia, was effective in favourably changing attitudes and behaviours relating to back pain management among both the general population and general practitioners. The campaign led to a clear decline in number of workers compensation claims for back pain, rates of days compensated, and medical cost of claims for back problems. The impact of the campaign was sustained over time [22, 23].

3 Prevention

Like most chronic conditions, arthritis is associated with a number of modifiable and non-modifiable risk factors, including age, gender, genetic predisposition and lifestyle factors.

It has been estimated that up to 70% of cases of osteoarthritis (OA) of the knee could be prevented by preventing obesity and joint injuries [24]. Less is known about modifiable risk factors for inflammatory and auto-immune forms of arthritis although smoking is a strong risk factor for rheumatoid arthritis and obesity is implicated in psoriatic arthritis (PsA), gout and increasingly, rheumatoid arthritis. There is currently some research into pre-clinical prevention in rheumatoid arthritis, based on biomarkers [25], and vaccination [26].

The risk factors that currently appear to offer the greatest potential for arthritis prevention at the population level are overweight/obesity, joint injuries, occupational factors and smoking.

3.1 Overweight and obesity

3.1.1 Associated risk

Osteoarthritis

Excess weight is the most important modifiable risk factor associated with the development and progression of osteoarthritis, especially of the knee [24, 27, 28-30]. Forty-five percent of the osteoarthritis burden in Australia is attributable to overweight and obesity [31].

Rising numbers of overweight and obese people, increases in obesity at earlier ages, and increases in the number of people who are very obese [32] are expected to lead to higher prevalence, earlier onset and greater severity of osteoarthritis (especially of the knee) in the future [12].

The risk of developing osteoarthritis rises as excess body weight increases, and the earlier in life a person gains excess weight, the greater that person's risk of developing osteoarthritis [33]. Obese people are 2.6 times as likely to develop knee osteoarthritis as people of healthy weight, while obese people are four to seven times as likely, and very obese people are 14 times more likely to develop knee osteoarthritis compared to people of normal weight [27, 33-35]. Each additional unit of weight gain results in a fourfold increase in joint loading [36], and for each five kilograms of weight gain, the risk of developing knee osteoarthritis increases by 36 per cent [37]. Obesity also leads to a modest increase in the risk of developing hip osteoarthritis [28] and, possibly, osteoarthritis of the hand [38].

The impact of excess weight on osteoarthritis risk is likely to be both mechanical (due to increased joint loading) and systemic (a result of metabolic and inflammatory factors) [39, 40].

Obesity control is also an important aspect of secondary prevention for osteoarthritis. In addition to increasing the risk of developing osteoarthritis, obesity adversely affects outcomes for people at every stage of the disease. Persistent obesity aggravates the pain and disability associated with osteoarthritis, accelerates disease progression and raises the likelihood of requiring joint replacement [33]. An Australian study found that greater weight and body mass index at age 18 to 21 years that persisted into middle age was associated with an increased risk of 25 per cent for knee replacement and 11 per cent for hip replacement [41]. In older women, obesity can increase the likelihood of needing knee replacement tenfold [42].

Obesity also leads to poorer outcomes from joint replacement surgery and accelerates implant failure, increasing the need for repeated operations. Nearly half of obese patients undergoing joint replacement surgery have poor outcomes, compared to less than 10 per cent of those of normal weight [33].

Inflammatory arthritis

Obesity is a risk factor for gout [43, 44] and psoriatic arthritis and possibly other autoimmune musculoskeletal diseases [45-47]. There is also increasing evidence that obesity increases the risk of developing rheumatoid arthritis [48]. Some have suggested obesity or overweight may be a factor in certain types of rheumatoid arthritis, especially in at-risk women, and may play a role in the pre-clinical stage [49].

In addition to being associated with an increased risk of some forms of inflammatory arthritis, obesity decreases the odds of achieving remission in rheumatoid arthritis and negatively impacts disease activity and patient-reported outcomes during therapy [50]. Obesity has also been found to hamper the effectiveness of tumour necrosis factor inhibitor (TNFi) therapy in rheumatoid arthritis, spondyloarthritis and psoriatic arthritis [51, 52]. However, some studies suggest that being overweight or obese may actually protect against joint damage in the early stages of rheumatoid arthritis [45].

3.1.2 Interventions to reduce risk

Almost two in three adults and one in four children in Australia are overweight or obese, with obesity rates even higher in some population groups, including people in lower socioeconomic groups, those living outside major cities and indigenous Australians [53].

It has been estimated that preventing obesity at the population level could reduce the prevalence of symptomatic knee osteoarthritis in Australia by 43 per cent, and of knee osteoarthritis requiring joint replacement by 53 per cent [27]. Comparable estimates for obesity and inflammatory forms of arthritis could not be found, with the exception of gout, for which 39% of the burden is attributable to overweight and obesity [31].

Weight loss of just seven per cent in obese individuals without knee osteoarthritis has been shown to improve knee structure [54], while losing five kilograms of excess weight has been estimated to reduce the risk of developing knee osteoarthritis, especially in women, by around 50 per cent [37, 55].

However, prevention of overweight and obesity is complex and no country to date has been successful in reversing the obesity pandemic [56]. The health behaviours which contribute to overweight and obesity are underpinned by a complex range of social, economic, educational and environmental factors. Evidence suggests that strategies targeting individual behaviours relating to diet, energy intake and physical activity without changing the many determinants of these behaviours are unlikely to achieve significant or sustained outcomes. A comprehensive, multi-sectoral approach to improving physical activity levels and nutrition aimed at reducing overweight and obesity at the population level is required [57-59].

The World Health Organisation suggests supportive environments and an integrated approach involving all sectors of society are central in preventing overweight and obesity. Evidence-based and population-based policies can make the healthy choices, in terms of diet and physical activity, the easiest choices, by making them easily accessible, available and affordable [60]. The Global Action Plan for the Prevention and Control of Noncommunicable Diseases 2013-2020 [61] provides a road map and policy options for addressing certain behavioural risk factors, including physical inactivity and unhealthy diet. Although the Action Plan does not specifically address musculoskeletal conditions, tackling these shared behavioural risk factors is likely to positively influence the population risk of developing arthritis.

Multi-factorial interventions that target diet and physical activity, with behaviour change components, can be successful at an individual level. Policy and regulatory approaches are generally more cost-effective than health promotion or clinical interventions, and are potentially even cost-saving [62].

The Australian Obesity Prevention Consensus [63] outlines eight policy actions that could underpin a national obesity prevention plan. These policies are drawn from the many national and international recommendations on obesity prevention:

1. Reduce exposure of children aged under 16 years to unhealthy food and drink marketing by implementing restrictions on marketing on free-to-air television.
2. Drive reformulation of packaged and processed foods to make them healthier and improve community access to healthy food options.
3. Support healthier food choices through better food labelling and rating.
4. Develop a national active travel strategy to promote walking, cycling and use of public transport.
5. Deliver public education programs to improve attitudes and behaviours around diet, physical activity and sedentary behaviour.
6. Reduce consumption of sugary drinks through levies that raise prices of sugar-sweetened soft drinks, energy drinks, fruit drinks and sport drinks.
7. Establish obesity prevention as a national priority with ongoing monitoring, evaluation and reporting of key measures.
8. Develop national guidelines for diet, physical activity and weight management.

Australia currently lacks a coordinated, strategic obesity prevention strategy [64]. A recent review of community-based initiatives reported programs were usually short-term (less than three years), delivered by health departments and local governments, primarily focussed on individual behaviour change strategies and demonstrated low use of research evidence and existing prevention frameworks [65]. Few initiatives adopt the recommended multi-level strategic approach incorporating policy, built environment, social marketing and/or partnership building [66].

However, in late 2018 the Council of Australian Governments agreed to develop a national obesity strategy. Some action is also underway in certain areas such as food re-formulation, food labelling [67] and encouraging increased participation of children and young people in sports and physical activities [68].

At the individual level, multi-modal approaches to weight loss incorporating diet, physical activity and exercise, and support for behavioural change have been shown to be effective[69].

3.2 Joint injuries

3.2.1 Associated risk

Joint injuries are an important risk factor for osteoarthritis and the leading cause of knee osteoarthritis in young adults [70]. A person who suffers a knee injury is four to five times more likely to develop knee osteoarthritis than someone who does not [35, 71]. In particular, ruptures of the anterior cruciate ligament (ACL), a major supporting ligament in the knee, are linked to osteoarthritis changes in 50 to 70 per cent of patients 10 to 15 years following the injury [72], regardless of whether or not an ACL reconstruction is performed [73].

It is estimated that 25 per cent of incident symptomatic knee osteoarthritis in men and 14 per cent in women could be prevented by preventing knee injuries [24].

Australia has the highest reported ACL injury rates in the world. About 72% of ACL reconstructions in Australia are sport-related and most occur in adolescents and young adults, with the result many people develop osteoarthritis at a relatively early age (30 to 50 years old), with associated pain and disability. The sports most frequently involved are Australian rules football, rugby union, rugby league, netball, basketball, soccer, and skiing [73]. Since 2000, the rate of knee reconstruction in Australia has increased by 43% for individuals of all ages and 74% for those aged less than 25 years. At greatest risk are men aged 20 -24 years and women aged 15 – 19 years, although the incidence of ACL reconstruction is increasing most rapidly among five to fourteen year old children [73].

3.2.2 Interventions to reduce risk

There is over 20 years of strong evidence from multiple clinical trials in Australia and overseas confirming that neuromuscular conditioning programs are effective in significantly reducing knee and ankle injuries [24]. These programs have been shown to reduce the risk of ACL injury by up to 60 per cent, of ankle sprains by 50% and of lower limb injuries by 39% [72, 74, 75]. Conditioning programs can protect against both acute and overuse or gradual onset injuries and reduce the severity of injuries that are sustained [75]. In addition to injury prevention, these programs can improve performance by increasing strength, balance, agility and running speed [73].

Neuromuscular training programs typically consist of a structured warm-up, and balance, stretching, strength and agility training. They replace traditional warm-ups, usually take 15- 20 minutes, and are designed to be undertaken 2-3 times per week.

Sports injury prevention programs have been implemented successfully in a number of countries, including Norway (handball), Switzerland (soccer) and New Zealand (rugby), showing sustained reductions in injury rates [76]. A number of international organisations including the International Olympic Committee (IOC) and International Federation of Association Football (FIFA) have supported the implementation of injury prevention programs.

In Australia, the FootyFirst program was developed specifically to reduce common leg injuries in community Australian football. It is based on evidence from a clinical trial showing that community Australian football players undertaking the program had a 50% reduction in knee injuries and a 22% reduction in lower limb injuries [77].

Player compliance, tailoring the exercise program to the specific sport and focusing on coach education have been identified as key factors in the success of injury prevention programs [76, 78].

Modelling suggests that targeting high risk participants aged 12-25 years as part of a national sports injury prevention program would reduce ACL injuries by 40 per cent, saving the health system over A$277 million in direct medical costs over the lifetime of the individuals affected [79]. An Australian agility training program would prevent 3,764 lifetime ACL ruptures, 842 lifetime cases of osteoarthritis and 584 total knee replacements per 100 000 individuals. For every 27 high-risk sports participants involved in an injury prevention program, one individual would avoid an ACL injury [75].

3.3 Occupational factors

3.3.1 Associated risk

Osteoarthritis

Occupational activity has long been recognised as a risk factor for osteoarthritis of the hip and knee. Occupations with a heavy physical workload that involves kneeling, squatting, heavy lifting or climbing are at particular risk for developing osteoarthritis of the lower limbs [80, 81]. Such occupational activities have been estimated to increase the risk of knee osteoarthritis by a factor of 1.6 [81]. Occupations associated with the greatest risk include farming, construction work (especially bricklaying and flooring installation), and health care workers [82]. It has been estimated that modifying tasks that typically involve heavy lifting and squatting could prevent 15 to 30 per cent of knee osteoarthritis [83].

Inflammatory arthritis

One study has reported that long-term occupational noise exposures might be a modifiable risk factor for rheumatoid arthritis, however further research is needed to confirm this association [84]. Inhalation of dust, metals and fumes is a significant trigger for rheumatoid arthritis development, particularly in men [85]. Working in cold environments is associated with an increased risk of anti-citrullinated protein antibody (ACPA)-positive and ACPA-negative rheumatoid arthritis, especially for work involving repetitive finger or hand movements [86].

3.3.2 Interventions to reduce risk

Mandated occupational health and safety (OHS) requirements in Australia outline safe work standards and establish obligations for employers to address health and safety hazards in the working environment. These obligations include considering the OHS implications of specific manual tasks and ‘body stressing’ that may increase employees’ risk of developing or aggravating osteoarthritis [87].

Safe Work Australia has a Code of Practice for Hazardous Manual Tasks that provides practical guidance on managing the risk of musculoskeletal disorders, including ‘joint and bone injuries or degeneration’, arising from hazardous manual tasks [87].

While musculoskeletal disorders are the most common conditions cited in worker’s compensation claims, accounting for 43 per cent of injury and disease-related claims in Australia in 2003, less than one per cent of claims are for osteoarthritis [88]. The long latency period for the development of osteoarthritis as well as difficulties in attributing causality almost certainly contribute to the under-representation of the condition in worker’s compensation claims.

Safe Work NSW is implementing a Musculoskeletal Disorder Strategy (2017-2022) to reduce serious work-related musculoskeletal injuries and illnesses by 30% by 2022 [89].

3.4 Smoking

3.4.1 Associated risk

Smoking is the main modifiable risk factor for developing rheumatoid arthritis [90, 91]. Exposure to smoking is estimated to account for approximately 20 to 30% of environmental risk for rheumatoid arthritis. Smoking appears to interact with genetic and environmental factors to increase susceptibility to rheumatoid arthritis [92]. The risk increases with the intensity of smoking, with a 26% increased risk among those who smoked 1 to 10 pack-years compared to non-smokers. The risk doubled among those with more than 20 pack-years [93].

Smoking is most strongly associated with ACPA-positive rheumatoid arthritis, particularly in individuals with a background genetic risk [49]. It has been suggested that there may be a biological interaction between smoking and genetic factors that drives the development of rheumatoid arthritis or rheumatoid arthritis-related autoimmunity [49]. Smoking cessation also appears to reduce the risk of developing rheumatoid arthritis over time [94, 95]. In addition, smoking is associated with greater disease severity and poorer clinical response to some therapies for rheumatoid arthritis [96, 97].

There does not appear to be any association between smoking and the development or severity of osteoarthritis [98].

3.4.2 Interventions to reduce risk

Smoking rates in Australia have dropped by nearly 10 percent over the past two decades, producing one of the lowest smoking prevalence rates in the world [99]. Daily smoking rates have halved from 24% in 1991 to 12% in 2016. Smoking rates are higher in some population groups including indigenous Australians (42%), people in rural and regional areas and in low socio-economic areas (18%), and people aged 40 years and over (16.9%) [53].

At an individual level, pharmacotherapy-based interventions such as nicotine replacement therapy can improve smoking quit rates by 50–70% [100] and a combination of behavioural and pharmacotherapy interventions can increase smoking cessation success even further [101].

In Australia, population awareness of the increased risk of rheumatoid arthritis due to smoking is low with a recent survey showing only 27% of respondents were aware of this association, the lowest awareness of any of the 23 conditions covered by the survey [102].

4 Consumer information and education

The primary goal of consumer information and education is to enable people with arthritis to manage their illness, adjust to their condition and maintain quality of life [103] .

Education and self-management approaches are recommended in clinical guidelines for both osteoarthritis [104, 105] and inflammatory arthritis [103] .

Information, education and self-management support can be provided within healthcare consultations, online or via telephone-based resources, using a structured, community-based program approach, or through community organisations.

4.1 Access to information and support

Evidence suggests that people with arthritis in Australia have limited access to information and support to help them to manage their condition. A 2011 survey found that two thirds of people with arthritis in Australia were faring badly with their condition; those who were faring badly were two to three times more likely to report poor access to information and support for their arthritis from health care professionals [17]. A more recent survey found that only around half of people receiving care for their arthritis were satisfied with the information and support they received at diagnosis and for the ongoing management of their condition. Only 30% were satisfied with the support they received for their emotional and mental wellbeing [106].

Nurses, allied health professionals and Aboriginal health workers have been identified as playing an important role in providing patient education and supporting chronic disease self-management within the health system in Australia. However, in a 2012 survey only 29% of nurses in general practice reported that they regularly undertake arthritis education, assessment and management tasks, compared to 59% for diabetes and 76% for cardiovascular disease[107]. Providing information, education and training programs for health professionals has been identified as an important strategy to build knowledge and confidence in the delivery of patient education for people with arthritis [103].

In Australia, access to specialist nurses for education, care and support for people with severe and inflammatory forms of arthritis is limited. Internationally, models of care involving rheumatology nurses are considered best practice and have been found to improve patient outcomes and reduce costs in both primary and specialist care [108, 109]. However, there are only 39 full-time-equivalent rheumatology nurses in Australia, or 1 for every 45,000 people with inflammatory arthritis. In a recent survey of 476 people with arthritis in Australia, few people had seen a rheumatology nurse as part of their care, but those who had reported much higher satisfaction across all aspects of their care than those who had not. In particular around twice as many people who had seen a rheumatology nurse as part of their care compared to those who had not, reported that they were satisfied or very satisfied with:

- the support they received for their emotional and mental wellbeing
- the coordination of their care
- the information and support they received for the ongoing management of their condition
- their ability to quickly access specialist advice or treatment when they needed it [106].

Implementing strategies to expand the rheumatology nurse workforce in Australia has been recommended to help support improved care and better outcomes for Australians living with severe and inflammatory forms of arthritis [106].

Arthritis organisations deliver a range of information and support services to people with arthritis, including information resources, self-management education programs and support groups. GPs however, rarely refer people to these organisations [110] and only one in three people with arthritis discusses self-management with their GP or specialist [111]. Strategies to promote awareness of, and increase referrals to, the information and supports available through arthritis organisations would assist in increasing consumer access to appropriate, evidence-based information and support.

4.2 Consumer Information needs

People with osteoarthritis report wanting more information about their condition and its prognosis, and about pharmacological and non-pharmacological options for managing their symptoms [112].

A focus group with consumers with inflammatory forms of arthritis was held to identify unmet needs as part of the consultations for the development of the *National Strategic Action Plan for Arthritis*. Participants especially highlighted the need for greater education, support and guidance to be provided at diagnosis and in the early stages of learning to manage and cope with their condition.

A major unmet need for women with autoimmune rheumatic conditions is for information and support to help them during pregnancy planning, pregnancy and early parenting [113, 114].

For children with juvenile idiopathic arthritis (JIA), parents and carers play a pivotal role in self-management activities, highlighting the need for family-based self-management education and support. As children mature and develop into adolescence and adulthood, they need to develop the skills and knowledge required to self-manage their condition successfully. This requires access to age and developmentally appropriate information resources and support strategies as part of a managed transition to adult services. The particular needs of adolescents for information and self-management support have been highlighted in the literature as a major area of unmet need [115, 116].

4.3 Structured self-management education programs

Structured self-management and disease education programs are designed to assist people with arthritis to manage their condition. These programs commonly provide disease information and teach practical strategies for controlling pain and minimising the impact of arthritis on everyday life.

Although the evidence base has limitations, self-management interventions in arthritis have been associated with small improvements with respect to pain and disability [117]. A Cochrane review concluded that self-management education programs resulted in small or no benefits for people with osteoarthritis [118]. Other reviews have reported positive results from patient education programs for osteoarthritis. A review by Brosseau et al (2011) found that patient educational programs reduced pain in the short term and increased short-term and longer-term compliance to exercise, and there are preliminary data on the outcomes and acceptability of internet-based educational programs for people with osteoarthritis [119, 120].

One Australian study of participants in arthritis self-management courses showed small but sustained improvements in reported levels of pain, fatigue and distress as well as self-efficacy and health-related behaviours [121].

The Osteoarthritis of the Knee (OAK) program, delivered by health professionals, is a structured self-management education program that has some similarities to the Stanford Chronic Disease model, but is specifically designed for people with osteoarthritis of the knee. A randomised controlled trial of the OAK program recorded statistically significant improvements for participants, compared to a control group, with regard to pain, quality of life and function at eight weeks and six months from baseline [122]. This program is currently run by Arthritis and Osteoporosis Western Australia.

A number of arthritis organisations in Australia run the Take Charge of Pain self-management education program for people with musculoskeletal pain, which is delivered by health professionals. The program was developed by Arthritis South Australia and utilises aspects of the Stanford model of chronic disease self-management and motivational interviewing as well as principles of adult learning to create an effective learning environment. An evaluation of the program recorded small but significant improvements in self-reported pain, health distress and self-efficacy [123].

4.4 Web-based programs

Increasing evidence indicates web-based applications to support self-management can help to increase self-efficacy and improve health behaviours in people with arthritis [124].

An evaluation of the web-based osteoarthritis self-management resource, My Joint Pain, found that users of the resource achieved benefits in health-directed activity, positive and active engagement in life, self-monitoring and insights, skill and technique acquisition, and social integration. Improvements in self-management, lifestyle, physical activity, and weight reduction were also observed [125].

4.5 Peer support programs

There is good evidence that peer support programs help people manage chronic disease and cope with stress or emotional challenges, and reduce unnecessary medical care. Peer support has four key functions: assisting people in the daily management of their condition; provision of social and emotional support; linkage to clinical and community resources; and ongoing support over the course of a person's chronic disease experience. Peer support is generally cost-effective and often cost-saving [126].

5 Guidelines, standards and models of care

5.1 Osteoarthritis guidelines and standards of care

A range of evidence-based national and international guidelines and standards of care have been developed to support the timely and effective management of osteoarthritis, and particularly, hip and knee osteoarthritis. These guidelines consistently emphasise that core management of osteoarthritis should comprise a combination of non-pharmacological and pharmacological interventions, with referral for consideration of surgery only if symptoms are no longer responsive to conservative management [104, 105, 127-132]. The core recommendations for osteoarthritis management across these guidelines can be broadly summarised as:

- Diagnosis should be based on clinical assessment alone.
- An individualised self-management plan should be developed based on a comprehensive assessment of symptoms, other health conditions and a psychosocial evaluation.
- Conservative (non-surgical) management involving weight loss, exercise, disease-relevant patient education and self-management support are first-line treatment strategies and are also recommended at all stages of the disease.
- If required, pharmacological therapies should be added to the core treatments.
- Patients should be included in shared decision-making for the development of a personalized pain management program involving treatment options such as exercise, orthotics, psychological and social interventions, sleep interventions, weight management and pharmacological treatments [129].
- Referral for consideration of surgery should be made only when conservative management no longer provides adequate pain relief or maintenance of function.

5.2 Inflammatory arthritis guidelines and standards of care

There are a number of national and international clinical guidelines and standards of care for the management of inflammatory forms of arthritis, including rheumatoid arthritis, juvenile idiopathic arthritis, psoriatic arthritis, ankylosing spondylitis and gout [103, 129, 133-140].

The main goals of management are to control disease activity, prevent or slow the rate of joint damage, alleviate pain, maintain function for employment and daily activities, monitor and address complications and comorbidities of the condition and its treatment, and maximise quality of life.

A number of the guidelines also highlight the need to address a person's changing requirements over time and to enhance their self-management skills as their disease progresses and as they reach major life milestones, including pregnancy and parenthood. More intensive multidisciplinary care and support is usually required as the disease progresses [103].

Most guidelines support shared care between primary and secondary care practitioners, with ongoing management provided in primary care and regular reviews by the treating rheumatologist and multidisciplinary team.

The following are the key common themes across conditions outlined in the various guidelines for inflammatory arthritis:

- The importance of early diagnosis and referral to specialist care for prompt initiation of therapy, ideally within six weeks of symptom onset. Patients with inflammatory arthritis who are under the care of a rheumatologist receive an earlier diagnosis, commence treatment earlier and have better long-term outcomes [133].
- A treatment approach that aims for clinical remission or low disease activity based on systematic measurement of treatment outcomes.
- The provision of age and culturally appropriate information, education and support for self-management throughout the course of the disease, tailored to patient needs
- Access to an appropriately skilled multidisciplinary team for the development and implementation of an individualised care plan to manage the ongoing physical, psychosocial and occupational impacts of the condition. The plan should include pain management interventions, exercise, joint protection and psychological support.
- Equitable access to appropriate non-pharmacological and pharmacological treatments, depending on the condition.
- Access to care coordination and psychosocial support.
- Effective ongoing management including monitoring for drug compliance, toxicity, safety and side effects, and managing complications and comorbidities.

5.3 Models of care

Models of care are evidence- and consultation-based frameworks that describe what and how health services and other resources should be delivered to people with specific health conditions. Models of care aim to guide the provision of 'the *right care*, delivered at the *right time*, by the *right team* in the *right place*, with the *right resources*.' They provide an effective way to embed evidence into health policy and practice and achieve system efficiencies [141].

A 2018 systematic review assessed the outcomes of implementing models of integrated care across a wide range of conditions and interventions. The review found a number of positive outcomes with evidence strongest for perceived increased patient satisfaction and improved quality of care and access to care. UK-only evidence also showed reduced outpatient appointments and waiting times, but evidence of other impacts such as levels of activity and costs was unclear [142].

A number of arthritis-related models of care already exist in some jurisdictions in Australia and are at various stages of implementation. These models have been developed by state-based musculoskeletal clinical networks, which have been identified as an important enabler for the development and implementation of models of care [143]. These models include:

- NSW ACI Osteoarthritis Chronic Care Program (OACCP) Model of Care
- NSW ACI Local Musculoskeletal Service (LMS)
- Osteoarthritis of the Hip and Knee Service (Victoria)
- Victorian Model of Care for Osteoarthritis of the Knee and Hip
- WA Inflammatory Arthritis Model of Care
- WA Service Model for Community-Based Musculoskeletal Health
- WA Elective Joint Replacement Service Model of Care
- Model of Care for NSW Paediatric Rheumatology Network
- Orthopaedic Physiotherapy Screening Clinic and Multidisciplinary Service (Queensland)
- Comprehensive Osteoarthritis Pathway and Musculoskeletal Triage and Assessment Service (Tasmania).

Where evaluations or reviews are available, these models of care have been shown to achieve system efficiency gains; to improve the quality of health care delivered; and to improve community access to appropriate, timely care [144-146].

The New South Wales Osteoarthritis Chronic Care Program (OACCP) provides multidisciplinary assessment and non-surgical management for people on the waiting list for joint replacement surgery. Evaluation of the model found that it improved clinical outcomes, facilitated earlier access to surgery, where necessary and reduced demand for surgery. As a result of the program, 11% of participants waiting for knee replacements and 4% awaiting hip replacements deciding they no longer required surgery [144]. The OACCP has been selected for state-wide roll-out as part of the NSW Leading Better Value Care Program (LBVC) starting in 2017/18.

A cost-effectiveness evaluation of the Orthopaedic Physiotherapy Screening Clinic and Multidisciplinary Service in Queensland concluded that this model was likely to be highly cost-effective. Compared with usual orthopaedic care the model cost an additional $1,691 per quality adjusted life year gained [147].

A 2015 implementation report for the Western Australian models of care reported that most of the recommendations or strategies of the elective joint replacement model of care had been implemented. In addition, some progress had been made in implementing the community based musculoskeletal health model of care, but there had been little progress in implementing the inflammatory arthritis model of care [145].

6 Key issues and gaps in care in Australia

6.1 Consumer experience

A 2011 Arthritis Australia survey of people with arthritis found that two in three were faring poorly with their condition and that not faring well was associated with their perceived standards of care and access to care and information, rather than the severity or duration of their arthritis, or other factors [17].

Common problems reported by people with arthritis include: limited services and inequitable access to publicly funded services; delays in diagnosis and treatment; limited access to multidisciplinary care; inadequate information and support for self-management and a heavy financial burden. People with arthritis also commonly report that their pain and fatigue are poorly managed, that there is little support provided for their emotional wellbeing and that their care is not holistic, with little support available to help them manage the impact of the condition on their lives, including their capacity to continue to socialise, work or study [18, 148].

Effective pain management is one of the highest priorities reported by people with arthritis. Poorly controlled pain in inflammatory arthritis is associated with lower quality of life and higher levels of disability, emotional distress and depression [149]. There is evidence to support a variety of pharmacological and non-pharmacological treatment options for pain management, especially physical activity and exercise and psychological interventions [129]. However, pain is most commonly treated with medication. Opioids are generally considered of limited use for managing arthritis pain because the clinical benefits appear to be limited, but the risk of adverse events is high,[150, 151] but one in 10 scripts for opioids in Australia is for osteoarthritis alone, while 58% are for musculoskeletal conditions [152].

Anxiety and depression are also common in people with arthritis and are associated with worse health and social outcomes as well as with higher direct medical costs. However access to psychosocial support or psychological services is rarely made available to patients as part of routine care [153].

People with arthritis also identify fragmentation of services, poor communication between health professionals and lack of continuity of care as key issues in the delivery of care. Service fragmentation is an issue at both the primary care and specialist levels. People report that they are left to navigate and coordinate services for themselves, with minimal direction from health care professionals. This is especially an issue for those people (e.g. non-English speakers) who may lack the health literacy or language skills to do this effectively. The issue of service fragmentation is exacerbated in the private system, where access to multidisciplinary teams is limited or non-existent [154].

Providing care coordination and navigation services can help to improve integration of care across all providers for people who need to access multiple health services or who struggle to navigate the health system on their own [155]. In one systematic review of interventions for managing multiple high-burden chronic diseases in older adults, care-coordination strategies involving case management administered by nurses reduced functional impairment in people with arthritis and depression [156].

In terms of barriers to care, consumers report that the main barriers to healthcare services are cost, followed by access issues, related to waiting times for appointments and referrals, and the convenience of the healthcare provider's location. Compliance with allied health programs are identified as problematic due to lack of time, transport, cost and a variety of other factors [110, 157, 162].

6.2 Management of osteoarthritis

Osteoarthritis is poorly managed in Australia, with less than half of people with the condition receiving care according to current guidelines [158-161]. Typically, treatment is limited to the use of analgesic and/or anti-inflammatory medications to manage symptoms until the condition worsens, at which point the patient is referred for a joint replacement.

Consumers report that the care and management they receive for their osteoarthritis is less than optimal [162] [17] and that they are advised to 'put up with' their condition and offered few options for their treatment [163]. Lack of information and advice from their GPs is a major concern [162].

GPs also report dissatisfaction with the care they are able to provide to people with osteoarthritis, and cite issues including lack of effective treatments and poor access to support for lifestyle changes and non-drug management [110]. Optimal primary care management is also negatively influenced by perceptions that osteoarthritis is not that serious, under-prepared clinicians, personal beliefs being at odds with recommended practice and difficult patient expectations [13].

A key discrepancy in the management of osteoarthritis is the poor uptake of non-pharmacological conservative management options, especially exercise and weight loss in primary care, with only 17 out of every 100 GP contacts with osteoarthritis patients utilising lifestyle management interventions [161].

Other areas of concern in the management osteoarthritis include overuse of imaging, over-reliance on medications, including opioids which were prescribed at one in five medical encounters for this condition in 2015-16, and over-reliance on surgery [128, 160, 161, 164]. In particular, people with osteoarthritis continue to undergo arthroscopic procedures despite good evidence that these procedures are not effective for this condition [165, 166].

The *National Osteoarthritis Strategy* (NOAS) has identified the following priorities for improving the non-surgical management of osteoarthritis in Australia:

- Support primary care practitioners to deliver high-value care to people with osteoarthritis, including increased prescription of lifestyle interventions
- Improve the uptake of evidence-based and affordable, tailored, non-surgical care and support for ongoing self-management by all Australians with osteoarthritis [167].

Further information on the evidence base for these priorities and strategies for their implementation are outlined in the NOAS.

6.2.1 Limited uptake of conservative management options

Weight loss

For obese people with established osteoarthritis, weight loss of between 5-10% of their body weight can result in significant pain relief, and this may in turn manifest in improvements in mobility, physical function and quality of life[168]. Weight loss greater than 10% achieves even larger improvements in symptoms [169].

However, although most people with osteoarthritis are overweight or obese, only 10% reported in 2014-15 that they were trying to lose weight to help manage their condition [170].

Exercise

There is a large body of evidence in support of exercise for osteoarthritis, with exercise achieving improvements in knee pain and physical function comparable to those reported from non-steroidal anti-inflammatory drugs (NSAIDs) [171]. Improvements in pain and function following exercise programs for hip osteoarthritis have also been shown [172]. Therapeutic water-based exercise has also been shown to have benefits for patients with lower limb (hip or knee) osteoarthritis [173].

However, a recent Australian study reported that only five percent of patients newly presenting with osteoarthritis were referred to a physiotherapist by their GP despite physical therapy interventions being widely recommended as a valuable conservative treatment [174]. The *National Health Survey 2014-15* also found that only 25% of people with osteoarthritis reported that they exercised most days and 14% did strength training to manage their condition. On the other hand, 83% reported taking medication for their condition [170].

6.2.2 Interventions to support conservative management

Weight loss

Strategies to support weight loss in people with osteoarthritis may include informal advice, referral to a dietician for appropriate counselling and structured weight loss programs incorporating dietary changes and/or exercise [175].

Exercise

Supported self-management and exercise programmes, delivered by health professionals, are valued by patients, feasible in clinical practice and can positively impact symptoms, function and medication use [176-178]. Information, clear advice about benefits and reassurance from health professionals can encourage greater exercise participation by patients with osteoarthritis [179].

Studies of innovative service delivery models for the provision of physiotherapist-supervised exercise management for people with knee osteoarthritis have found that the use of Skype and telephone coaching is feasible and beneficial [180, 181]. Use of booster sessions with a physiotherapist can also help improve exercise adherence for older adults with osteoarthritis and/or back pain [182].

Specific neuromuscular exercise programs delivered by trained physiotherapists have demonstrated both short and long term improvements in pain, function and quality of life [177]. The Good Life with Arthritis in Denmark (GLA:D) program, is an evidence-based education and exercise program developed by researchers in Denmark for people with hip or knee osteoarthritis that has recently been introduced to Australia. The exercise program consists of two to three group education sessions and 12 small group exercise sessions taking place twice per week for six weeks. GLA:D is delivered by physiotherapists who are trained and accredited to deliver the exercise program and is designed to be run in private practices, community health centres and hospital outpatient facilities. Research from the GLA:D program in Denmark has demonstrated improvements in pain, quality of life, physical function, physical activity, painkiller use and sick leave [177].

Generally, however, cost and limited availability of lifestyle support services as well as the annual limit of five allied health professional services available under MBS chronic disease management items, are identified as barriers for consumers in adopting lifestyle approaches to managing their condition. In addition to cost, access issues related to waiting times for appointments and referrals, and inconvenience of the healthcare provider's location are major barriers. Compliance with allied health programs has been identified as problematic due to lack of time, transport, cost and a variety of other factors [110, 157, 162].

Multidisciplinary models of care

Multidisciplinary conservative care programs for osteoarthritis have been shown to reduce willingness for joint replacement surgery. Most recently, a randomised controlled trial to investigate the effectiveness of total knee replacement plus non-surgical treatments in comparison to non-surgical interventions alone, found that both groups reported significant improvements in pain, health related quality of life and functional outcomes. Although improvements were greater in the group undergoing joint replacement, two out of three patients eligible for total knee replacement who received non-surgical treatment, had still not proceeded to surgery at the two-year follow up [183].

Implementing multidisciplinary models of conservative management for people with severe knee osteoarthritis could result in substantial cost savings for the Australian healthcare system, if implemented at a broader population level. The potential cost savings from avoiding or delaying knee replacements alone would be over $170 million in 2015, increasing to over $233 million in 2030 [184].

There are many Models of Care that have been implemented both in Australia and internationally that address the importance of primary and secondary prevention, care coordination, access to a multidisciplinary team to address the biopsychosocial factors, self-management support and care planning for the person with condition [185]. Many of these models demonstrate that care for people with musculoskeletal conditions can be delivered effectively and efficiently by various competent health professionals, including with extended scope of practice, and utilising digital technologies to support health-care delivery and self-management [185].

The majority of multidisciplinary osteoarthritis-related models of care in Australia, as outlined in section 5.3, relate to the delivery of care within the public hospital sector for people with advanced osteoarthritis. Improving osteoarthritis care within the primary care sector for people at an earlier stage of their condition has been identified as an important strategy for reducing the overall burden of the condition for both individuals and the health system [154].

A number of models to improve the delivery of multidisciplinary care for osteoarthritis in the primary care setting have been, or are being developed in Australia. These include:

1. The NSW Agency for Clinical Innovation's Local Musculoskeletal Service is a model for delivering better osteoarthritis and osteoporosis care across primary and secondary care settings. A trial of this model is being conducted in NSW as part of the Leading Better Value Care initiative.
2. The PARTNER research project is looking at a model to support better osteoarthritis management in primary care [159]. The model is currently being trialled in the Australian primary care setting and involves referral of eligible patients to a centralised multidisciplinary service for tailored education, muscle strengthening and weight-loss programs, and other appropriate interventions as required. Results from evaluation of the effectiveness and cost-effectiveness of this new model compared to usual care are expected in 2020.

3. The *Victorian Model of Care for Osteoarthritis of the Hip and Knee,* which has yet to be implemented, includes a focus on community- based care and identifies that innovative models of service delivery are required to better meet consumer needs and to support the delivery of evidence-based care. These models should include:
    - Funding mechanisms that support components of care for osteoarthritis that are known to be effective and move towards supporting care packages, rather than care episodes.
    - Improved access to allied health providers and strategies that support effective self-care (e.g. exercise facilities).
    - Models that support effective use of the workforce through widespread implementation of advanced practice roles for allied health and nursing staff.
    - Building workforce capacity in best-practice osteoarthritis and pain care, particularly among primary care providers, through a range of flexible professional development options.
    - Supporting care delivery in local settings, rather than tertiary hospital settings. This might include establishment of community-based musculoskeletal clinical centres for people with advanced osteoarthritis or complex presentations; establishment of community-based, multidisciplinary osteoarthritis programs; and multidisciplinary outreach services for rural areas.
    - Establishment of systems to manage and triage orthopaedic surgery referrals to public hospitals to facilitate timely provision of surgery, to those who need it.
    - Utilising technology to support better access to and delivery of care, including telehealth and web platforms [131].

6.2.3 Surgery

Joint replacement surgery is a highly effective and cost-effective intervention for osteoarthritis when conservative therapies are no longer effective. Hip and knee replacements provide substantial and sustained improvements in pain, physical function and quality of life [186].

Despite the demonstrated effectiveness of joint replacement surgery, not all patients experience optimal outcomes and, as with all surgical procedures there is a risk of complications. A substantial proportion of patients is unsatisfied or continues to experience persistent pain after total hip replacement (6-27%) and total knee replacement (15-44%) [187,188]. As joint replacement prostheses have a limited lifespan, future revision surgery may also be required. In view of these considerations, national and international clinical guidelines recommend that joint replacement surgery should only be offered for severe, symptomatic osteoarthritis after conservative management strategies have been trialled [189, 190].

In addition, up to one quarter of total joint replacements are performed on inappropriate candidates according to evidence-based criteria [191]. Surveys conducted in people on orthopaedic waiting lists have shown the uptake of conservative options, such as physiotherapy and rheumatology, was very low or non-existent [163]. Only approximately 20-28% patients have tried exercise or weight loss before being placed on the waitlist [192]. The reasons for this may include: lack of knowledge about services by gatekeepers (general practitioners); lack of uptake of services by patients for financial reasons or because of difficulty accessing services or competing priorities, such as caring responsibilities; insufficient capacity to meet demand in community health settings. A more equitable and clinically responsive system would ensure all conservative care options had been undertaken and those with the highest need (based on physical, functional, quality of life, economic and other issues) received prompt care [193].

In 2017, there were 47,644 hip and 63,554 knee replacement procedures undertaken in Australia, an increase of 27% from 2012. Nearly all of these procedures were for osteoarthritis and around 70% are undertaken in the private system [194]. Hip and knee replacements for osteoarthritis cost the health system around $2.3 billion in 2012/13 [195] more than any other surgical procedures, and this cost is projected to rise to $5.3 billion by 2030 [3].

In 2016-17, the waiting time for hip and knee replacements in the public system was 195 days at the 50th percentile for knee replacements and 110 days for hip replacements, but this varied substantially across states. Waiting time at the 50th percentile for hip replacement ranged from 80 days in Queensland to 217 days in NSW and for knees, from 97 days in Victoria to 320 days in Tasmania [196]. These waiting times are in addition to often lengthy waiting periods for an initial consultation with an orthopaedic surgeon. Extended waiting times for surgery, when it is needed, can lead to deterioration in a person's condition and quality of life [197].

Joint replacement surgery in the private sector can result in significant out-of-pocket expense for the patient and this can vary from state to state. A recent report found wide cost variations between states, with NSW surgeons charging on average $2673 in out-of-pocket expenses for hip replacements, almost five times that of South Australian surgeons. The out-of-pocket cost for a knee replacement in NSW is reported to be an average of $2400 compared to $1609 in Victoria and $397 in South Australia [198].

The *National Osteoarthritis Str*ategy (NOAS) has identified the following priorities for improving the surgical management of osteoarthritis in Australia:

- Optimise decision-making processes leading to total joint replacement surgery and maximise client outcomes following total joint replacement surgery for people with severe osteoarthritis.
- Implement non-surgical management of severe osteoarthritis in the community.
- Improve access, efficiency and cost effectiveness of services across the healthcare system for managing people with severe osteoarthritis. This includes providing an efficient clinical pathway from diagnosis to surgery as well as the provision of joint replacement surgery, to those who need it, within timeframes consistent with current Australian policy on urgency categorisation [167].

Further information on the evidence base for these priorities and strategies for their implementation are outlined in the NOAS.

6.2.4 Post-surgery review and rehabilitation

In Victoria there has been a state-wide implementation of post-arthroplasty review clinics for patients following total hip and knee arthroplasty, led by advanced musculoskeletal physiotherapists in collaboration with orthopaedic specialists. An evaluation of this service found that the clinics delivered a safe, cost-efficient model of care that improved patient access and quality of care compared to traditional specialist-led workforce models. The average cost saving per occasion of service was $38, representing a reduced pathway cost of 44% [199].

The delivery of post-surgery rehabilitation after joint replacement surgery varies across the public and private sector with inpatient rehabilitation more commonly provided in the private hospital sector than in the public hospital sector. About 40% of patients with private health insurance who have a total knee replacement undergo inpatient rehabilitation compared to only 5-10% of those not privately insured. However, recent Australian studies have found that inpatient rehabilitation pathways, while significantly more expensive, did not achieve better health outcomes than community or home-based rehabilitation programs for uncomplicated joint replacement surgery [200, 201].

6.3 Management of inflammatory arthritis

6.3.1 Delays in diagnosis and treatment of inflammatory arthritis

There is overwhelming evidence that early diagnosis, prompt initiation of specialist treatment and early achievement of remission are the major predictors of positive long-term outcomes for inflammatory arthritis. There is a 'window of opportunity' early in the disease course when aggressive treatment with disease modifying anti-rheumatic drugs (DMARDs) can dramatically improve clinical outcomes for people with rheumatoid arthritis, with sustained benefits over time. This window of opportunity may be as little as three or four months from symptom onset. Initiation of treatment within 12 weeks of symptom onset is associated with a 30 per cent slower rate of joint destruction and nearly double the chance of achieving sustained DMARD-free remission over a six-year period, compared to delayed treatment [202] [203].

Consequently, the treatment goal of early arthritis is now clinical remission, or as low disease activity as possible, utilising early and aggressive treatment with DMARDs [133].

Evidence also suggests that early treatment of inflammatory arthritis may be cost-saving in the longer term because remission might be achieved with significantly less use of expensive biologic medications [204].

Despite the evidence base for early initiation of treatment, delays in the diagnosis and treatment of inflammatory arthritis are common. Recent international studies report average delays from symptom onset to the initiation of treatment of six to nine months [202, 205-208].

A 2013 review of interventions to address delays in diagnosing RA and other forms of inflammatory arthritis identified three potential points where delays commonly occur [209]:

1. **Patient delay**
   Delays often occur between the onset of symptoms and the patient seeking medical attention, primarily due to lack of awareness of rheumatoid arthritis by the patient experiencing symptoms. Accurate symptom attribution and the perception that symptoms are indicative of a serious condition that requires intervention are important drivers for timely help-seeking [210]. A review of drivers and barriers to help-seeking behaviour by adults with rheumatoid arthritis symptoms identified limited awareness of the condition, its potential severity and the importance of early treatment as major impediments to seeking early medical attention [15]. Similar reviews have also identified inaccurate beliefs about the cause, nature and impacts of the symptoms, and the use of self-administered treatments, contributed to delay in seeking help [210].

2. **Primary care delay**
   Primary care physicians (GPs) play an important role in identifying people with suspected rheumatoid arthritis symptoms, referring them appropriately for specialist assessment and care, and providing initial management of symptoms. Delays in referral can occur as there are no precise diagnostic tests or criteria that enable a GP to determine unequivocally that a person has an inflammatory arthritis and symptoms can be attributed to a range of other conditions [133].

3. **Rheumatology delay**
   Delays between referral from primary care and first assessment by a rheumatologist can result from failure of the patient to attend their first appointment, inadequate information and prognostic data in the referral and lack of access to a rheumatologist [211].

The Australian experience

The most recent evidence indicates similar delays are experienced by people with early arthritis in Australia, especially if they reside in rural and remote areas or their doctors are in public practice [212]. A recent Australian study reported the median delay from symptom onset to review by a rheumatologist was 26.4 weeks. Less than one in five patients were seen within the three- to four-month 'window of opportunity' period. The greatest contributor and predictor of overall delay in this study was patient delay, namely delays in patients seeking medical treatment. Patient delay was greater in patients with lower disease activity scores, higher tender joint count and lower socioeconomic status [211].

These results mirror a previous Australian study that found the median time from symptom onset to initiation of DMARD therapy was 173 days, with some patients experiencing delays of up to a year. Again, the greatest proportion of this delay (104/173 days) occurred between symptom onset and referral to a rheumatologist [213]. GPs have also reported that limited access to specialists is a major barrier to the effective care of people with arthritis [110].

Limited access to rheumatologists in rural and remote areas and lengthy waiting lists for public rheumatology clinics in some states, suggest that delays may be greater in certain geographic areas and in the public system. In Queensland, for example, only 35% of Category 1 patients were seen within the clinically recommended times in public outpatient rheumatology clinics in the quarter ending on 1 April 2018 [214]. An Australian study of ankylosing spondylitis found that the average delay in diagnosis was eight years with lengthier delays among women and those with younger-onset disease [215].

Delays in diagnosis and treatment of JIA are also common, due to lack of recognition of the condition by primary practitioners or non-rheumatology specialists and limited access to specialist paediatric rheumatology services [216]. A 2012 survey in Queensland showed that four in ten children with JIA experience delays of more than six months and one in six waits more than a year to be accurately diagnosed. Nearly half of all children with JIA saw four or more health professionals before being correctly diagnosed [217].

A 2012 survey of rheumatologists found that more than half of all patients with suspected inflammatory arthritis had to wait more than six weeks from the date of referral for an initial consultation with a rheumatologist. Delays in being reviewed by a rheumatologist were most common in Tasmania, South Australia, the Northern Territory and Queensland [218]. A 2011 report found that people with new-onset rheumatoid arthritis in some parts of rural Queensland were waiting up to two years before seeing a rheumatologist [219].

6.3.2 Strategies to support early diagnosis and treatment

Patient awareness

Several reviews have identified the need to implement targeted public health interventions to inform people about rheumatoid arthritis symptoms and reduce delays in seeking help [209](see also section 2, Arthritis Awareness).

Internet-based questionnaires have been proposed to help patients identify the cause of their symptoms as attributable to early arthritis [220] although their availability is low [209]. Questionnaires have been shown to be useful in identifying some cases but overall did not improve patient delay due to the low prioritisation by the patient to seek help from a health professional [220]. Interactive health communication applications and eHealth interventions have been shown to have a positive effect on a patient's knowledge and decision-making [124].

GP education

Educational strategies for primary-care practitioners have reported success in terms of improving practitioners' awareness, knowledge and ability to detect inflammatory arthritis and increasing referrals to rheumatologists. Screening tools such as self-administered patient questionnaires and referral guidelines have also been used to increase timely diagnosis and referral of those suspected as having rheumatoid arthritis [208, 209].

Triage processes

'Early arthritis clinics' – specialist clinics for the early assessment of patients with inflammatory arthritis – have been successful in reducing delays in initiating treatment for rheumatoid arthritis. These clinics offer a more structured approach to triage, assessment and referral of patients with inflammatory arthritis. In addition, innovative triage models such as telephone hotlines or online clinics could be used [221, 222].

A study of a centralised referral system for triaging patients (CReATe Rheum) reported improved referral quality, reduced wait times and improved system efficiencies [223]. The system involved use of a standardised referral form to accurately capture clinically relevant indicators of urgency, a rheumatology nurse to triage referrals and a centralised service hub and database. Prioritisation or triage tools have also been reported to improve waiting times for patients with early inflammatory arthritis [224].

Triage by rheumatology nurses has been found to be effective and accurate, with 90 percent of referrals correctly assigned to the appropriate triage category [223]. In one study, GPs and rheumatology nurses who had been trained in assessing early inflammatory arthritis for referral, achieved accuracy approaching that of a group of experienced rheumatologists [225]. Appropriately trained nurses have been shown to be able to detect early arthritis and provide triage services to streamline access to rheumatologists [225]. In the UK, nurse-led early arthritis clinics were found to reduce the time between symptom onset and first rheumatologist assessment for people with inflammatory arthritis from 16 weeks to three weeks, as well as time between symptom onset and the initiation of DMARD therapy [226]. Recent audits of rheumatology services in the UK found that there was a strong, statistically significant correlation between nurse staffing levels and timely initiation of treatment for patients. Services with higher rates of nurse staffing were twice as likely to achieve timely initiation of combination DMARD treatment and 58% more likely to achieve treatment targets [227].

Advanced practice physiotherapists have also been shown to provide effective musculoskeletal triage for orthopaedic and rheumatology services. An analysis of national audit data in Ireland following the introduction of advanced practice physiotherapist (APP) roles in hospitals found that APPs were able to autonomously manage patients at 77% of appointments, with most patients able to be conservatively managed. Therefore, patients who needed to see orthopaedic and rheumatology specialists gained earlier access [228].

6.3.3 JIA

Across Australia there are only 13 paediatric rheumatologists working 7.6 FTE, less than half of what is needed to meet clinical need [229], with no resident services in Tasmania or the Northern Territory. Building workforce capacity is hampered by limited access to training in Australia. There are only two accredited training sites for paediatric rheumatology (in Melbourne and Perth) and no dedicated funding for paediatric rheumatology training in Australia. Those who wish to take up the specialty need to go overseas or source their own funding for training. To address this issue, Arthritis Australia, the Australian Paediatric Rheumatology Group of the Australian Rheumatology Association and Zoe's Angels Inc. have recently offered two-year scholarships to support paediatricians and paediatric trainees interested in training in paediatric rheumatology. However, this is not a sustainable solution to funding training for paediatric rheumatology.

Team-based care is the 'gold standard' for managing JIA but is rarely delivered. In 2011, Australia-wide, public funding for specialist allied health care professionals in paediatric rheumatology consisted of just 2.7 FTE for nursing, 1.15 for physiotherapy, 0.85 for occupational therapy and 0.5 for psychology [230]. Confidence among allied health professionals in Australia in managing paediatric rheumatic disease is also very low [231] while the cost of these services is a significant barrier to access.

Strategies to address these issues include:

- Providing dedicated funding for paediatric rheumatology training in Australia
- Increasing access to public multidisciplinary paediatric rheumatology services
- Funding paediatric rheumatology nurses to provide education, psychosocial support and care coordination
- Developing information and educational materials for health care professionals to support early diagnosis and referral to specialist care and to enhance team-based care [154].

6.3.4 Gout

Estimates vary but a systematic review of gout prevalence in Australia found that gout affects 1.7% of Australians, although prevalence in indigenous males is much higher at 9.7% [232].

Evidence from Australia and the rest of the world shows that the management of gout is suboptimal, as demonstrated by infrequent serum urate testing, low levels of urate-lowering therapy prescription and, when prescribed, inadequate dosing, resulting in serum urate levels above target [233]. Treating patients to a target serum urate is essential for reducing gout flares and resolving tophi. Once target serum urate has been reached, six-monthly monitoring by testing serum urate is recommended to ensure continuing adequate management and adherence [233]. However, a recent study based on a representative population survey in South Australia found the self-reported prevalence of gout was 6.8% but only half of respondents adhered to urate-lowering therapy [234].

The need to improve the management of gout was an issue raised in a number of initial consultations undertaken for the development of the *National Strategic Action Plan for Arthritis*. GP education, improved patient education and support for self-management, and access to affordable lifestyle interventions were identified as important strategies to improve the management of gout [154].

6.3.5 Ongoing management of inflammatory arthritis

The aims of ongoing management are to minimise disease activity, address complications and comorbidities and optimise physical, psychological and social function.

An Australian study [235] published in 2013 showed a large proportion of patients with rheumatoid arthritis remained in moderate or high disease activity. However, a more recent study showed that remission rates in people with the condition had improved from 37% in 2009 to 54% in 2014 [236].

A recent systematic scoping study of the needs of people with inflammatory arthritis found that while there had been significant advances in pharmaceutical management, a number of broader health needs of patients warranted attention. People with inflammatory arthritis expressed the following health needs:

- Therapies to reduce pain and fatigue and help them maintain their mobility, function and independence.
- Information to enable decision making and self-management, including practical information to help them to gain control of their health, learn to manage their condition and plan for the future, including information on exercise, physical therapies and self-help strategies.
- Access to health professionals who take a holistic approach to care, provide continuity of care and are easy to access, especially during a disease flare. In addition, access to skilled allied health professionals to improve function, mobility and psychological wellbeing.
- Support to enhance their social connection, employment and financial security [237].

Strategies to address these needs included improving patient information and education on the disease and its impact; building workforce capacity and education to improve access to appropriately skilled health professionals; leveraging digital technologies to support service and information delivery and involving patients in the development of more effective and efficient models of care [237].

6.4 Limited access to multidisciplinary care

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. Access to appropriately skilled multidisciplinary team care for severe or inflammatory forms of arthritis is limited mainly to a few tertiary hospital-based clinics. Even in this setting, access can be limited or priority given to patients with other conditions. Access to multidisciplinary team care in the private system is limited or non-existent [154].

The cost of accessing private allied health services, which are inadequately covered by Medicare and private health insurance, forms a significant barrier to optimal access to multidisciplinary care. Medicare only subsidises five allied health occasions of service per year under current Chronic Disease Management items, which are inadequate for most people with moderate to severe arthritis, many of whom will have more than one chronic condition [154].

Lack of appropriately skilled allied health practitioners to manage inflammatory arthritis is also a concern. A study of physiotherapists in Western Australia found that only one in five was confident in their knowledge of evidence-based physiotherapy interventions for rheumatoid arthritis and just one in three was confident in their knowledge of what is required to manage a person with the condition effectively and safely throughout the course of their disease [238]. Access to appropriately skilled allied health services for JIA across the country is negligible [230].

Developing education and training programs targeted at specific allied health practitioner groups and nurses would help to address this skills shortfall. RAP-eL, an online training course for physiotherapists on managing rheumatoid arthritis, has been shown to improve physiotherapists' confidence in their ability to manage people with the condition, as well as likely practice behaviours and clinical knowledge of best-practice rheumatoid arthritis management [239].

There is scope to enhance the role of allied health professionals and nurses to support multidisciplinary care for people with arthritis. In a number of local and international models, advanced practice physiotherapists act as case managers and take a leading role in the multi-disciplinary management of both osteoarthritis and inflammatory arthritis. Internationally, specialist rheumatology nurses and nurse practitioners also play a significant role in patient education, support and management and have been shown to increase access to multidisciplinary care [109]. The development of models and training pathways that support advanced practice roles for allied health practitioners and nurses can help to build an appropriately skilled multidisciplinary workforce for the delivery of best-practice arthritis and musculoskeletal care.

A number of broad structural factors within the Australian health care environment affect the implementation of multidisciplinary care in Australia. Many of these factors reflect the difficulties of providing effective care for people with chronic conditions within a health system that is still predominantly structured to deliver acute care.

Primary Health Networks (PHNs) have been established to increase the efficiency and effectiveness of medical services for patients and improve coordination of care and can provide a catalyst for improving access to integrated, multidisciplinary care in their regions [240]. PHNs could provide a locus for community-based multidisciplinary musculoskeletal clinics, support the development of local referral pathways (eg using HealthPathways) and facilitate telehealth and outreach clinics.

A shift from fee-for-service based funding models to funding for packages of appropriate care, is likely to be required to support the delivery of multidisciplinary care for arthritis, as well as for chronic conditions more broadly [131].

6.5 Workforce capacity

6.5.1 Specialist workforce

Shortages and maldistribution of rheumatologists and paediatric rheumatologists are a major impediment to consumer access to appropriate and timely care, especially for people with inflammatory arthritis and those living in rural and remote areas.

In addition, 74% of rheumatology practice is in the private sector, so public services are few with lengthy waiting times for access [241].

Shortages of paediatric rheumatologists are particularly acute. There are less than nine FTE paediatric rheumatologists in Australia to manage around 10,000 children with rheumatic conditions and no dedicated funding for paediatric rheumatology training (see section 6.3.3).

6.5.2 Nurses and allied health professionals

Internationally, models of care involving rheumatology nurses for people with severe and inflammatory forms of arthritis are considered best practice. Evidence shows that rheumatology nurse care for people with these conditions is effective and cost-effective and results in:

- better education and improved psychosocial support for patients; reduced delays in access to specialist care
- improved care coordination and continuity of care
- reduced health system costs in primary and secondary care
- improved patient outcomes and satisfaction with care[109].

However, there are only 39 FTE rheumatology nurses in Australia and their role is poorly defined and recognised. Strategies to build the rheumatology nurse workforce in Australia are required [106].

Nurses in primary care also play an important role in chronic disease management by providing patient education, support for self-management and care coordination [242].

6.5.3 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 professionals [209]. A number of practical tools have been suggested to assist GPs in the diagnosis and management of arthritis, including HealthPathways, sample management plans, checklists for appropriate tests to aid diagnosis, and information about what to include in referral letters [154].

6.6 Disadvantaged groups

Special attention needs to be provided to disadvantaged groups who experience significant barriers to accessing appropriate care. In addition to people from rural and remote areas, disadvantaged groups include people with socio-economic disadvantage, those with low health literacy, indigenous Australians and people from culturally diverse backgrounds.

Information resources need to be culturally appropriate and tailored to the needs of particular groups and available in a range of languages, formats and delivery options to facilitate access. Culturally appropriate delivery of health services is also important. For example, the Inala Indigenous Health Service located in south Brisbane, provides culturally appropriate multi-disciplinary chronic disease management and support services for indigenous people, including clinics delivered by specialists, including a rheumatologist [243].

6.6.1 Rural and remote

Arthritis is more common and more severe in rural Australia [244]. However, most rheumatologists are located in metropolitan areas, making access difficult for people in rural and remote areas. As a result people living in underserviced areas face the added stress and cost of needing to travel long distances to receive appropriate care. Alternatively, they are managed by health practitioners who are not optimally trained to deliver best-practice care, risking inadequate or inappropriate treatment and poor outcomes. Lack of access to rheumatologists is of particular concern because under the Pharmaceutical Benefits Scheme, only rheumatologists and clinical immunologists can prescribe biological DMARDs which are used to treat inflammatory forms of arthritis.

Access to appropriately skilled allied health professionals is also problematic in rural and remote areas of Australia.

Some rheumatology services in rural and remote areas are provided via outreach programs, but there is limited sustainable funding to cover the costs of these services and access to local rooms and services for clinics can be problematic. Coverage of rheumatology outreach services by the Medical Specialists Outreach Assistance Program is patchy. The Australian Rheumatology Association provides some funding to support rheumatologists to provide outreach clinics in rural areas, but this is not a sustainable funding solution [245].

Telehealth consultations are considered viable for rheumatology [219] and offer great potential to facilitate access to rheumatologists and multidisciplinary teams for people in underserviced areas. A mixed model offering both face-to-face and virtual consultations appears to offer the best option [154]. In the Australian context, telehealth services have been reported to improve access to and quality of care for patients, to support local professional development and to be cost-effective and acceptable to patients and clinicians [246-248].

Australian patients are also willing to embrace novel, remote tele-rehab models for their osteoarthritis [249] but there are barriers such as lack of funding for allied health tele-rehab consultations (both Medicare and private health insurance), and clinician reluctance to change their traditional models of face to face care [250-252].

6.6.2 Aboriginal and Torres Strait Islander peoples

Aboriginal and Torres Strait islander people are 1.4 times as likely to report that they have rheumatoid arthritis compared to the total Australian population, although this difference is not statistically significant [248]. Systemic lupus erythematosus has been reported to be two to four times more common and also more severe in Aboriginal Australians, in both adults and children, with higher associated morbidity and mortality [252-254].

A recent review found that there was an increased musculoskeletal pain burden among indigenous Australians compared to non-indigenous Australia, and, especially for osteoarthritis, a mismatch between the disease burden and access to health care. Although prevalence was similar or slightly higher, Aboriginal people accessed primary care for knee or hip osteoarthritis at approximately half the rate of non-Aboriginal people, and were less than half as likely to have knee or hip replacement surgery. Communication difficulties with health practitioners were the main reason why Aboriginal people with musculoskeletal pain choose not to access care. To increase accessibility, the authors suggest health services should initially focus on improving experiences of care for Aboriginal and Torres Strait Islander peoples, by improving patient-practitioner communication. In addition, increasing practitioner cultural awareness, ensuring Aboriginal Health Practitioners are employed and involved in care, and delivering services in a culturally safe space, such as Aboriginal Community Controlled Health Care Services, are recommended [255].

6.6.3 Culturally and linguistically diverse groups

The prevalence of arthritis is similar in Australians born in mainly English speaking countries to those born in Australia, but is lower in those born in other countries [256].

People from culturally and linguistically diverse groups often experience barriers to accessing health services due to cultural and language barriers and low health literacy [257]. People from CALD groups express a preference for culturally appropriate services with bilingual health professionals or appropriate language services to allow them to communicate with health professionals. They also express a preference for simple, plain-language culturally appropriate health information and education materials available in both English and their first language, as well as information that is short and visually appealing [258, 259].

6.6.4 Low socio-economic status

Arthritis, like many other chronic conditions, is significantly more prevalent with decreasing socio-economic status. People in the most socioeconomically disadvantaged quintile of the population are 67% more likely to report that they have arthritis than those in the least disadvantaged quintile [260].

The costs of accessing care are a particular issue for people with socio-economic disadvantage and a major reason for skipping recommended care and therapies. Often people with arthritis have had to reduce their working hours or retire from work early as a result of their condition and experience significant financial hardship as a result of the combined impact of reduced income and the high costs associated with managing their condition [9].

7 Disability

Arthritis is the second leading cause of disability in Australia after back pain. Nearly 550,000 people have arthritis as their main disabling condition, 13% of all people who report a disability. Of these more than one in four experiences severe or profound core activity limitations [261].

Arthritis has a strong negative effect on a person’s ability to participate in self-care, work, family and social activities. An Australian report noted that more than one-third of people with arthritis have limited ability to engage in daily activities as a result of their arthritis, such as managing their home or garden, and undertaking domestic duties or personal care. People with arthritis also reported significant adverse impacts of their condition on their health, employment and finances, often requiring short-term, long-term or permanent access to formal support [18, 262].

In Australia in 2009, the estimated cost of arthritis through lost labour force participation among older workers (45-64 years) consisted of lost income of $3.787 million, extra welfare payments of $291 million, and lost taxation revenue of $394 million [262]. A recent study has shown that 13.3% of people aged 45-64 years out of the labour force due to ill-health exited because of their arthritis in 2010 (45,000 people) with a similar proportion projected to exit in 2030 (60,000 people). In this and other studies, arthritis is consistently the second most common chronic condition (after back problems) leading to exits from the labour force for this age group [263].

People with arthritis-related disability who are aged less than 65 years often report difficulties in accessing disability services because they are too young to access supports available through the aged care system, or they are considered to have a health condition rather than a disability [18].

The National Disability Insurance Scheme (NDIS) currently being rolled out across Australia does list rheumatoid arthritis and JIA as conditions that may be eligible for NDIS supports, subject to a functional assessment. However, it is not clear at this stage how people with arthritis are faring under the Scheme. In addition, there is anecdotal evidence that people with arthritis who do not qualify for the NDIS are losing access to their existing disability services because these are increasingly being taken up for the NDIS. Some arthritis organisations in Australia have or are applying for accreditation as NDIS service suppliers.

People with arthritis-related disability have identified a number of service and support needs including:

- Access to better information about their condition, including: medication and side effects; managing pain and fatigue; support groups and emotional support available; aids and equipment and how to source them; and the availability of social and disability services and how they can be accessed.
- Increased support for family and friends who provide informal support for people with arthritis.
- Improved information about and access to formal disability supports, including improving awareness of the disabling impact of arthritis in the provision of social protection and social services [18].

8 Ageing and aged care

Arthritis and musculoskeletal conditions have been identified as a global threat to healthy ageing, according to a report for the WHO on ageing and health. Musculoskeletal health is critical for people's mobility and their ability to work and actively participate in all aspects of life, and to maintain economic, social and functional independence across their life-course. A strong relationship exists between arthritis and musculoskeletal pain and a lack of physical activity in the elderly resulting in functional decline, frailty, loss of well-being and loss of independence [264].

Around half of all Australians aged 65 years and over have arthritis, with osteoarthritis being the most common form in this age group [260]. Osteoarthritis as a comorbid condition in older people also has a significant negative impact on management and outcomes for cardiovascular diseases and, although there are fewer studies in this area, diabetes as well [265]. Arthritis is the leading cause of disability among the elderly [261].

Arthritis is also the third most prevalent health condition among residents of aged care facilities in Australia, affecting 15% of residents. Resources and strategies to provide and evaluate quality clinical care for arthritis and for pain in this population have been identified as an area of need [266]. Anecdotal evidence suggests management of arthritis among residents of aged care facilities is an issue in terms of both pain management and limited mobility.

Developing programs to improve arthritis management in older people both in the community and in residential aged care may help them to maintain their independence for longer, reduce the burden on informal carers, reduce premature admission to residential aged care facilities and delay requirements for higher level care.

Research into the prevention and management of musculoskeletal conditions across the life course will be crucial to enhance musculoskeletal health and prevent disability in older people and will be a critical to achieve healthy ageing objectives [264].

9 Conclusions

There are many opportunities to improve the management of arthritis in Australia to enhance the health-related quality of life of people living with the condition and to reduce the burden of arthritis on the health and welfare systems. These opportunities include:

- Raise awareness and understanding of arthritis and opportunities for prevention and improved management among the public and health professionals.
- Enhance prevention of arthritis by supporting strategies to address obesity, prevent sports injuries, reduce occupational risks and reduce smoking rates.
- Improve consumer self-management by improving access to tailored information, education and support provided by health professionals and available through arthritis consumer organisations.
- Promote best-practice care for the management of all types of arthritis through information, education and training of health professionals and through funding and models that support the delivery of multidisciplinary care. Particular areas of focus include improving the uptake of conservative management of osteoarthritis and reducing delays in diagnosis and treatment of inflammatory arthritis.
- Implement existing arthritis-related models of care more widely and consistently across Australia.
- Develop tools, strategies and models to promote appropriate and timely access to joint replacement surgery.
- Enhance access to appropriate care for people in rural and remote and other underserviced areas by expanding outreach and telehealth services.
- Develop programs and resources to address the specific needs of Aboriginal and Torres Strait Islanders, culturally and linguistically diverse groups, socioeconomically disadvantaged people and people in residential aged care.
- Work with disability service providers and funders to improve appropriate access to supports for people with arthritis-related disability.

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