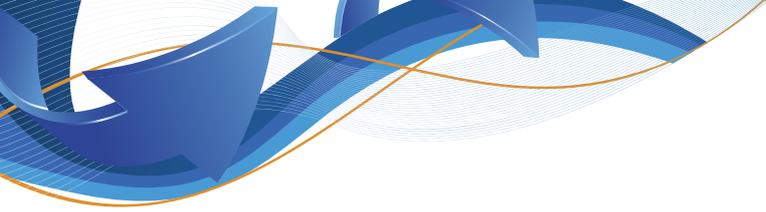


Time to Move: Rheumatoid Arthritis

A national strategy to reduce a
costly burden



Arthritis Australia
March 2014



TIME TO MOVE: ARTHRITIS

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

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

Time to Move: Osteoarthritis;

Time to Move: Rheumatoid Arthritis; and

Time to Move: Juvenile Idiopathic Arthritis.

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

What is arthritis?

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

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

Osteoarthritis

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

Rheumatoid arthritis

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

Juvenile idiopathic arthritis

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

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Executive summary

Rheumatoid arthritis (RA) is a serious, chronic autoimmune condition affecting nearly half a million Australians. RA causes pain, fatigue, joint swelling and stiffness. If poorly treated, the condition can be highly disabling because it causes progressive and irreversible joint damage and loss of function, notably in manual dexterity, strength and mobility. RA also reduces life expectancy by six to seven years in those affected.

Contrary to the commonly held perception that arthritis is an old person's disease, RA affects Australians of all ages. Indeed, 58 per cent of people with RA are of working age (25 to 64 years).

RA exacts a significant personal, social and economic cost in Australia. Costs to the health system are conservatively estimated at more than half a billion dollars annually while lost productivity due to disability caused by RA is substantial. Within five years of diagnosis, up to 20 per cent of people with RA are no longer able to work because of their condition.

There is no cure for RA; however, dramatic advances in treatment over the past decade have resulted in major improvements to short-, medium- and long-term outcomes. As a result, much of the joint damage, deformity and disability associated with the condition can now be prevented.

Early diagnosis of RA is crucial because there is a window of opportunity early in the disease during which aggressive treatment with disease-modifying antirheumatic drugs (DMARDs) can alter the course of the disease, prevent or delay joint damage, increase the chance of disease remission and improve long-term outcomes, including the reduction of disability. This window of opportunity may be as little as three months from symptom onset.

This creates a moral imperative to ensure that people with RA receive timely and appropriate care that will allow them to lead healthy, independent lives.

Evidence, however, indicates that we are failing people with RA in Australia. Many are not receiving best-practice care, severely compromising their future health and functional capacity.

Early diagnosis and treatment of RA are critical in preventing irreversible joint damage and achieving good long-term outcomes. Yet delays in diagnosing RA in Australia are common. A recent study found that the median time between symptom onset and initiation of treatment was 173 days, with some patients experiencing delays of up to a year. Treatment needs to be provided by rheumatologists but access to rheumatologists – and

hence to the newest effective treatments – is limited in many parts of Australia, especially rural and remote regions.

Multidisciplinary team care is also critical, and is consistently recommended in local and international guidelines and standards of care for people with RA. However, multidisciplinary team care for RA is not widely available in Australia, particularly in rural and remote areas and in the private sector, in which the majority of practice takes place.

Limited services, inequity of access, delays in treatment, fragmentation of care, lack of psychosocial support and a heavy financial burden are common problems reported by people trying to cope with the devastating impact of RA.

If we are to address these problems and ensure that the nearly half a million Australians with RA are cared for appropriately, then we must drive system-level changes to deliver the following key elements of care:

- early diagnosis and referral to a rheumatologist for the initiation of appropriate treatment as soon as possible – ideally within six weeks of symptom onset;
- access to integrated multidisciplinary team care by appropriately skilled practitioners;
- the provision of information, education and support for self-management that is appropriate to the needs of the person with RA;
- access to care coordination and psychosocial support;
- access to appropriate evidence-based pharmacological and non-pharmacological treatment;
- a treatment approach that aims for clinical remission or low disease activity based on the systematic measurement of treatment outcomes;
- effective ongoing management including monitoring of drug compliance, toxicity, safety and side effects, and managing complications and comorbidities; and
- access to appropriate disability support services in line with individual needs.

Recommendations

- 1. Develop and implement strategies to increase public, health practitioner and policymaker awareness and understanding of RA, including the importance of early diagnosis and treatment**
- 2. Support early diagnosis of people with RA, and urgent referral to rheumatologists for prompt initiation of therapy**
 - 2.1 Utilise existing telephone hotlines/website booking services (e.g. HealthDirect, HealthEngine) to facilitate urgent referrals to rheumatologists for early diagnosis and treatment
 - 2.2 Support improved education of primary health care professionals to promote early diagnosis and treatment of people with RA
 - 2.3 Conduct early arthritis clinics in underserved areas to provide triage and improve early access to specialist care
- 3. Provide equitable and timely access to individualised, coordinated multidisciplinary care by appropriately skilled practitioners**
 - 3.1 Establish community-based multidisciplinary arthritis clinics/teams providing both public and private services in collaboration with Medicare Locals and other stakeholders. Core members of the multidisciplinary team should include a rheumatologist, a rheumatology nurse, a physiotherapist, an occupational therapist, a psychologist and a social worker
 - 3.2 Develop system incentives/funding models to support the delivery of multidisciplinary care in the private sector, including increased access to Medicare-subsidised allied health visits under Chronic Disease Management items, in line with clinical requirements
 - 3.3 Provide services in rural and other underserved areas through specialist and multidisciplinary outreach clinics, with additional support offered via telehealth services
- 4. Improve information, education and support for people with RA to help them self-manage their condition**
 - 4.1 Utilise rheumatology nurses and other allied health professionals within the multidisciplinary team to provide patient education, self-management support, psychosocial support and coordination of care
 - 4.2 Develop a comprehensive information package and tools for people newly diagnosed with RA to help them understand the condition and its treatment, navigate their way around available services and supports, set and monitor individual treatment goals and coordinate their own care
 - 4.3 Refer people newly diagnosed with RA to state or territory arthritis organisations for access to age-appropriate and culturally suitable information resources, self-management education, and support groups
- 5. Maximise the effectiveness of pharmacological treatments for RA**
 - 5.1 Support the adoption of a target-based treatment approach for people with RA that aims for clinical remission or low disease activity, based on systematic measurement of treatment outcomes
 - 5.2 Review existing restrictions on access to biologic DMARDs under the Pharmaceutical Benefits Schedule (PBS) to ensure that they allow appropriate, timely, evidence-based access to these therapies for those who would benefit from them
 - 5.3 Streamline the application process for access to biologic DMARDs through the PBS
 - 5.4 Develop information materials to support effective medication management by other health professionals who provide care for people with RA
- 6. Provide effective ongoing management of people with RA that addresses their health and psychosocial needs over the long term**
 - 6.1 Establish shared care protocols between primary and specialist care providers that address ongoing management issues, including the monitoring and management of complications and comorbidities
 - 6.2 Provide at least a six-monthly review by a rheumatologist and multidisciplinary team for people with stable disease (reviewing those with more active disease more frequently) as well as quick access to specialist advice for people with RA experiencing major flares
 - 6.3 Encourage the provision of healthy lifestyle advice and support for people with RA in primary care
 - 6.4 Ensure timely access to surgical advice, including access to joint rheumatology and orthopaedic clinics
 - 6.5 Develop strategies to support workforce retention for people with RA
 - 6.6 Work with disability and aged care service providers and the NDIS to ensure appropriate access to programs and services that support independence and life participation for people with RA-related functional limitations



Recommendations

7. Build health workforce capacity to support the early diagnosis of RA and effective treatment for people with the disease

- 7.1 Increase the number of rheumatologists in underserved areas by expanding the existing Specialist Training Program
- 7.2 Build a cadre of rheumatology nurses/nurse practitioners, including in rural and remote regions and other underserved areas, to support RA management
- 7.3 Develop information and education materials, programs and tools for GPs, specialists, nurses and allied health practitioners, including physiotherapists and pharmacists, to support the early diagnosis of RA and effective management for people with the disease
- 7.4 Develop or use existing online tools (e.g. Health Pathways, Map of Medicine) to provide an information portal allowing easy access by GPs and other health practitioners to information on RA diagnosis and management, shared care protocols and clear referral pathways, as well as a guide to local services and resources.

Priorities and implementation

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

- strategies to support early diagnosis and urgent referral to a rheumatologist;
- adoption of a target based treatment approach;
- provision of equitable access to specialist services and multidisciplinary care;
- development of a rheumatology nursing workforce.

Implementation of these recommendations will require collaboration between stakeholders across all sectors of the health system, as well as the aged care and disability sectors. Arthritis Australia will work with relevant stakeholders to encourage and support the implementation of the Time to Move strategy.

1. Introduction

The **Time to Move** strategy provides a road map for improving the care of people with osteoarthritis, rheumatoid arthritis (RA) and juvenile idiopathic arthritis across Australia.

This document outlines an optimal model of care for the management of people with RA. The intention of the model of care is to identify key elements of best-practice treatment and support for people with RA, recognising that local delivery models will vary across Australia depending on existing systems and resources.

Although the document focuses on RA, people with other forms of inflammatory arthritis will also benefit from implementation of the proposed model of care.

A 'patient journey' framework was used to develop the model. Examining the patient journey across the continuum of care, from wellness through to advanced disease, provides an accepted framework for considering how clinical and support services can be reorganised and improved to achieve high-quality patient-centred care. In this paper, consideration of the patient journey has been expanded to take into account factors within the broader context of the Australian healthcare environment in order to identify community, systemic and health workforce issues that affect the provision of care.

A number of local and international guidelines, recommendations, standards of care and models of care informed the development of the model, including:

- National Service Improvement Framework (NSIF) for Osteoarthritis, Rheumatoid Arthritis and Osteoporosis (Department of Health and Ageing, 2006)¹
- Clinical Guidelines For The Diagnosis And Management Of Early Rheumatoid Arthritis (Royal Australian College of General Practitioners 2009)²
- Inflammatory Arthritis Model Of Care (Department of Health, Western Australia, 2009)³
- Service Model For Community-Based Musculoskeletal Health In Western Australia (Department of Health, Western Australia, 2013)⁴
- Standards Of Care For People With Rheumatoid Arthritis (Eumusc.net, 2013)⁵
- EULAR Recommendations For The Management Of Early Arthritis (EULAR, 2007)⁶
- Top Ten Quality Standards For RA (British Society for Rheumatology, 2012)⁷
- Guideline For The Management Of Rheumatoid Arthritis (The First Two Years) (British Society for Rheumatology and British Health Professionals in Rheumatology, 2006)⁸

- Guideline For The Management Of Rheumatoid Arthritis (After The First Two Years) (British Society for Rheumatology and British Health Professionals in Rheumatology, 2009)⁹
- Standards Of Care For People With Inflammatory Arthritis (Arthritis and Musculoskeletal Alliance UK, 2004)¹⁰
- 2012 Update Of The 2008 American College Of Rheumatology Recommendations For The Use Of Disease-Modifying Anti-Rheumatic Drugs And Biologic Agents In The Treatment Of Rheumatoid Arthritis (American College of Rheumatology, 2012)¹¹
- EULAR Recommendations For The Management Of Rheumatoid Arthritis With Synthetic And Biological Disease-Modifying Anti-Rheumatic Drugs: 2013 Update (EULAR, 2013)¹²

A series of stakeholder consultations was also held around the country between August and November 2013 to inform the development of the model of care.



2. Background

2.1 About RA

RA is a serious, chronic, inflammatory autoimmune condition, causing pain, fatigue, joint swelling, stiffness, and disability. The condition is systemic and can affect many parts of the body, including the heart, respiratory system, nerves and eyes. RA can occur at any age but is most commonly diagnosed between the ages of 35 and 65 years, and is around 1.6 times more common in women than in men.¹³

There is no cure for RA. If poorly treated, the condition can be highly disabling because it causes progressive and irreversible joint damage and loss of function, notably manual dexterity, strength and mobility. Joint damage occurs rapidly following the onset of the condition, with 75 per cent of joint erosion occurring within two years.¹⁴

RA varies in its presentation, severity and course. Around one-third of cases will go into complete remission within two years. In most cases, however, it becomes chronic and progressive, punctuated by 'flares' of more active disease, during which symptoms worsen severely, and periods of comparative remission. In around 20 per cent of cases, the course of the disease is aggressive and unremitting.¹³

RA is associated with increased mortality due to related complications and comorbidities including infections and cardiovascular disease (CVD). An Australian study found that life expectancy for people with disease onset in the early 1990s was reduced by six to seven years over the 14 years of the study, although changes in management of RA over the past decade may have improved this prognosis.¹⁵

Major advances in treatment for RA in the past decade have resulted in significant improvements to short-, medium- and long-term outcomes, provided the condition is diagnosed early and appropriate treatment commenced as soon as possible. As a result, much of the joint damage, deformity and disability associated with RA can now be prevented.

2.2 Impact of RA in Australia

RA affects nearly half a million Australians and costs the nation's health system around half a billion dollars in direct costs annually, with the bulk of these costs (86 per cent) relating to prescription medications.¹⁶ Contrary to perceptions that arthritis is an old person's disease, RA affects Australians of all ages, and 58 per cent of people with RA are of working age (between 25 and 64 years).¹⁷ As a result of population ageing, RA prevalence is expected to increase to around 700,000 Australians by 2032,¹⁷ an average of around 10,000 new cases per year.

RA is an important cause of disability and has a major impact on quality of life, with pain, fatigue, joint damage and loss of function affecting a person's mobility and his or her ability to undertake daily activities. While specific figures for RA are not available, arthritis is the second most common cause of disability in Australia. Nearly 600,000 Australians – 15 per cent of all those who report a disability – are disabled by arthritis, with one in four of these experiencing severe or profound activity limitations.¹⁸

Australians with RA are three times more likely to report severe or very severe pain, and nearly twice as likely to report high or very high psychological distress, compared to those without the condition.¹⁶

RA also has a major impact on workplace productivity. In Australia, only 31 per cent of people with RA aged between 16 and 64 years are in full-time employment compared to 52 per cent of those without RA. In addition, 41 per cent of people with RA are not in the labour force at all, compared to 22 per cent of the general population.¹³

Work disability tends to occur early in the disease. An Australian study found that of those who were employed at the time of diagnosis, 20 per cent had stopped working within five years of that time.¹⁹ Reduced earning capacity, coupled with the high costs associated with managing the condition¹³ can cause serious financial stress for individuals with RA and their families. One Australian study found that the average income of people with RA was only 66 per cent of the average income of the broader population.²⁰

While no RA-specific estimates are available, the annual loss of GDP due to arthritis-related early retirement in Australia was recently estimated to be \$9.4 billion.²¹



RA was recorded as the underlying cause of death in 186 deaths and an associated cause in 733 deaths in Australia in 2010.¹⁶ Evidence suggests, however, that the impact of RA on mortality may be much higher than these figures indicate, due to under-recording. A recent Australian study found that RA was listed as an associated cause of death in only 16 per cent of deaths in people with the condition.¹⁵

Australian data relating to RA incidence, treatment, costs and outcomes are limited, and this is a major barrier to recognition of the impact and potential severity of RA by the public, clinicians and policymakers. As a result, little is known about existing quality of care, and this situation may impede improvements in care.

Establishing quality indicators and improved data collection, for example through consolidation or expansion of the existing Australian Rheumatology Association Database (ARAD) and the Optimising Patient outcomes in Australian Rheumatology (OPAL) database, should be considered.

Opportunities for improvement – RA data

- Improve data collection and research on RA incidence, treatment, costs and outcomes, e.g. by consolidating or expanding existing databases such as the ARAD and OPAL databases
- Develop a quality indicator framework and data sources to monitor the management and quality of RA care in Australia



3. The patient journey

3.1 Risk factors and prevention

The cause of RA is unknown but generally, it is considered to be a multifactorial disease that involves both genetic and environmental factors. Genetic factors are estimated to contribute 50 to 60 per cent of the risk of developing RA.²²

Smoking is the main modifiable risk factor associated with RA.^{22,23} Smoking appears to interact with genetic factors to increase susceptibility to RA.²⁴ The risk increases with the intensity of smoking but even smoking just a couple of cigarettes a day more than doubles the risk of developing RA. Smoking cessation also appears to reduce the risk of developing RA over time.²⁵

Consequently, strategies to support smoking cessation for individuals with a family history of RA, or who carry genes associated with an increased risk of RA, appear to offer the greatest potential for improving primary prevention of RA.²⁶

Evidence relating to the role of overweight and obesity as risk factors in the development of RA is mixed, although it may be a factor in certain types of RA, especially in women.^{27,28,29} Other environmental factors that may play a role in RA include infections, pollutants and dietary factors, although evidence linking these with the disease is limited.²²

At the population level, international guidelines recommend that people of all ages adopt a bone- and joint-healthy lifestyle to reduce their risk of developing musculoskeletal conditions, including RA. This means engaging in physical activity, maintaining a healthy weight, adhering to a balanced diet with adequate calcium and vitamin D, avoiding smoking and alcohol misuse, and avoiding joint injury and overuse.³⁰

Opportunities for improvement – Risk factors and prevention

- Support increased funding for research into RA risk factors to support the development of prevention strategies
- Promote healthy lifestyles at the population level
- Support the cessation of smoking in individuals at increased risk of RA

3.2 Early detection and diagnosis

Early diagnosis of RA is crucial because there is a window of opportunity early in the disease during which aggressive treatment with disease modifying anti-rheumatic drugs (DMARDs) can alter the course of the disease, prevent or delay joint damage, increase the chance of achieving disease remission and improve long-term outcomes, including reduced disability.^{31,32,33}

Evidence suggests that early treatment may also be cost-saving in the longer term because remission might be achieved with significantly less use of expensive biologic medications.³¹

This window of opportunity for the initiation of treatment may be as little as three to four months from symptom onset.² Most international guidelines recommend early referral to a rheumatologist for assessment and initiation of treatment, as soon as possible and ideally within six weeks from symptom onset.^{2,6,34}

Despite the importance of initiating treatment early, delays in the diagnosis and treatment of RA are common. Recent international studies report average delays from symptom onset to the initiation of treatment of six to nine months.^{33,35,36,37}

Similar delays are experienced in Australia. A recently completed Australian study found that the median time from symptom onset to initiation of DMARD therapy was 173 days, with some patients experiencing delays of up to a year. Most of the median delay (104 days) occurred between symptom onset and referral to a rheumatologist.³⁸ The situation is likely to be worse in some areas of Australia. A 2011 report found that people with new-onset RA in some parts of rural Queensland were waiting up to two years before seeing a rheumatologist.³⁹

Stakeholder consultations for this project also consistently highlighted lack of awareness and delayed diagnosis of RA, deeming them crucial issues that need to be addressed. Participants particularly identified the need to educate GPs so that they consider the possibility of RA and make the crucial diagnosis and referral promptly.

As a result of delays in diagnosis, people with RA experience a potentially avoidable burden of disease and disability at great personal, social, and economic cost.



A 2013 review of interventions to address delays in diagnosing RA and other forms of inflammatory arthritis identified three main areas of delay:

- delays between the onset of symptoms and the patient seeking medical attention, due to lack of awareness of RA;
- delays in referrals from primary care to rheumatologists; and
- delays between referral and first assessment by a rheumatologist.⁴⁰

Reducing delays in initiating DMARD treatment for people with RA has been conservatively estimated to be cost-effective in the Australian context. An additional \$900 could be spent per patient to reduce the time to DMARD initiation before the incremental cost-effectiveness ratio breached the arbitrary cut-off of \$50,000 per quality-adjusted life year (QALY) saved.ⁱ

In addition, reducing existing delays in initiating DMARD treatment is likely to result in substantial downstream health-cost savings due to lower levels of both disability and early retirement.³¹

Delays in seeking medical attention

The most recent evidence available for Australia suggests a median delay from the onset of RA symptoms to first doctor appointment of around one month, although some people delayed seeking advice for up to four months.³⁸

A review of drivers and barriers to help-seeking behaviour by adults with RA symptoms identified limited awareness of RA, its potential severity and the importance of early treatment, as major impediments to seeking early medical attention. The review highlighted the need to implement targeted public health interventions to inform people about RA symptoms and reduce delays in seeking help.⁴¹

Community case-finding strategies (e.g. screening at community health fairs) have also been used to identify cases of undiagnosed RA and other forms of inflammatory arthritis,^{40,42} although the cost-effectiveness of these approaches has not been reported.

Delays in referrals from primary care

The most recent evidence available for Australia suggests that a significant proportion of the delay in early initiation of treatment for RA occurs at the point of referral from primary care to a rheumatologist.³⁸

GPs are usually the first port of call for people with RA symptoms so they play an important role in identifying people with possible RA, referring them appropriately for specialist assessment and care, and providing initial management of symptoms. Early diagnosis of RA can be difficult, however, as there are no precise diagnostic tests or criteria that enable a GP to determine unequivocally that a person has RA. The condition is variable in its presentation, and early inflammatory arthritis is often undifferentiated.^{6,43}

The RACGP clinical practice guidelines for the diagnosis and management of RA in general practice recommend that any patient presenting with symptoms suggestive of RA that persist beyond six weeks be referred to a rheumatologist for the initiation of treatment.² However, no strategy for disseminating these guidelines to GPs was implemented, and the extent to which GPs are aware of the guidelines or use them is unclear.

Educational strategies for primary-care practitioners have reported success in terms of improving practitioners' awareness, knowledge and ability to detect inflammatory arthritis (which may progress to RA), 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 RA.⁴⁰

There is substantial scope for using internet-based programs and tools to provide easily accessible information to GPs and allied health practitioners on diagnosing and managing RA, including information on local services and referral pathways. Existing tools being implemented by some Medicare Locals, such as Health Pathwaysⁱⁱ and Map of Medicine,ⁱⁱⁱ could be used, or new resources could be developed.

ⁱ Van Doornum S, Tacey M, Tropea J, Liew D 2013. The health and economic consequences of delay in starting disease-modifying anti-rheumatic drugs in Australian patients with early rheumatoid arthritis. American College of Rheumatology Annual Meeting (Poster)

ⁱⁱ Health Pathways provides an online health information portal for primary care clinicians to use at the point of care; it also includes a guide to local resources. <http://www.canterburyinitiative.org.nz/Home.aspx> and http://www.hnehealth.nsw.gov.au/innovation_support/programs_for_20102011/health_pathways, both viewed 27/10/2013

ⁱⁱⁱ Map of Medicine is a collection of evidence-based, practice-informed care maps that connect knowledge and services around a clinical condition and can be customised to reflect local needs and practices <http://www.mapofmedicine.com/solution/whatisthemap/>, viewed 27/10/2013

3. The patient journey

Delays between referral and first assessment by a rheumatologist

Many people in Australia face long delays before they can see a rheumatologist, especially if they reside in rural and remote areas and/or their doctors are in public practice.⁴⁴ 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 are most common in Tasmania, South Australia, the Northern Territory and Queensland.⁴⁵ In Queensland, waiting times for public rheumatology clinics are lengthy. In the quarter to December 2013, the waiting time for the most urgent cases was 111 days, while those in the next most urgent category waited three years.ⁱ GPs also report that limited access to specialists is a major barrier to the effective care of people with arthritis.⁴⁶

'Early arthritis clinics' – specialist clinics for the early assessment of patients with inflammatory arthritis – have been successful in reducing delays in initiating treatment for RA. These clinics offer a more structured approach to triage, assessment and referral of patients with inflammatory arthritis.^{14,47} Some hospital-based early arthritis clinics operate in Australia, but there is scope for creating clinics at the community level as well.¹⁴ In addition, innovative triage models such as telephone hotlines or online clinics could be used.⁴⁸

There is also the potential to use rheumatology nurses (or other appropriately trained health practitioners, such as GPs and allied health professionals) to undertake triage for referral to rheumatologists, and this may be a useful strategy in underserved areas or to reduce rheumatologist waiting lists. 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.⁴⁹ In another, a nurse-led early arthritis clinic reduced the average delay in access to specialised rheumatology care from three months to three weeks.⁵⁰

Opportunities for improvement – Early detection and diagnosis

- Increase public awareness of RA and the need for early diagnosis and treatment
 - Implement public-awareness-raising strategies
 - Develop and implement RA information, education campaigns and tools (e.g. assessment algorithms and referral protocols, waiting-room materials), targeting GPs and other primary care practitioners such as physiotherapists and pharmacists who may encounter people with RA symptoms
 - Promote uptake of the RACGP guidelines for the diagnosis and management of early RA
- Facilitate early referral to a rheumatology service
 - Develop or use existing online tools to support GPs including information on diagnosis and management, clear referral pathways and a guide to local services and resources
 - Establish a rheumatology telephone hotline/ website/online clinic for appointments for urgent referrals
 - Establish early arthritis clinics for triage, assessment and diagnosis - face-to-face or online
 - Train rheumatology nurses or other health practitioners to undertake triage for referral to a rheumatologist in underserved areas

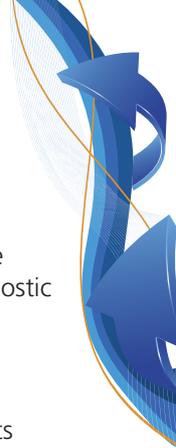
3.3 Early treatment

In the past 15 to 20 years, there have been major advances in treatment for RA. People with RA treated in recent years demonstrate major reductions in disease activity and joint damage, reduced disability and improved quality of life, compared to earlier cohorts.⁵¹

In Australia, a significant reduction in arthritis-related disability in 45- to 64-year-olds has been attributed in part to new and more effective treatments.⁵²

Key to achieving these changes has been a shift in the treatment paradigm to early and aggressive DMARD therapy and the advent, in the past ten years, of newer genetically engineered biologic DMARDs (bDMARDs).

ⁱ <http://www.health.qld.gov.au/hospitalperformance/op-main.aspx?hospital=99999> Viewed 17/3/2014



Once early and accurate diagnosis is achieved, the key objectives of early treatment of RA are to suppress disease activity and slow the progression of joint damage, prevent loss of function, control pain and enhance self-management.³⁴

RA affects each person differently, with individual variation in the range of symptoms, number of joints affected and severity, so treatments must be matched to individual patient characteristics. However, key elements of treatment and care based on existing guidelines and models and standards of care include:

- access to an appropriately skilled multidisciplinary team to help manage the physical, psychosocial and occupational impacts of the condition (see RACGP guidelines, NSIF and others);
- provision of patient information, education and support to improve their understanding of the disease and its treatment, and to support self-management; and
- access to evidence-based pharmacological and non-pharmacological treatments.

3.3.1 Optimal pharmacological therapy

DMARDs

Prompt initiation of DMARD therapy, with the goals of achieving clinical remission or low disease activity as soon as possible, is the mainstay of early RA treatment.^{11,12,53}

Early and aggressive treatment with DMARDs dramatically improves clinical outcomes for people with RA, with sustained benefits over time. 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.³³

A meta-analysis published in 2006 looked at the long term benefit of early versus delayed initiation of DMARDs on disease progression. The pooled estimate of effects demonstrated a 33% reduction in long term (up to five years) radiographic progression of RA for people receiving early compared to delayed DMARD therapy. This effect was observed over several years regardless of subsequent treatment. The authors note that this level of reduction would prevent functional disability, joint replacement and work disability.^{iv}

Some evidence suggests that early treatment may be especially beneficial in patients with the worst prognostic features.³²

Early initiation of treatment is also likely to result in substantial cost savings later in the course of the disease, as evidence suggests that it can help patients achieve remission with significantly less use of expensive bDMARDs than is needed when the initiation of treatment is delayed.³¹

There are a number of DMARDs available including conventional DMARDs, such as methotrexate, and newer, more expensive bDMARDs that target individual molecules in the immune system. Usually, more than one DMARD is prescribed at a time as combination therapy has been shown to be more effective than monotherapy. In Australia, conventional synthetic DMARDs can be prescribed by GPs but only rheumatologists or clinical immunologists can prescribe bDMARDs.

Response to these medications varies across patients and needs to be closely monitored and adjusted as required to achieve clinical remission or minimal disease activity. Patients may need to trial a number of therapies and combinations to optimise the benefit. DMARDs may be associated with significant side effects, including toxicity (conventional DMARDs) and serious infections (bDMARDs), which also necessitate careful monitoring.

Conventional DMARDs (especially methotrexate) are generally recommended as first-line treatment for RA, with bDMARDs introduced only if conventional DMARDs are ineffective or result in unacceptable side effects. Under PBS restrictions in Australia, bDMARDs can be prescribed only by a specialist for those who meet defined criteria for disease severity and who have failed at least six months of treatment with two conventional DMARDs.

Measuring the effectiveness of early treatment

Measuring the effectiveness of treatment is crucial, both to ensure that patients are optimising their health outcomes, and that health dollars are spent on treatments that work.

Treat To Target (T2T), is an international initiative to define RA treatment targets and recommendations in order to optimise treatment. The recommendations were developed by a committee of international experts. The T2T strategy entails measuring disease activity and adjusting therapy to optimise outcomes, with the primary target of achieving clinical remission or low disease activity, with treatment adjusted, until the treatment target is reached.^{12, 53, 54, 55}

^{iv} Finckh A, Liang MH, van Herckenrod CM, de Pablo P. Long-term impact of early treatment on radiographic progression in rheumatoid arthritis: a meta-analysis. *Arthritis and Rheumatism* Vol. 55, No. 6, December 15, 2006, pp 864–872 DOI 10.1002/art.22353



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The findings of a literature review considered T2T to be a valid approach to treatment based on the optimal use of conventional and biologic DMARDs.⁵⁵

The extent to which the T2T approach is used in Australia is unclear, but widespread adoption of a target-based approach that is easy to apply in the Australian context could help ensure optimal therapy for RA as well as other forms of inflammatory arthritis.

In stakeholder consultations for this project, people with RA emphasised the importance of a person-centred rather than a medication-centred approach to RA treatment. Consequently, any target-based approach adopted needs to include measures of relevance and importance to people with RA and a shared decision-making approach.

bDMARDs as first-line treatment

Some evidence suggests that bDMARDs may play a role alongside methotrexate in first-line treatment, and may improve response rates in early RA, especially in the most severe cases. The cost-effectiveness of this approach, however, is unclear.⁵⁶

The most recent guidelines from the American College of Rheumatology recommend bDMARDs as first-line treatment for a subgroup of early RA patients with more severe disease and poorer prognosis.¹¹ Recently updated European guidelines, however, continue to recommend conventional DMARDs as first-line therapy.⁵⁸

DMARD use in Australia

In Australia, there were 3.4 million DMARD prescriptions subsidised by the PBS for RA in the five-year period from 2003–2007, at a cost of \$472 million; 96 per cent of these scripts were for conventional DMARDs. Around 236,000 people received at least one conventional DMARD during this period whereas only 7,298 people received bDMARDs; however, bDMARDs cost more than half of the total cost for all DMARDs. Almost three-quarters of conventional DMARD scripts were written by GPs.⁵⁹

Management by other health professionals

People with RA often receive conflicting information and advice from other health professionals, such as pharmacists, regarding their RA medications. Simple measures, such as the development of information materials to accompany DMARD scripts, may help to address this issue.

Other pharmacological therapies

In addition to DMARDs, non-steroidal anti-inflammatory drugs (NSAIDs), analgesics and corticosteroids are also widely prescribed to relieve RA symptoms, but have limited or no effect on disease progression.^{6,60} Systemic corticosteroids are usually used as a bridging therapy in early RA until DMARD therapy is initiated and starts to take effect. Long-term use of steroids is not recommended.²

Barriers to access to medications

Eligibility criteria for bDMARDs

Detailed eligibility criteria relating to disease severity, prior therapy and treatment response must be met for a person with RA to qualify for PBS-subsidised treatment with bDMARDs. In particular, bDMARDs can be prescribed only after other drug treatments have failed. As a result, in order to meet the criteria, some people with severe RA may need to endure a period of time on ineffective therapy (six months), potentially compromising future outcomes. The potentially negative impact of these eligibility criteria is compounded in people who have experienced a delay in diagnosis because the criteria apply from initiation of therapy rather than from symptom onset.

Stakeholder consultations identified that difficulties in accessing bDMARDs were an important issue and suggested that a more flexible approach be adopted that allows individualised treatment plans, tailored to each person's needs.

As noted earlier, there is a view that earlier treatment with bDMARDs may result in improved outcomes for people with certain subtypes of RA, with the prospect that medication can be withdrawn earlier. As more evidence becomes available, current PBS prescribing restrictions should be reviewed.

Existing PBS eligibility criteria do not appear to be evidence-based. A recent Australian study examined how well PBS severity measures used in the reimbursement criteria for bDMARDs related to a person's health-related quality of life. It concluded that the criteria did not seem to target those patients with the most impaired quality of life.⁶¹ There is scope to review existing PBS eligibility criteria and restrictions for bDMARDs so that they align more closely with evidence regarding the impact of disease activity on patient function and quality of life.

An additional issue is the burdensome and time-consuming application process for PBS subsidy that is required to initiate and continue bDMARD treatment. Detailed application forms must be completed and sent to Medicare for approval, and this adds to the delays in initiating and continuing appropriate treatment.

Limited access to rheumatologists

The PBS limits prescribing of bDMARDs for RA to rheumatologists and clinical immunologists, which presents a significant barrier to patients under the care of other health practitioners needing to access these medications. The situation is especially restrictive for people with RA living in rural and remote regions, or in other areas with limited access to rheumatologists. A systematic approach to extending rheumatology services to people living in rural and remote areas, including greater use of outreach and telehealth services, is required to improve access to appropriate care and medications.

3.3.2 Multidisciplinary care

Multidisciplinary care is a key principle for the management of RA as it allows the best possible care to be provided, reducing patients' risk of developing the complications and disability associated with the condition. Multidisciplinary care is recommended in most local and international guidelines and standards of care.^{2,8,9,33}

Assessment of an individual's health and psychosocial needs by a multidisciplinary team at diagnosis is usually recommended; the aim is to develop an individualised care plan and provide information, education and support to help the person with RA self-manage their condition.^{1,2,9} Typically, members of the multidisciplinary team include but are not limited to GPs, rheumatologists, nurse specialists, physiotherapists, occupational therapists, pharmacists, psychologists, dieticians, exercise physiologists and social workers.^{2,3} Planned, periodic reviews by the multidisciplinary team, usually annually, to review progress, identify new issues and adjust therapy, are also recommended.

There are limited data pertaining to access to multidisciplinary team care for people with RA in Australia. Available evidence and stakeholder consultations suggest, however, that access is limited and ad hoc.³

Barriers to multidisciplinary care

Lack of multidisciplinary teams

Stakeholder consultations have identified that lack of multidisciplinary care approaches to RA is an important issue at all levels of care.

Access to appropriately skilled multidisciplinary team care for people with RA is limited mainly to a few tertiary hospital-based clinics. Access to publicly funded services is even more restricted. Where public access to allied health care is available, it is often limited, or priority is given to patients with other conditions. Podiatry care, for instance, typically prioritises patients with diabetes over those with RA.

In addition, rheumatology practice in Australia occurs mainly in private, community-based settings that do not normally provide access to multidisciplinary team care. It is not clear to what extent privately practising rheumatologists refer their patients with RA to allied health practitioners but anecdotal evidence suggests that it is limited.

Referral to allied health services at the primary care level is also limited. In 2008–09, GP referrals to allied health were made at a rate of only 2.1 per 100 RA problems managed, while 2007–08 data show that only 8.6 per cent of people with RA reported seeking help from an allied health professional in the previous 12 months. The uptake of managed care plans by people with RA is unknown.¹⁶

Lack of appropriately skilled allied health practitioners

People with RA often report difficulty finding community-based allied health professionals with the skills and experience to manage RA effectively. A recent study of physiotherapists in Western Australia found that only one in five was confident in their knowledge of evidence-based physiotherapy interventions for RA and just one in three was confident in their knowledge of what is required to manage a person with RA effectively and safely throughout the course of their disease. This highlights the pressing need for professional development in this area.⁶²

Cost

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. People with RA can access MBS rebates for allied health services under Chronic Disease Management items but currently, subsidised visits are limited to just five per year.



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This number is inadequate to meet the range of allied health services that a person with RA is likely to require for optimal care, and needs to be increased.

Moreover, under the Medicare Chronic Disease Management items, only GP referrals to allied health services attract rebates, creating inequities in access to these services for people with conditions such as RA that are managed primarily by specialists. People in this position are required to visit their GPs to have individualised care plans developed and receive referrals to allied health professionals that would more appropriately be managed by their main treating practitioner as part of routine patient management. This adds unnecessarily to health care costs.

Fragmentation of care

Care coordination has been shown to yield clinical and economic benefits, locally and internationally, in a range of musculoskeletal and chronic conditions.^{4,63,64}

However, stakeholder consultations for this project identified fragmentation of services and lack of continuity of care as key issues in the delivery of care for people with RA. Service fragmentation is an issue at both the primary care and specialist levels.

People with RA 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. Around 80 per cent of rheumatology practice takes place in private practice.⁶⁵

Many stakeholders suggested a 'one-stop' multidisciplinary clinic providing coordinated appointments with different service providers as an ideal solution. This model would make it easier to access multidisciplinary care, would facilitate communication across service providers, and is similar to the model recommended in the Service Model For Community-Based Musculoskeletal Health released recently in Western Australia.⁴ Clinics could be hospital-based or community-based, with the latter facilitated by Medicare Locals. Telehealth and other outreach options could be used to extend services into rural and remote areas.

Increased utilisation of nurses to provide coordination of care as well as other elements of monitoring and care has also been shown to be effective in enhancing continuity of care for people with severe RA.⁶⁶

3.3.3 Information, education and support for self-management

Enabling patient self-management has been identified as a key strategy for managing chronic disease^{67,68} and is generally recommended in most clinical guidelines, standards and models of care for people with RA. There is no consensus definition but the term is generally used to describe the activities undertaken by a person with a chronic condition, in conjunction with their family and care community, to manage the symptoms, treatments, psychosocial and lifestyle consequences of their condition, so as to maintain optimal health.⁶⁹

Effective self-management requires access to information, education and support from health professionals and carers.¹ Information and education are also important to empower people with RA to make informed decisions about their treatment and care, which is an essential part of delivering effective patient-centred care.

Interventions to support self-management vary in content and method of delivery but generally aim to improve the knowledge and skills a person requires to manage their condition effectively. Although the evidence base has limitations, self-management interventions in arthritis have been associated with small improvements with respect to pain and disability.⁷⁰ 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.⁷¹ Programs based on cognitive behaviour therapy are recommended in some guidelines.⁸

Nurse-led education programs in patients with RA have been shown to significantly improve patients' knowledge about the disease, its treatment and self-management strategies.⁷²

Arthritis organisations across Australia are an important source of information and support services in the community, providing information on the disease and its management, self-management education programs, patient support groups and camps. As yet, however, there appears to be no systematic approach to referring those newly diagnosed with RA to these organisations for support. There is also scope to develop more comprehensive information tools and resources that better meet the needs of people with RA.

Stakeholder consultations highlighted the lack of adequate information and support for people with RA at the time of diagnosis. The importance of empowering people to understand and manage the condition was also stressed.

3.3.4 Non-pharmacological management

Physical and occupational therapy

Physical therapy has an important role in the management of RA, both in its early stages and throughout the course of the disease, and is endorsed in most local and international guidelines and recommendations.^{2,6,73,74} Physical and occupational therapy can relieve pain and fatigue and improve function for people with RA.^{75,77}

Access to appropriately skilled physiotherapists, however, is limited in Australia. Typically, public hospital physiotherapy services offer only a small number of sessions, so most people need to access community-based services. However, a recent Australian survey identified low levels of confidence among community-based physiotherapists in recognising RA and managing a patient with RA effectively and safely throughout the course of the disease.⁶²

Hydrotherapy is also used in the treatment of RA. Usually, it involves specific, physiotherapist-led exercises, performed in a warm-water pool. The warmth and buoyancy of the water can help to relieve pain, relax muscles and increase the person's range of movement, while the water's resistance builds muscle strength. Evaluations of hydrotherapy have shown that it has positive effects in reducing pain and improving the health status of people with RA, but long-term benefits have not been assessed.⁷⁸

In Australia, access to hydrotherapy is restricted by the limited availability of appropriate warm-water pools and of practitioners who are suitably qualified to conduct sessions.

Local and international guidelines support the role of occupational therapy in maintaining function for RA patients, both in the early stages and throughout the course of the disease. Occupational therapy interventions include training of motor function, instruction on joint protection and energy conservation, counselling, instruction about assistive devices and the provision of splints.

There is strong evidence that comprehensive occupational therapy can help people with RA to undertake daily chores (such as dressing, cooking and cleaning) with less pain. Benefits are seen with occupational therapy that includes training, advice and counselling, and with advice on joint protection. However, occupational therapy does not appear to improve overall levels of wellbeing or reduce pain.⁷⁷ Targeted, comprehensive occupational therapy may improve functional and work-related outcomes in employed RA patients at risk of work disability.⁷⁹

Psychosocial support

A diagnosis of RA affects all aspects of a person's life and can have a devastating impact on their psychological as well as their physical wellbeing. Partners, families and carers may also be affected.⁸⁰

Depression and anxiety are common but under-recognised in people with RA.^{80,81} In Australia, twice as many people with RA report high levels of psychological distress than those without the condition.¹³ In one study of British and Australian patients, around one in five had both anxiety and depression.⁸²

Depression is two to three times more common in people with RA than it is in the general population, and is associated with an increased risk of work disability, mortality and heart attack as well as with higher direct medical costs.^{83,84} People with worse functional status are more than twice as likely as those with better function to have moderately severe to severe depression.⁸¹ Pain and fatigue are the best overall predictors of self-reported depression.⁸²

Depression may also exacerbate pain and disease activity in RA, reducing adherence to medication and decreasing the efficacy of pharmacological and some non-pharmacological RA treatments.⁸³

Even in patients without clinical depression and anxiety, coping with the pain and fatigue of RA – and the effects of these symptoms on work, social and recreational activities, and relationships – can have a negative impact on psychological wellbeing.⁸⁰

Effective treatments include cognitive behavioural therapy (CBT), meditation and relaxation, biofeedback, patient education to increase self-efficacy, and exercise. Appropriate treatment is associated with reduced pain, improved functional and psychological status and self-efficacy, and improved adherence to treatment strategies, with evidence suggesting that interventions are more effective early in the course of the disease.^{80,85}

An Australian study found that a CBT intervention in early RA had sustained benefits over five years, including physical and psychological benefits and reduced utilisation of health care services amounting to cost savings averaging \$1700 per patient, compared to an intervention cost of \$1000. The study also reported that psychological services were rarely made available to patients as part of routine care.⁸⁶

Existing guidelines, standards and models of care recommend that people with RA receive early guidance on coping with their disease from all members of the multidisciplinary team, to enable them to cope at diagnosis and throughout the course of the disease. People experiencing higher levels of distress should have access to psychological support to help them cope with



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their condition, stay at work and participate in normal activities.^{2,5,8,9}

Arthritis organisations across Australia are an important source of psychosocial support services in the community, providing self-management education programs and patient support groups. However, there appears to be no systematic approach to referring those newly diagnosed with RA to these organisations for support.

There is scope to provide more age-appropriate and culturally suitable support groups for younger people with RA and those of culturally and linguistically diverse (CALD) backgrounds. Support groups normally meet face to face but more accessible and flexible options such as online support groups may help to increase engagement, (especially for certain subgroups, such as young women) and are supported by some arthritis state organisations.

Opportunities for improvement – Early treatment

- Improve access to rheumatologists and appropriately skilled multidisciplinary teams (see Workforce, page 25)
- Establish a target-based approach to RA treatment that is easy to apply in the Australian context
- Establish community-based multidisciplinary arthritis clinics/teams providing both public and private services
- Provide services in rural and underserved areas through outreach clinics and/or telehealth services organised through hub-and-spoke arrangements with larger centres
- Develop education programs for GPs and nurses in general practice to upskill them in supporting people with RA as part of shared care arrangements, including the development of shared care protocols between primary and specialist care services
- Increase the number of annual Medicare-subsidised allied health visits available to people with RA under Chronic Disease Management items and extend these to include referrals to allied health professionals by specialists and consultant physicians
- Use rheumatology nurses/nurse educators or other allied health professionals in the multidisciplinary team to provide patient information, education and self-management support as well as the coordination of care
- Develop a comprehensive information package and tools for people newly diagnosed with RA to help them self-manage their condition, navigate their way around available services, set and monitor individual treatment goals and coordinate their own care
- Refer those newly diagnosed to arthritis state and territory organisations for access to information resources, self-management education and peer support groups
- Develop innovative approaches to providing peer support, such as online support groups and groups catering to specific cultural needs
- Provide improved psychosocial support for people with RA, including better access to psychologists and innovative programs such as online psychotherapy
- Review existing restrictions on PBS access to biologics and streamline the application process required

3.4 Ongoing management

The main goals of RA management in established disease are to control disease activity, slow the rate of joint damage, alleviate pain, maintain function for employment and daily activities, monitor and address complications and comorbidities of the disease and its treatment, and maximise quality of life.^{2,8} There is also the need to address a person's changing needs 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.

Most guidelines support shared care between primary and secondary care practitioners in established RA, with ongoing management provided in primary care, and regular reviews by the treating rheumatologist and multidisciplinary team.^{2,9} In Australia, reviews by a rheumatologist are required at least once every six months for people on bDMARDS to meet existing PBS prescribing requirements.

The role of GPs includes monitoring disease progression, adverse events and drug toxicities, and screening for and managing comorbidities, in conjunction with the treating rheumatologist. Notably, the RACGP guidelines mainly address early management and provide limited guidance on the ongoing monitoring and management of later complications of RA. There is scope to improve guidance to GPs on ongoing management and support for people with RA through revised clinical practice guidelines or agreed shared-care protocols with rheumatologists.

3.4.1 Pain Management

Effective pain management is one of the highest priorities reported by people with RA. Poorly controlled pain is associated with lower quality of life and higher levels of disability, emotional distress and depression.¹

Effective pain management for people with RA usually requires a range of strategies, highlighting the importance of multidisciplinary team care. These strategies include effective disease control through DMARD therapy; pharmacological pain management; psychological interventions such as cognitive behaviour therapy; self-management education; and physical and occupational therapy.

3.4.2 Disease flares

Many people with RA experience sudden increases in the severity of their condition ('flares') and therefore need rapid and direct access to specialist advice and health services. Flares are usually a sign that the disease is progressing and

that medication needs to be adjusted to re-induce remission or low disease activity. Prompt and effective management of flares is required to control pain and reduce damage to joints.

The ARMA standards of care recommend that any person experiencing a flare should have direct access to specialist advice and the option for an early review with appropriate multidisciplinary team members.

Stakeholder consultations identified that timely access to rheumatologists during a disease flare was sometimes problematic. Strategies to allow rapid access to specialist advice and prescriptions need to be implemented. Such strategies could include rheumatologists reserving timeslots for emergency cases, online emergency clinics and a telephone hotline providing advice, manned by rheumatology nurses.

3.4.3 Comorbidities

Comorbidity is common in people with RA as a result of both their condition and its treatment. One Australian study found that more than half of people with RA commencing bDMARD therapy had at least one comorbid condition, while almost a quarter had two or more. The most commonly reported comorbidities were hypertension, osteoporosis and depression, and 10 per cent of patients reported prior malignancy.⁸⁷

Cardiovascular disease

CVD is the most common comorbidity for RA and is a major contributor to the reduced life expectancy associated with the condition. It appears that the increased risk is due to a higher prevalence of traditional risk factors for CVD in those with RA as well as to the increased inflammatory burden imposed by the condition.⁸⁸

Accumulating evidence indicates that RA is an independent risk factor for CVD that is comparable in magnitude to type 2 diabetes.⁸⁹ However, early and effective DMARD treatment of RA, especially with tumour necrosis factor (TNF) inhibitors and methotrexate, is independently associated with a lower risk of CVD.⁸⁸ Effective RA treatment is also likely to improve physical activity levels and hence may reduce other CVD risk factors such as obesity, high blood pressure and diabetes.⁸⁸

International guidelines recommend that people with RA be assessed regularly for CVD risk and treated in accordance with treatment guidelines for the general population.^{8,88} However, as existing risk assessment models for CVD are based on the general population, EULAR recommends that CVD risk score models should be adapted for people with RA with certain disease characteristics by introducing a multiplication factor of 1.5.⁸⁸

¹ Lee YC 2013. Effect and treatment of chronic pain in inflammatory arthritis. *Curr Rheumatol Rep* Jan 2013 15 (1): 300 doi: 10.1007/s11926-012-0300-4



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It is not clear how well-managed CVD risk and events are for people with RA in Australia. International evidence suggests that poor CVD risk management is common in people with RA⁹⁰ while a recent Australian study found that people with RA received less secondary prevention interventions and were twice as likely to die within 30 days of a heart attack as were members of the general population. This difference was not fully explained by relevant clinical factors.⁹¹

The RACGP guidelines recommend that GPs actively monitor and address CVD risk factors in people with RA, and provide lifestyle advice to encourage them to stop smoking, adopt healthy dietary patterns, control their weight and exercise. However, there is scope to update and expand these guidelines to incorporate recommendations on CVD risk assessment and management in line with more recent international guidelines.

Establishing preventive cardio-rheuma clinics, as trialled in Norway, may also help to address the issue of inadequate CVD prevention in patients with RA.⁹⁰

Malignancy

Compared with the general population, people with RA face an elevated risk of some cancers, such as lymphoma, lung cancer and skin cancer. Their risk of other cancers, such as those of the bowel and breast, however, is reduced.⁹²

There are concerns, that treatment with biologic medications, in particular the TNF inhibitors, may increase the risk of certain cancers in people with RA. Because of the relatively recent advent of bDMARDs, it is too soon to be certain of their long-term safety profile, although evidence to date suggests that there is limited overall increased risk of malignancy associated with their use.⁹²

Some evidence suggests an increased risk of melanoma with use of these medications⁹³ and this is of particular concern in Australia, which has one of the highest rates of melanoma in the world. Evaluation of the melanoma risk associated with biologic medications for RA was one of the major reasons for the establishment of the ARAD database in Australia. Evidence from the database indicates that people with RA receiving TNF inhibitors may have an increased risk of both melanoma and non-melanoma skin cancer, as well as higher rates of lymphoma, than those people with RA who had never received these medications.¹

¹ Van Doornum S, Staples MP, March L, 2011. Risk of malignancy in Australian rheumatoid arthritis patients treated with tumour necrosis factor inhibitors. ARC/ARHP 2011 Scientific Meeting. (Poster)

3.4.4 Secondary prevention

Weight control

A number of studies suggest that being overweight or obese may actually protect against joint damage in the early stages of RA and that changes in body weight do not correlate with disease activity. Other studies suggest that in the longer term, obesity is associated with higher inflammatory activity, reduced functional capacity and worse quality of life.²⁶ Conversely, being underweight is associated consistently with worse disease activity, greater severity of symptoms and lower quality of life.²⁶

Nonetheless, maintaining a healthy weight is generally considered to be especially important for people with RA, to help maintain overall health and fitness, and to reduce the risk of developing other conditions, particularly CVD, for which people with RA are already at elevated risk (see Comorbidities, page 18). If a person with RA is overweight, weight reduction may also assist in reducing pain by reducing the load on weight-bearing joints.²

The most recent NHMRC guidelines for managing weight and avoiding obesity recommend multicomponent lifestyle interventions incorporating healthy eating, increased physical activity and support for behaviour change, tailored to the needs of the individual. Primary health care professionals, especially GPs and practice nurses, are identified as having an important role in referring patients to dietitians and lifestyle programs and, in managing follow-up, maintenance and relapses over the long term. A systematic and proactive approach to managing care is recommended to support effective weight management in primary care.⁹⁴

Exercise

Exercise therapy is effective in addressing the adverse effect of RA on muscle strength, endurance and aerobic capacity, as well as helping to lower the risk of CVD, which is elevated in people with RA. Physical activity is also beneficial for bone health and mood and enhances psychological wellbeing, all of which can be an issue for people with RA.

Dynamic exercise (i.e. of low to moderate aerobic intensity) and hydrotherapy have been shown to improve strength, aerobic capacity and physical functioning in people with RA, and may also relieve symptoms



such as pain. Exercise does not appear to exacerbate symptoms.^{2,95} Physical activity has also been shown to reduce fatigue in people with RA.⁷ In addition to strengthening and aerobic activities, tai chi and yoga may be of benefit.^{96,97}

However, high-intensity weight-bearing exercise may accelerate joint damage in patients with more severe disease or pre-existing extensive damage.^{73,98}

Community-delivered exercise programs can achieve statistically and clinically important improvements in pain and physical function in people with a range of rheumatic diseases, including RA. Evidence suggests that programs do not need to be targeted to a particular arthritis type to be effective.⁹⁹ There is also some evidence that internet-based physical activity interventions with individually tailored supervision, exercise equipment and group contacts may be of benefit in encouraging participants to meet physical activity recommendations.¹⁰⁰

State arthritis organisations offer a wide variety of exercise programs suitable for people with RA, including tai chi, warm-water exercise (hydrotherapy) and general self-management courses that encourage exercise. Currently, however, there is no nationally recommended, evidence-based exercise program for arthritis in Australia. Canada has a program called People with Arthritis Can Exercise (PACE) program and the US has the Arthritis Foundation Exercise Program; both of which provide programs based on the PACE randomised controlled trial.¹⁰¹

Currently, Arthritis Australia is implementing a program to enhance the training of exercise professionals and to accredit exercise programs suitable for arthritis to assist people with RA and referring health practitioners in accessing appropriate programs.

Smoking cessation

Stopping smoking does not appear to reduce disease activity once people have developed RA.¹⁰² Some studies suggest that smoking reduces the effectiveness of RA treatment, but results are mixed.^{103,104,105} In any case, quitting smoking is important for people with RA as it helps reduce their already elevated risk of CVD.

3.4.5 Employment issues

RA is a major cause of work disability in Australia, with one in five people no longer employed within five years of diagnosis and many more restricted in the type and hours of work they can do.¹⁹ Reduced earning capacity, coupled with the high out-of-pocket costs associated with the condition, adds to the distress for people with RA and their families.

Early and effective treatment of RA reduces work disability, but additional measures are required to help support people with RA who remain in the workforce.

Employment restrictions for people with RA can vary significantly depending on a range of job, disease, personal and environmental factors. These factors include the severity of the disease, the physical demands of the job, personal factors such as age of disease onset and time since diagnosis, and environmental factors such as workplace accessibility and difficulties commuting.^{106,107} Many of these factors are modifiable.

Workplace changes can help people with RA to maintain employment. These might include flexible work arrangements, workplace modifications, and counselling and training to assist people with RA in changing jobs or careers when necessary. For example, in a study of workplace disability in people with RA, individuals whose workstations had been ergonomically modified were 2.6 times less likely to be work-disabled.¹⁰⁸

3.4.6 Complementary and alternative therapies

People with arthritis and musculoskeletal conditions are major users of complementary and alternative medicines (CAM), with around 60 per cent of people trying a range of products in an effort to gain relief from the chronic pain and disability associated with their condition.¹⁰⁹ Of these, around 60 per cent take omega-3 fish oils and glucosamine while about 13 per cent take chondroitin.¹¹⁰

There is good evidence that high-dose omega-3 fatty acids can improve RA patient-reported pain, morning stiffness, and number of painful and/or tender joints (RACGP). In addition, a recent Australian trial found that in people with early RA, taking fish oil significantly increased their likelihood of achieving remission and reduced the failure rate for triple DMARD therapy, requiring less use of biologic and other medications.¹¹¹

There is insufficient evidence to support the efficacy of other alternative therapies, including alternative physical therapies, for those with RA.² Often these therapies are costly and can add to the financial burden of people with RA but have only minimal beneficial effect.

A major concern in relation to the use of CAM is the potential for adverse drug reactions when used along with conventional pharmaceutical medications, especially as CAM use is not regularly disclosed or discussed during consultations with medical practitioners.¹¹² Fish oil, for example, may interfere with anticoagulants¹¹³ and this is a major concern, given that RA and CVD conditions are common comorbidities.

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There is a need to build on existing patient information about the use of CAM. This information should include potential adverse interactions with other drugs, and address the importance of discussing all medicines they are taking, including CAM, with their treating doctors. A tool is also needed to monitor efficacy and side effects, including indicators of drug interactions.

Opportunities for improvement – Ongoing management

- Review existing RACGP guidelines to improve guidance on the management of established RA.
- Develop information and education resources in easily accessible formats (e.g. online) for GPs assisting in the care of people with RA, including an easily accessible, easy-to-use medication guide to assist GPs in monitoring medication safety and side effects.
- Develop shared-care protocols between primary and specialist care providers for the ongoing management of people with RA
- For all RA patients, provide regular reviews by a rheumatologist and multidisciplinary team, and quick access to their services for the timely management of major flares.
- Increase GPs' awareness of comorbidities and the complications that may be associated with RA, especially the increased risk of CVD, and the need for regular screening and monitoring of RA patients
- Encourage healthy lifestyles in people with RA, stressing the importance of physical activity, maintaining a healthy weight, and quitting smoking
 - Provide access to physical therapists for advice on appropriate forms of exercise and physical activity, and any modifications that might be required to enable patients' participation
 - Develop consumer information resources on the benefits of exercise for people with RA
 - Provide RA patients with access to dieticians for advice on healthy diet and weight management, if required
 - Encourage improved healthy lifestyle advice for people with RA in primary care e.g. through greater utilisation of nurses in general practice or more referrals to healthy lifestyle programs
 - Develop strategies to support workforce retention for people with RA

3.5 Long-term care

The advanced stages of RA can be characterised by substantial and progressive disability resulting in reduced independence and quality of life.¹ However, evidence is accumulating that early diagnosis and effective treatment of RA in the early course of the disease leads to major improvements in health outcomes in the later stages of the condition (see Early treatment, page 10).

When the disease does progress in severity, its impact can be minimised with appropriate care and support. Optimal care during these stages requires ongoing management of the condition and its symptoms, access to psychosocial support and timely access to appropriate surgery. It also means providing access to services and assistance that enables people with advanced-stage RA to maintain their independence and supports their participation in life activities.¹ Coordinated multidisciplinary care is an essential part of optimising positive outcomes as the condition progresses.

3.5.1 Surgery

As RA progresses, surgery may be required to repair damaged joints. Joint replacement surgery (especially knee replacement) is the most common surgical procedure undertaken for RA, followed by joint fusion (arthrodesis).¹¹⁰

Joint replacement surgery is effective in relieving pain, restoring function, preventing progressive deformity and improving quality of life for people with RA. Evidence suggests that functional outcomes are better for patients if surgery is performed earlier in the disease course before joint damage has progressed too far, so specialist surgical advice should be sought relatively early in the course of the disease.^{1,114} Some evidence suggests that although beneficial, especially for pain, joint replacement tends to have poorer outcomes for people with RA than it does for those with osteoarthritis.¹¹⁵

In older cohorts, approximately one in four people with RA required joint replacement surgery over the course of their disease, with 25 to 50 per cent of these people requiring more than one procedure.¹ However, recent advances in the management of RA have seen a marked reduction in the rates of orthopaedic surgery for RA in many countries.¹¹⁶

In Australia, RA accounts for only a small proportion of joint replacement procedures as the bulk of them are done for osteoarthritis. There were only 470 total or



partial hip and knee replacements for RA in 2010–11. In line with international trends, there has been a 20 per cent reduction in knee replacements for RA between 2004–05 and 2010–11, although the number of hip replacements remains relatively unchanged.¹⁶

Access to public elective surgery in Australia is rationed by waiting lists. In 2011–12, median waiting times for elective joint replacement surgery in Australia were around 120 days for hips and around 180 days for knees, but this varied considerably from state to state.¹¹⁷ There is scope to improve the management of elective-surgery waiting lists in Australia to increase equity of access to surgery and reduce waiting times. Models for the better management of people on waiting lists for joint replacement (mainly for osteoarthritis) are currently operating in some parts of Australia, but prospects for their broader implementation are unclear.

Inflammation and overgrowth of the synovium is usually the immediate cause of joint swelling and pain in people with RA. Synovectomy, in which much of the synovium is removed, usually arthroscopically, has been shown to reduce pain and improve joint function in people with RA who do not respond to medications, and may delay the need for more complex surgery. The procedure appears to be of greatest benefit in the early stages of the condition, when the cartilage is intact, highlighting the need for RA patients to seek an early surgical opinion in these cases.^{118,119}

In arthrodesis, the affected joint is fused to restrict the movement that causes pain. This is usually considered a last-resort treatment because it can restrict mobility, but is useful in joints where range of motion is not critical.

The ARMA Standards of Care for People with Inflammatory Arthritis recommends that people whose joints and/or tendons are deteriorating should have a specialist surgical review, and suggests that joint clinics for rheumatology and orthopaedics are good models for providing care and enabling individuals to access the full range of expertise and treatment.¹⁰

3.5.2 Disability support

Disability in RA is associated with joint damage, pain and fatigue and influenced by factors such as age, gender, low socio economic status, income and education level, and pain and depression.¹ Studies of people diagnosed with RA prior to recent changes in RA treatment found 10 per cent required home modifications or regular use of a wheelchair within five years of disease onset, 18 per cent needed mobility aids and the majority were unable to perform household chores.¹

In Australia, arthritis is the second most common cause of disability after back pain, and one in four people

with arthritis-related disability report severe or profound disability. While there are no RA-specific prevalence data available, a recent Australian study found that work disability tends to occur early in RA: of those employed at diagnosis, 20 per cent had finished work within five years.¹⁹

Disability support for people with RA over the age of 65 years is provided through the aged-care system, while support for those below this age is available from disability support services. However anecdotal evidence suggests that people with arthritis are often denied access to disability services, including the Disability Support Pension, because their condition is considered a medical condition and not a disability, despite the associated limitations on mobility. As a result, younger people with RA tend to miss out on support services because they are too young for aged-care services and considered ineligible for disability support.

Recent government initiatives in the area of disability offer the potential to significantly improve inclusion, support and life opportunities for people with disability, their families and carers. This includes the rollout of the National Disability Insurance Scheme (NDIS) and state and national initiatives under the National Disability Strategy (NDS).

Informal advice is that people with severe arthritis-related disability will be eligible for support under the National Disability Insurance Scheme. The fluctuating nature of the condition, and the lack of visible impairment despite pain and fatigue, however, present challenges for assessment processes under the scheme. There is a need to monitor the rollout of the NDIS, as well as relevant initiatives under the NDS, to ensure that people with RA-related disability receive fair and appropriate support. Support for carers, to assist them in maintaining their own quality of life, is also important.

The good news is that improvements in treatment for early-stage RA over the past 10 to 15 years are likely to mean a reduction in the severity of disability associated with the condition. Already, there is some evidence to suggest that these advances in treatment are lowering the prevalence of arthritis-related disability in Australia.⁵²

Opportunities for improvement – Long term care

- Ensure timely access to surgical advice for people with RA, including through joint rheumatology and orthopaedic clinics
- Monitor the rollout of the NDIS to ensure that people with severe RA-related disability receive appropriate support



4. Australian health care environment

4.1 Supporting multidisciplinary care in Australia

A number of broad structural factors within the Australian health care environment affect the implementation of best-practice care for RA. Many of these factors reflect the difficulties of providing ongoing, integrated, multidisciplinary, patient-centred care for chronic health conditions within a health system that is still predominantly structured to deliver acute care.

The creation of Medicare Locals to plan, integrate and coordinate primary health care services on a local basis provides significant opportunities for improving multidisciplinary care for RA. Medicare Locals could provide a locus for community-based multidisciplinary clinics for RA, support the development of local referral pathways, and facilitate telehealth and outreach services. Tools, including Map of Medicine^v and Health Pathways^{vi}, have been developed to assist in establishing local referral pathways and are being implemented in some Medicare Locals.

Inadequate funding for allied health services in both the public and private sectors is an important barrier to people with RA seeking to access multidisciplinary care, and needs to be addressed. In particular, under Medicare Chronic Disease Management items, only five Medicare-subsidised allied health visits per patient, per year, are provided. This number is inadequate to address the range and frequency of allied health visits required to support optimal care.

4.2 Workforce

A recent survey of people with arthritis found that two in three were not faring well with their condition, and that poor access to specialists, GPs and allied health professionals was a key factor in how poorly they were faring.¹²⁰ GPs also report that limited access to specialists and allied health practitioners is a major barrier to effective care of people with arthritis.⁴⁶

Rheumatologists

Many people in Australia face long delays to see rheumatologists, especially in Queensland, rural and remote areas, and in public practice.⁴⁴ In 2012, more than half of all patients had to wait more than the recommended six-week period for an urgent initial consultation with a rheumatologist.⁴⁵

A 2012 report by the Australian Rheumatology Association identified shortages in the rheumatologist workforce, especially in Queensland, where the lack of a tertiary hospital rheumatology department limits training opportunities.

Regional and rural areas are also poorly serviced, with only 13 per cent of the rheumatology workforce living outside capital cities.

The report found that there were 195 full-time-equivalent (FTE) rheumatologists in Australia or around one for every 118,000 Australians.⁴⁵ This compares unfavourably with international benchmarks. The UK, for example, recommends one FTE rheumatologist per 90,000 people.¹²¹

Existing rheumatologist shortages are expected to compound in the future, with an expected increase in demand for care due to projected increases in arthritis prevalence, an ageing workforce (one-third of rheumatologists are aged more than 55 years) and changes in work practices.

Stakeholder consultations highlighted lack of access to, and long waiting times to see rheumatologists as a critical issue. Some people report that they end up at the hospital emergency department when they have RA flares because they cannot get appointments with their rheumatologists at short notice.

Increasing the number of training positions for rheumatologists through an expansion of the Australian Government's Specialist Training Program¹²² is one option that could help address current and likely shortfalls. Other options include expanding the roles of non-rheumatology clinicians including nurses, GPs and allied health professionals to support improved care for people with RA in underserved areas.

^v Map of Medicine is a collection of evidence-based, practice-informed care maps that connect knowledge and services around a clinical condition and can be customised to reflect local needs and practices <http://www.mapofmedicine.com/solution/whatisthemap/>, viewed 27/10/2013

^{vi} Health Pathways provides an online health information portal for primary care clinicians to use at the point of care; it also includes a guide to local resources. <http://www.canterburyinitiative.org.nz/Home.aspx> and http://www.hnehealth.nsw.gov.au/innovation_support/programs_for_20102011/health_pathways, both viewed 27/10/2013



Nurses

Internationally, nurses, including advanced practice nurses and nurse practitioners, are playing an increasing role in delivering rheumatology care and services.^{123,124}

In Australia, there is limited nursing support for people with musculoskeletal conditions, with few specialist rheumatology nurses and no funding for practice nurses to provide musculoskeletal care. There is substantial scope for developing a rheumatology nursing workforce to provide improved care for people with RA and to support rheumatologists, freeing up their time to spend on more complex aspects of patient care.

The availability of an appropriately skilled nursing workforce could also support service delivery in currently underserved areas, especially rural and remote regions. The recent development of an online Graduate Certificate in Musculoskeletal and Rheumatology Nursing, which has been available through the Australian College of Nursing since 2012, will assist in building this workforce. Providing scholarships could increase the uptake of this Certificate.

Allied health professionals

Access to appropriately skilled allied health professionals and to social workers and counsellors is limited in many areas, especially in rural and remote regions and in the public sector, resulting in long waiting lists and delayed treatment for acute and chronic RA-related issues. This in turn limits referral options for multidisciplinary support.

Increasing medical students' exposure to rheumatology during training, and developing education and training programs targeted at specific practitioner groups, would help to address this skills shortfall.

General practitioners

Often, people with RA are cared for by GPs in underserved areas. There is scope to develop education and training programs to upskill GPs in underserved areas, improving appropriate care for people with RA on a shared care basis.

4.3 Services in regional and rural areas

Issues arising from limited access to specialist and multidisciplinary rheumatology services are exacerbated in many rural and regional areas. As a result, people with RA living in underserved areas face the added stress and costs 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 for RA, risking inadequate or inappropriate treatment and poor outcomes. Lack of access to rheumatologists is of particular concern because under the PBS, only rheumatologists and clinical immunologists can prescribe bDMARDs.

Stakeholder consultations highlighted the lack of access to rheumatologists in rural areas and delays in accessing rheumatologists as issues of major concern. Some stakeholders reported that there were people with RA in certain areas who had never seen a rheumatologist, and this is supported by a 2011 report that found people with new-onset RA in some parts of rural Queensland were waiting up to two years before they could see a rheumatologist.³⁸

Increasingly, outreach and telehealth services are being used to deliver specialist services in rural and remote areas of Australia.

Reviews of outreach specialist services are limited, but have generally been positive about the overall effectiveness and cost-effectiveness of such services. In addition to improving access to specialists in rural and remote areas, the benefits of outreach services include upskilling local primary care practitioners, improving continuity in patient management, and reducing costs to patients, their families and the health system through reducing the amount of travel needed to access specialist care.¹²⁶

In recent years there has been an increase in the number of rheumatology outreach clinics around Australia. The Australian Rural Rheumatology Service, an outreach model combining clinical care and education services in rheumatology, is currently being piloted in the New England Medicare Local Region. Early indications are that this model has been very successful and could be expanded to cover areas that are currently underserved.

In the UK, outreach rheumatology nurse clinics have also proved valuable in providing personalised care, disease management support, social and educational support, and continuity of care close to home for people with RA.¹²⁶



4. Australian health care environment

Telehealth services are considered viable for rheumatology^{39,127} and offer great potential to facilitate access to rheumatologists and multidisciplinary teams for people in underserved areas. A mixed model offering both face-to-face and virtual consultations appears to offer the best option. 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.^{128,129,130}

Dedicated local support and training would be required to maximise the benefits of this model. This support could be provided by GPs or rheumatology nurses, who could provide assistance with medication monitoring, patient education and engagement with local health care providers for people with RA or other inflammatory forms of arthritis.

4.5 Disadvantaged groups

Special attention needs to be provided to the needs of CALD and other disadvantaged groups, including those with low health literacy. Information resources need to be available in a range of languages and the potential need for greater assistance with care coordination and support should be recognised. A culturally matched peer support program could also be considered.

Opportunities for improvement – Australian health care environment

- Work with Medicare Locals to improve access to multidisciplinary services for RA management
 - Assess and plan for local needs
 - Provide a locus for multidisciplinary clinics, telehealth and outreach services
 - Develop local referral pathways
- Develop, implement and evaluate a demonstration project multidisciplinary musculoskeletal clinic in partnership with one or more Medicare Locals
- Increase funding for allied health services in the public sector
- Support the development of multidisciplinary teams in both the public and private sectors
- Increase the number of annual Medicare-subsidised allied health visits allowed per patient under the Chronic Disease Management program, and extend this to include referrals to allied health professionals by specialists and consultant physicians
- Build workforce capacity to provide best-care management of RA
 - Increase the number of rheumatologists in underserved areas by expanding the existing Specialist Training program, with priority given to Queensland, which experiences the most severe shortages
 - Develop and implement education and training programs to upskill GPs, nurses and allied health practitioners in the area of RA management
 - Build a cadre of rheumatology nurses to support RA management and provide education, psychosocial support and coordination of care for people with RA
- Provide outreach and telehealth services that combine clinical care and education components to rural, remote and other underserved areas
- Develop resources and programs to target CALD and other disadvantaged groups, including culturally matched peer support programs

5. Existing models of care

5.1 WA inflammatory arthritis model of care³

The WA Model of Care for Inflammatory Arthritis is the only documented formal model of care that directly addresses care for people with RA in Australia. The model addresses care for a range of adult forms of inflammatory arthritis as well as JIA.

It makes a number of recommendations to support:

- early diagnosis and intervention, including early synovitis clinics to expedite diagnosis, referral and treatment;
- improved management, including:
 - consumer education, advice and self-management tools,
 - improved access to multidisciplinary care, and
 - improved monitoring of disease activity and of the effectiveness and side effects of DMARD treatment;
- workforce professional development and education, including training for rheumatology nurses, extended-scope allied health practitioners and chronic disease management teams; and
- rural rheumatology clinics and telehealth services for rural areas.

5.2 Service model for community-based musculoskeletal health, Department of Health, Western Australia⁴

The recently-launched WA Service model for community-based musculoskeletal health sets out details of how to create community-based multidisciplinary clinics to provide integrated and coordinated care for people with complex or chronic conditions such as inflammatory arthritis.

The clinics would be based in a range of community locations including GP clinics, Medicare Locals, community health centres, non-tertiary hospitals, non-government organisations (e.g. Arthritis and Osteoporosis WA) and Aboriginal medical services. Access would be by referral from GPs or other primary health care professionals.

In addition to clinical services, the clinics would provide assessment, triage and referral services for people with musculoskeletal conditions. Service coordinators would organise integrated care for RA patients, including links with referring GPs and coordinated telehealth services for rural consumers and health professionals.

5.3 UK Department of Health musculoskeletal services framework

The UK musculoskeletal services framework outlines a model of care for these conditions in which multidisciplinary musculoskeletal clinics provide the interface between primary care and hospital-based care. These clinics are a one-stop shop for assessment, diagnosis, and treatment or referral to other specialists.

The emphasis is on holistic care, offered as close to home as possible, that addresses the psychological and social as well as the physiological needs of people with musculoskeletal conditions.

The UK Department of Health framework outlines three main approaches to caring for people with these conditions: case management, disease management and supported self-care.¹³¹

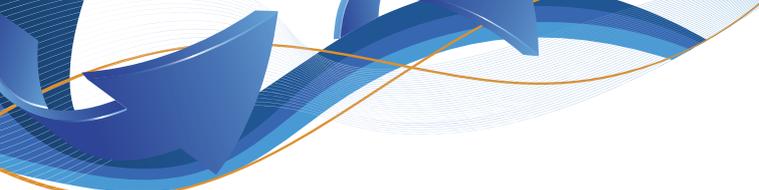
So far, however, implementation of the model outlined in the UK framework has been limited.¹³² Initial reports of a two-year pilot of the model commenced in Northern England in 2011 show that episodes of care increased by 62 per cent but overall expenditure was reduced, while the average cost per episode of care fell by 41%. The pilot service was very well received by both patients and GPs.¹³³

5.4 Eumusc.net

Eumusc.net is a three-year project that aims to raise and harmonise the quality of care for people with musculoskeletal conditions across all EU Member States.¹³⁴ The project has developed standards of care for OA and RA based on evidence and best practice, which are available in a health professional and a patient version.

Key elements of these standards of care include:

- timely access to an appropriately competent clinician for early diagnosis and DMARD treatment as soon thereafter as possible;
- the provision of information, education and support to people with RA in relation to their disease, its management and all aspects of living with the condition;
- access to a multidisciplinary team for assessment, advice and training in all matters related to their disease;
- an individual treatment plan that incorporates goals defined by the person with RA and the health professional that includes a communication, monitoring and self-management education plan;
- regular assessment for symptoms, disease activity, comorbidity and function at at least three-monthly intervals;
- access to evidence-based pharmacological and non-pharmacological treatment;
- rapid access to care during flares; and
- information and support that encourages adopting and maintaining a healthy lifestyle.



5. Existing models of care

5.5 Models using health professionals in extended roles

A number of models being implemented overseas involve health professionals, including nurses and physical and occupational therapists, in extended roles with the aim of improving care for people with musculoskeletal conditions.

In the UK, rheumatology nurses and rheumatology nurse practitioners have extended their roles in the assessment and management of RA to include musculoskeletal examination, medication monitoring, patient education, joint injections, nurse prescribing, referrals to other health professionals and follow-up clinics.

Numerous studies have shown that nurse-led care can produce similar and, in some cases, better outcomes than medical care in people with RA, at less cost.⁶⁶⁻⁷² A recent UK study found that specialist nurses in rheumatology improved patient outcomes and reduced costs in both primary and specialist care.¹³⁵

European recommendations for rheumatology nursing management of inflammatory arthritis outline areas in which nursing care has been shown to be effective.

They are:

- patient information, education, and self-management support;
- care coordination and continuity of care;
- patient counselling and psychosocial support;
- participation in comprehensive disease management, including delivery of interventions in line with agreed protocols and guidelines, disease monitoring and follow-up care; and
- nurse-led telephone help lines to provide rapid access to advice e.g. during flares, enhance continuity of care and provide ongoing support.⁷²

In Ontario, Canada, experienced physical and occupational therapists who have received advanced training in arthritis care provide assessment, diagnosis, triage and independent management for patients with a range of musculoskeletal disorders, including RA. They operate in rural communities and urban centres, providing both adult and paediatric care. A review of the clinical performance of these 'Advanced Clinician Practitioners in Arthritis Care' found that they were seeing mainly patients with OA, RA or JIA in a follow-up capacity, with most patients referred by GPs or specialists. Patients report high satisfaction with these practitioners, but patient clinical outcomes have not been reported.¹³⁶

Among other chronic care models in Australia is the Inala Chronic Disease Management Project, implemented to improve the community's management of people with complex type 2 diabetes. The program, which was based on a specially-trained GP delivering a specialist level of care in the community supported by a multidisciplinary team that included an endocrinologist, is achieving significant improvement in disease outcomes and processes of care.¹³⁷

6. Stakeholder consultations

A series of stakeholder consultations was held across Australia, including people with arthritis, carers, medical practitioners, nurses, allied health workers and researchers, to identify key issues and priorities to be addressed in the Time to Move strategy.

The key issues raised in relation to RA were:

- the need to increase awareness and understanding of the burden, severity and course of RA in the community, and amongst GPs and policymakers;
- delays in diagnosis and referral to rheumatologists; early RA needs to be treated as an emergency;
- lack of access to, and long waiting times to see rheumatologists, especially in regional and rural areas, in light of the fact that those who cannot see a rheumatologist do not have access to biological treatments, as these can only be prescribed by a rheumatologist;
- the need for patient-centred rather than medication-centred care from rheumatologists, with patients included in the decision-making process about their care;
- lack of access to multidisciplinary care and to appropriately skilled allied health professionals;
- the need for better coordination of care – including ‘one-stop shop’ multidisciplinary clinics and nurse educators to support and coordinate care at all levels, including primary care;
- inequity of access to services and to publicly funded services;
- lack of access to treatments, particularly with the restrictions on biologics and the hoops people with RA have to jump through to be eligible for these;
- lack of access to appropriate information and education on the condition and its treatment, especially at diagnosis, and lack of support for self-management;
- the importance of psychosocial support, including access to psychological services, and peer support;
- recognition of the financial impact of RA in terms of a person’s ability to continue in employment while managing the disease, and the costs of care;
- the need to address changing care requirements across the life course of a person with RA, e.g. through pregnancy, motherhood, or the cessation of driving; and
- issues related to health literacy and information for CALD communities.

Solutions suggested included:

- community awareness-raising campaigns;
- education/training of GPs and allied health professionals to empower them to better manage RA;
- improving access to multidisciplinary care, including by establishing centres of excellence at tertiary and community levels, and opening up referral pathways to appropriately skilled practitioners at the community level;
- workforce development, including:
 - increasing the number of rheumatologists,
 - developing a workforce of extended-practice specialist arthritis practitioners that includes GPs, allied health practitioners and nurses,
 - increasing the number of specialist nurse educators (similar to diabetic nurse educators), and
 - providing sufficient numbers of case managers/ care coordinators to support people with RA;
- the development of standardised treatment algorithms/protocols across primary/secondary/tertiary care to enable consistency of shared care;
- the provision of improved information to support self-management in people with RA, including information about locally available services and the provision of age-appropriate peer support, especially at the time of diagnosis;
- the use of telehealth services to support the delivery of services needed by those with RA living in regional and rural areas; and
- increased research.



7. Conclusion

There is extensive scope for delivering greatly improved and more equitable care, in line with international best practice, to people with RA in Australia.

The objectives of the national model of care will be to deliver the following key elements of care to people with RA:

- early diagnosis and referral to a rheumatologist, followed by the initiation of appropriate treatment as soon as possible – ideally, within six weeks of symptom onset;
- access to integrated, coordinated multidisciplinary team care by appropriately skilled practitioners led by a rheumatologist, including the development and implementation of an individualised care plan;
- provision of information, education, counselling and support for self-management that's appropriate to the needs of the person with RA;
- access to care coordination and psychosocial support;
- timely access to appropriate evidence-based pharmacological, non-pharmacological and surgical treatments;
- effective ongoing and long-term management including the monitoring of drug compliance, toxicity, safety and side effects; managing complications and comorbidities; and timely access to surgery as required;
- access to programs and services in the home, community and work environments that support independence and participation in people with RA; and
- access to appropriate disability support services, in line with individual needs.

8. Recommendations

- 1. Develop and implement strategies to increase public, health practitioner and policymaker awareness and understanding of RA, including the importance of early diagnosis and treatment**
- 2. Support early diagnosis of people with RA and urgent referral to rheumatologists for prompt initiation of therapy**
 - 2.1 Utilise existing telephone hotlines/website booking services (e.g. HealthDirect, HealthEngine) to facilitate urgent referrals to rheumatologists for early diagnosis and treatment
 - 2.2 Support improved education of primary health care professionals to promote early diagnosis and treatment of people with RA
 - 2.3 Conduct early-arthritis clinics in underserved areas to provide triage to improve early access to specialist care
- 3. Provide equitable and timely access to individualised, coordinated multidisciplinary care by appropriately skilled practitioners**
 - 3.1 Establish community-based multidisciplinary arthritis clinics/teams providing public and private services, in collaboration with Medicare Locals and other stakeholders. Core members of the multidisciplinary team should include a rheumatologist, a rheumatology nurse, a physiotherapist, an occupational therapist, a psychologist and a social worker
 - 3.2 Develop system incentives/funding models to support the delivery of multidisciplinary care in the private sector, including increased access to Medicare-subsidised allied health visits under Chronic Disease Management items, in line with clinical requirements
 - 3.3 Provide services in rural/underserved areas through specialist and multidisciplinary outreach clinics, with additional support offered via telehealth services
- 4. Improve information, education and support for people with RA in help them self-manage their condition**
 - 4.1 Utilise rheumatology nurses and other allied health professionals within the multidisciplinary team to provide patient education, self-management support, psychosocial support and coordination of care
 - 4.2 Develop a comprehensive information package and tools for people newly diagnosed with RA

to help them understand the condition and its treatment, navigate their way around available services and supports, set and monitor individual treatment goals, and coordinate their own care

- 4.3 Refer people newly diagnosed with RA to their state arthritis organisation for access to age-appropriate and culturally suitable information resources, self-management education and support groups

5. Maximise the effectiveness of pharmacological treatments for RA

- 5.1 Support the adoption of a target-based treatment approach for people with RA that aims for clinical remission or low disease activity based on systematic measurement of treatment outcomes
- 5.2 Review existing restrictions on PBS access to biologic DMARDs to ensure that they allow appropriate, timely, evidence-based access to these therapies for those who would benefit from them
- 5.3 Streamline the application process for access to biologic DMARDs through the PBS
- 5.4 Develop information materials to support effective medication management by other health professionals who provide care for people with RA

6. Provide effective ongoing management of people with RA that addresses their health and psychosocial needs over the long term

- 6.1 Establish shared-care protocols between primary and specialist care providers that address ongoing management issues including the monitoring and management of complications and comorbidities
- 6.2 Provide at least a six-monthly review by a rheumatologist and multidisciplinary team for people with stable disease (reviewing those with more active disease more frequently) as well as quick access to specialist advice for people with RA experiencing major flares.
- 6.3 Encourage the provision of healthy lifestyle advice and support for people with RA in primary care
- 6.4 Ensure timely access to surgical advice, including access to joint rheumatology and orthopaedic clinics
- 6.5 Develop strategies to support workforce retention for people with RA
- 6.6 Work with disability and aged-care service providers and the NDIS to ensure appropriate access to programs and services that support independence and life participation for people with RA-related functional limitations

7. Build health workforce capacity to support the early diagnosis of RA and effective treatment for people with the disease

- 7.1 Increase the number of rheumatologists in underserved areas by expanding the existing Specialist Training program
- 7.2 Build a cadre of rheumatology nurses/nurse practitioners, including in rural and remote regions and other underserved areas to support RA management
- 7.3 Develop information and education materials, programs and tools for GPs, specialists, nurses and allied health practitioners, including pharmacists, to support the early diagnosis of RA and effective management for people with the disease
- 7.4 Develop or use existing online tools (e.g. Health Pathways, Map of Medicine) to provide an information portal allowing easy access by GPs and other health practitioners to information on RA diagnosis and management, shared care protocols and clear referral pathways as well as a guide to local services and resources.
- 7.5 Develop information and education materials, programs and tools for GPs, specialists, nurses and allied health practitioners, including pharmacists, to support the early diagnosis of RA and effective management for people with the disease

9. Priorities and implementation

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

- strategies to support early diagnosis and urgent referral to a rheumatologist;
- adoption of a target based treatment approach;
- provision of equitable access to specialist services and multidisciplinary care;
- development of a rheumatology nursing workforce.

Implementation of these recommendations will require collaboration between stakeholders across all sectors of the health system, as well as the aged care and disability sectors. Arthritis Australia will work with relevant stakeholders to encourage and support the implementation of the Time to Move strategy.



References

- ¹ National Health Priority Action Council (NHPAC), 2006. *National Service Improvement Framework for Osteoarthritis, Rheumatoid Arthritis and Osteoporosis*. Australian Government Department of Health and Ageing, Canberra
- ² The Royal Australian College of General Practitioners (RACGP), 2009. *Clinical guidelines for the diagnosis and management of early rheumatoid arthritis*. The Royal Australian College of General Practitioners
- ³ Department of Health, Western Australia, 2009. *Inflammatory Arthritis Model of Care*. Perth: Health Networks Branch, Department of Health, Western Australia
- ⁴ Department of Health, Western Australia, 2013. *Service model for community-based musculoskeletal health in Western Australia*. Perth: Health Strategy and Networks, Department of Health, Western Australia
- ⁵ Stoffer MA et al., 2013. Development of patient-centred standards of care for rheumatoid arthritis in Europe: the eumusc.net project. *Ann Rheum Dis*, published online August 6, 2013. doi: 10.1136/annrheumdis-2013-203743
- ⁶ Combe B, Landewe, Lukas C, Bolosiu HD, Breedveld F, Dougados M Emery P, Ferraccioli G, Hazes J M W, Klareskog L, Machold K, Martin-Mola E, Nielsen H, Silman A, Smolen J, Yazici H. EULAR recommendations for the management of early arthritis: report of a task force of the European Standing Committee for International Clinical Studies Including Therapeutics (ESCSIT). *Ann Rheum Dis* 2007; 66:34-45. doi: 10.1136/ard.2005.044354
- ⁷ The British Society for Rheumatology, 2012. *Top Ten Quality Standards for RA*. http://www.rheumatology.org.uk/includes/documents/cm_docs/2012/t/top_10_quality_standards_for_ra.pdf
- ⁸ Luqmani R et al., 2006. British Society for Rheumatology and British Health Professionals in Rheumatology Guideline for the management of rheumatoid arthritis (the first two years). *Rheumatology* 2006; 45:1167-1169
- ⁹ Luqmani R et al., 2009. British Society for Rheumatology and British Health Professionals in Rheumatology guideline for the management of rheumatoid arthritis (after the first 2 years). *Rheumatology* 2009; 48(3): 436-439
- ¹⁰ Arthritis and Musculoskeletal Alliance UK (ARMA). *Standards of Care for People with Inflammatory Arthritis 2004*
- ¹¹ Singh, JA, Furst DE et al., 2012. 2012 update of the 2008 American College of Rheumatology recommendations for the use of disease-modifying antirheumatic drugs and biologic agents in the treatment of rheumatoid arthritis. *Arthritis Care & Research*; 64(5): 625-639
- ¹² Smolen JS, et al., 2013. EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2013 update. *Ann Rheum Dis* 2013; 0:1-18 doi:10.1136/annrheumdis-2013-204573
- ¹³ Australian Institute of Health and Welfare, 2009. *A picture of rheumatoid arthritis in Australia*. Arthritis series no. 9. Cat. no. PHE 110. Canberra: AIHW
- ¹⁴ Roberts LJ, Cleland LG, Proudman SM, Thomas R, 2006. Early combination disease modifying antirheumatic drug treatment for rheumatoid arthritis. *Med J Aust* 2006; 184(3): 122-125
- ¹⁵ Lassere MN, Rappo J, Portek IJ, Sturgess A, Edmonds JP, 2013. How many life years are lost in patients with rheumatoid arthritis? Secular cause-specific and all-cause mortality in rheumatoid arthritis, and their predictors in a long-term Australian cohort study. *Internal Medicine Journal* 2013; 43(1): 66-72
- ¹⁶ AIHW, 2013. A snapshot of rheumatoid arthritis. *AIHW bulletin* 116. Cat no AUS 171. Canberra: AIHW
- ¹⁷ Arthritis and Osteoporosis Victoria, 2013. *A problem worth solving*. Elsternwick: Arthritis and Osteoporosis Victoria
- ¹⁸ Australian Bureau of Statistics, 2012. 2009. *Disability, Ageing and Carers, Australia 2009: Profiles of Disability*
- ¹⁹ Shanahan EM, Smith M, Roberts-Thomson L, Esterman A, Ahern M, 2008. Influence of rheumatoid arthritis on work participation in Australia. *IMJ* 38, 2008; 166-173
- ²⁰ Shanahan EM, Smith MD, Roberts-Thomson L, Esterman A, Ahern MJ, 2008. The effect of rheumatoid arthritis on personal income in Australia. *Intern Med j* 2008, Jul; 38(7): 575-9
- ²¹ Schofield DJ, Shrestha RN, Percival R, Passey M, Callander E, Kelly S, 2013. The personal and national costs of lost labour force participation due to arthritis: an economic study. *BMC Public Health* 2013; 13:188
- ²² Tobón, GJ et al. The environment, geo-epidemiology, and autoimmune disease: Rheumatoid arthritis. *Journal of Autoimmunity* 2010; 35(1): 10-14



- ²³ Bang S et al. Smoking increases rheumatoid arthritis susceptibility in individuals carrying the HLA-DRB1 shared epitope regardless of rheumatoid factor or anti cyclic citrullinated peptide antibody status. *Arthritis Rheum* 2010, Feb; 62(2): 369-77. doi: 10.1002/art.27272
- ²⁴ Bang SY, Lee KH et al., 2010. Smoking Increases Rheumatoid Arthritis Susceptibility in Individuals Carrying the HLA-DRB1 Shared Epitope, Regardless of Rheumatoid Factor or Anti-Cyclic Citrullinated Peptide Antibody Status. *Arthritis and Rheumatism*; 62(2): 369-377
- ²⁵ Di Giuseppe D, Orsini N, Alfredsson L, Askling J, Wolk, 2013. Cigarette smoking and smoking cessation in relation to risk of rheumatoid arthritis in women. *Arthritis Research and Therapy* 2012, 15; R56
- ²⁶ Panush RS et al. Epilogue: How will we care for patients with early arthritis. *Rheumatic Disease Clinics of North America* 2012; 38: 427-429
- ²⁷ Stavropoulos-Kalinoglou A, Metsios G, Koutedakis Y, Kitas GD, 2010. Obesity in rheumatoid arthritis. *Rheumatology* 2011, Mar; 50(3): 450-62 doi:10.1093/rheumatology/keq266
- ²⁸ Wesley A, Bengtsson C, Elkan AC, Klareskog L, Alfredsson L, Wedrén S. Association between body mass index and anti-citrullinated protein antibody-positive and anti-citrullinated protein antibody-negative rheumatoid arthritis: results from a population-based case-control study. *Arthritis Care Res* (Hoboken) 2013, Jan; 65(1): 107-12. doi: 10.1002/acr.21749
- ²⁹ Crowson CS, Matteson EL, Davis JM, Gabriel SE. Contribution of obesity to the rise in incidence of rheumatoid arthritis. *Arthritis Care Res* (Hoboken) 2013, Jan; 65(1): 71-7. doi: 10.1002/acr.21660
- ³⁰ Woolf AD, 2007. Healthcare services for those with musculoskeletal conditions: a rheumatology service. Recommendations of the European Union of Medical Specialists Section of Rheumatology/European Board of Rheumatology 2006. *Ann Rheum Dis* 2007; 66: 293-301
- ³¹ Gremese E, Salaffi F, Bosell SL et al., 2013. Very early rheumatoid arthritis as a predictor of remission: a multicentre real life prospective study. *Ann Rheum Dis* 2013; 72: 858-862 doi: 10.1136/annrheumdis-2012-201456
- ³² Lukas C, Combe B, Ravaut P, Sibilia J, Landewe R, van der Heijde D, 2011. Favorable effect of very early disease-modifying antirheumatic drug treatment on radiographic progression in early inflammatory arthritis. *Arthritis and Rheumatism*; 63(7): 1804-1811
- ³³ Van der Linden MPM, le Cessie S, Raza K, van der Woude, Knevel R, Huizinga TWJ, van der Helm-van Mil AHM. Long-term impact of delay in assessment of patients with early arthritis. *Arthritis and Rheumatism* 2010; 62(12): 3537-3546
- ³⁴ Luqmani R et al 2006 British Society for Rheumatology and British Health Professionals in Rheumatology Guideline for the management of rheumatoid arthritis (the first two years). *Rheumatology* 2006; 45:1167-1169
- ³⁵ Tavares R, J. Pope et al., 2012. Time to disease-modifying antirheumatic drug treatment in rheumatoid arthritis and its predictors: A national, multicenter, retrospective cohort. *The Journal of Rheumatology*. 10.3899/jrheum.120100
- ³⁶ Raza K et al. Concise report: Delays in assessment of patients with rheumatoid arthritis: variations across Europe. *Ann Rheum Dis* 2011; 70(10): 1822-1825
- ³⁷ UK National Audit Office, 2009. *Services for people with rheumatoid arthritis*. <http://www.nao.org.uk/wp-content/uploads/2009/07/0809823.pdf>
- ³⁸ Van Doornum S, Tropea J, Tacey M, Liew D. 2013. Time to Institution of disease modifying anti-rheumatic drugs in Australian patients with early RA. American College of Rheumatology Annual Meeting (Poster)
- ³⁹ Roberts LJ, LaMont EG, Lim I, Sabesan S, Barrett C 2012. Telerheumatology: an idea whose time has come. *Internal Medicine Journal*. Royal Australasian College of Physicians, 2012; 1072-1078
- ⁴⁰ Villeneuve E, Nam JL et al., 2013. A systematic literature review of strategies promoting early referral and reducing delays in the diagnosis and management of inflammatory arthritis. *Annals of the Rheumatic Diseases*
- ⁴¹ Stack RJ, Shaw K, Mallen C, Herron-Marx S, Horne R, Raza K, 2012. Delays in help seeking the onset of the symptoms of rheumatoid arthritis: a systematic synthesis of qualitative literature. *Ann Rheum Dis* 2012; 71: 493-497
- ⁴² Deane KD, Striebich CC, Goldstein BL, Derber LA, Parish MC, Feser ML, Hamburger EM, Brake S, Belz C, Goddard J, Norris JM, Karlson EW, Holers VM. Identification of undiagnosed inflammatory arthritis in a community health fair screen. *Arthritis Rheum* 2009, Dec 15; 61(12): 1642-9
- ⁴³ National Collaborating Centre for Chronic Conditions. *Rheumatoid arthritis: national clinical guideline for management and treatment in adults*. London: Royal College of Physicians, February 2009
- ⁴⁴ Melbourne Health, 2004. *Victorian Rheumatology Workforce Survey 2004*. Clinical Epidemiology and Health Service Evaluation Unit, Melbourne Health



References

- ⁴⁵ Piper S. Rheumatology Workforce in Australia 2012. Poster presentation at the Australian Rheumatology Association 53rd Annual Scientific Meeting, May 2012, Canberra
- ⁴⁶ Arthritis Australia 2012. *Whose problem is it anyway?: The Voice of GPs on Arthritis*
- ⁴⁷ Quinn MA, Emery P. Are early arthritis clinics necessary? *Best Pract Res Clin Rheumatol* 2005; 19: 1-17
- ⁴⁸ <http://www.anywherehealthcare.com.au/>, viewed 6/11/2013
- ⁴⁹ Gormley GJ, Steele WK, Gilliland A, Leggett P, Wright GD, Bell AL, Matthews C, Meenagh G, Wylie E, Mulligan R, Stevenson M, O'Reilly D, Taggart AJ, 2003. Can diagnostic triage by general practitioners or rheumatology nurses improve the positive predictive value of referrals to early arthritis clinics? *Rheumatology (Oxford)* 2003, Jun; 42(6): 763-8
- ⁵⁰ El Miedany Y, Palmer D, El Gaafary M, 2006. Diagnosis of early arthritis; outcomes of a nurse-led clinic. *British Journal of Nursing* 2006; (15)7: 394-9
- ⁵¹ Pincus T, Sokka T, Kautiainen H. Patients seen for standard rheumatoid arthritis care have significantly better articular, radiographic, laboratory, and functional status in 2000 than in 1985. *Arthritis Rheum* 2005, Apr; 52(4): 1009-19
- ⁵² Australian Bureau of Statistics, 2011. *Disability, Australia, 2009*. Cat no 4446.0 <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4446.0main+features52009>, viewed 8/11/2013
- ⁵³ Smolen, J et al. Treating rheumatoid arthritis to target: recommendations of an international task force. *Annals of the Rheumatic Diseases* 2010; 69(4): 631-637
- ⁵⁴ Bernstein E et al. Erratum to: Treating rheumatoid arthritis to target: an international initiative. *Curr Rev Musculoskelet Med* 2011, Sep; 4(3): 157. doi: 10.1007/s12178-011-9089-4
- ⁵⁵ Schoels M et al. Evidence for treating rheumatoid arthritis to target: results of a systematic literature search. *Annals of the Rheumatic Diseases* 2010; 69(4): 638-643
- ⁵⁶ Scott DL, 2012. Biologics-based therapy for the treatment of rheumatoid arthritis. *Clinical Pharmacology and Therapeutics*; 91(1) 30-43
The Lancet, published online 2013, 26 October 2013. [http://dx.doi.org/10.1016/S0140-6736\(13\)61751-1](http://dx.doi.org/10.1016/S0140-6736(13)61751-1)
- ⁵⁷ Smolen JS, Emery P, Fleischmann R, van Vollenhove RF et al., 2013. Adjustment of therapy in rheumatoid arthritis on the basis of achievement of stable low disease activity with adalimumab plus methotrexate or methotrexate alone: the randomised controlled OPTIMA trial. *The Lancet*, published online, 26 October 2013. [http://dx.doi.org/10.1016/S0140-6736\(13\)61751-1](http://dx.doi.org/10.1016/S0140-6736(13)61751-1)
- ⁵⁸ EULAR media release, 3 July 2013. EULAR issues updated rheumatoid arthritis (RA) management Recommendations. <http://www.eular.org/myUploadData/files/EULAR%20RA%20recommendations%20FINAL.pdf>, viewed 8/11/2013
- ⁵⁹ Australian Institute of Health and Welfare, 2011. *The use of disease-modifying anti-rheumatic drugs for the management of rheumatoid arthritis*. Arthritis series no 16. Cat no PHE 138. Canberra, AIHW
- ⁶⁰ Agency for Healthcare Research and Quality, 2012. Drug therapy for rheumatoid arthritis: an update. *Comparative effectiveness review* 2012, Nov; 55: HRQ Pub no 12(13)-EHC025-3, USA. http://effectivehealthcare.ahrq.gov/ehc/products/203/1315/rheum_arth_clin_fin_to_post.pdf, viewed 6/11/2013
- ⁶¹ Standfield L, Norris S, Harvey C, Elliot L, Riordan J, Hall S, Day R, Nash P, Thirunavukkarasu K, Robertson J Palmer T, 2010. Relationship between rheumatoid arthritis disease severity, health-related utility and resource use in Australian patients: A cross-sectional multicentre study. *Clinical Therapeutics*; 32 (7): 1329-1342
- ⁶² Fary RE et al. Translating policy into practice for community-based management of rheumatoid arthritis: targeting professional development needs among physiotherapists. *International Journal of Rheumatology* 2012; Article ID 240689: 9 pages
- ⁶³ Marsh D, Akesson K, Beaton DE et al. Coordinator-based systems for secondary prevention in fragility fracture patients. *Osteoporosis Int* 2011; 22: 2051-65
- ⁶⁴ Berry LL, Rock BL, Houskamp BS, Brueggeman J, Tucker L, 2013. Care coordination for patients with complex health profiles in inpatient and outpatient settings. *Mayo Clinic Proceedings*; 88(2): 184-194
- ⁶⁵ Personal advice from Mona Marabani, rheumatologist



- ⁶⁶ Van den Hout WB, Tijhuis JMW, Breedveld FC, Vliet Vlieland TPM, 2003. Cost effectiveness and cost utility analysis of multidisciplinary care in patients with rheumatoid arthritis: a randomised comparison of clinical nurse specialist care, inpatient team care, and day patient team care. *Ann Rheum Dis* 2003; 62: 308-315
- ⁶⁷ World Health Organization, 2002. *Innovative Care for Chronic Conditions: Building Blocks for Action*. WHO, Geneva
- ⁶⁸ National Health Priority Action Council 2006. *National Chronic Disease Strategy*. Australian Government Department of Health and Ageing. Canberra
- ⁶⁹ Wilkinson A, Whitehead L. Evaluation of the concept of self-care and implications for nurses: a literature review. *International Journal of Nursing Studies* 2009; 46: 1143-1147
- ⁷⁰ Warsi A, LaValley MP, Wang PS, Avorn J, Solomon DH. Arthritis self-management education programs: a meta-analysis of the effect on pain and disability. *Arthritis Rheum* 2003; 48: 2207e13
- ⁷¹ Osborne R, Wilson T, Lorig KR, McColl GJ 2007. Does self-management lead to sustainable health benefits in people with arthritis? A 2-year transition study of 452 Australians. *J Rheumatol* May 2007; 34(5): 1112-1117
- ⁷² Van Eijk-Hustings Y, van Tuberg A, Bostrum C et al 2011. EULAR recommendations for the role of the nurse in the management of chronic inflammatory arthritis. *Ann Rheum Dis* 2011; doi:10.1136/annrheumdis-2011-200185
- ⁷³ Ottawa Panel. Ottawa Panel evidence-based clinical practice guidelines for therapeutic exercises in the management of rheumatoid arthritis in adults. *Physical Therapy* 2004; 84(10): 934-972
- ⁷⁴ NICE, 2009. *The management of rheumatoid arthritis in adults*. NICE Clinical guideline 79, 2009
- ⁷⁵ Hurkmans E, van der Giesen FJ, Vliet Vlieland TPM, Schoones J, Van den Ende ECHM. Dynamic exercise programs (aerobic capacity and/or muscle strength training) in patients with rheumatoid arthritis. *Cochrane Database of Systematic Reviews* 2009; Issue 4, Art no: CD006853. DOI: 10.1002/14651858.CD006853.pub2
- ⁷⁶ Cramp F, Hewlett S, Almeida C, Kirwan JR, Choy EHS, Chalder T, Pollock J, Christensen R. Non-pharmacological interventions for fatigue in rheumatoid arthritis. *Cochrane Database of Systematic Reviews* 2013; Issue 8, Art no: CD008322. DOI:10.1002/14651858.CD008322.pub2
- ⁷⁷ Steultjens E, Dekker J, Bouter L, van Schaardenburg D, van Kuyk M, van den Ende C. Occupational therapy for rheumatoid arthritis. *Cochrane Database of Systematic Reviews* 2004; Issue 1, Art no:CD003114
- ⁷⁸ Al-Qubaeissy KY, Fatoye FA, Goodwin PC, Yohannes AM, 2012. The Effectiveness of Hydrotherapy in the Management of Rheumatoid Arthritis: A Systematic Review. *Musculoskelet. Care* 2013; 11: 3-18
- ⁷⁹ Macedo AM, Oakley SP, Panavi GS, Kirkham BW. Functional and work outcomes improve in patients with rheumatoid arthritis who receive targeted, comprehensive occupational therapy. *Arthritis Rheum* 2009, Nov 15; 61(11): 1522-1530; doi:10.1002/art.24563
- ⁸⁰ Gettings L, 2010. Psychological well-being in rheumatoid arthritis: a review of the literature. *Musculoskelet Care* 2010; 8: 99-106
- ⁸¹ Sleath B, Chewning B, De Vellis BM, Weinberger M, De Vellis RF, Tudor G, et al. Communication about depression during rheumatoid arthritis patient visits. *Arthritis Rheum* 2008; 59: 186-191
- ⁸² Covic T, Cummin SR et al., 2012. Depression and anxiety in patients with rheumatoid arthritis: Prevalence rates based on a comparison of the Depression, Anxiety and Stress Scale (DASS) and the Hospital, Anxiety and Depression Scale (HADS). *BMC Psychiatry* 2012; 12:6. doi:10.1186/1471-244X-12-6
- ⁸³ Rathbun AM, Reed GW et al., 2012. The temporal relationship between depression and rheumatoid arthritis disease activity, treatment persistence and response: a systematic review. *Rheumatology* (Oxford) 2012, Dec 11
- ⁸⁴ Joyce AT, Smith P et al., 2009). Hidden cost of rheumatoid arthritis (RA): Estimating cost of comorbid cardiovascular disease and depression among patients with RA. *The Journal of Rheumatology*; 36(4): 743-752
- ⁸⁵ Astin JA, Beckner W, Soeken K, Hochberg MC, Berman B. Psychological interventions for rheumatoid arthritis: a metaanalysis of randomized controlled trials. *Arthritis Rheum* 2002; 47: 291-302
- ⁸⁶ Sharpe L, Allard S, Sensky T. Five-year Follow-up of a cognitive-behavioural therapy intervention for patients with recently-diagnosed rheumatoid arthritis: effects on health care utilisation. *Arthritis and Rheumatism (Arthritis Care & Research)* 2008; 59(3): 311-316
- ⁸⁷ Briggs AM, March L, Lassere M, Reid C et al 2009. Baseline Comorbidities in a Population-Based Cohort of Rheumatoid Arthritis Patients Receiving Biological Therapy: Data from the Australian Rheumatology Association Database. *International Journal of Rheumatology* 2009; article ID 861481, 8 pages. <http://dx.doi.org/10.1155/2009/861481>



References

- ⁸⁸ Peters MJL, Symmons DPM, McCarey D, Dijkmans BAC et al., 2009. EULAR evidence-based recommendations for cardiovascular risk management in patients with rheumatoid arthritis and other forms of inflammatory arthritis. *Ann Rheum Dis* 2010; 69: 325-331
- ⁸⁹ Nurmohamed MT. Cardiovascular risk in rheumatoid arthritis. *Autoimmune Rev* 2009, Jul; 8(8): 663-7
- ⁹⁰ Dessein PH, Semb AG, 2013. Could cardiovascular disease risk stratification and management in rheumatoid arthritis be enhanced? *Ann Rheum Dis* November 2013; 72(11): 1743-1746
- ⁹¹ Van Doornum S, Brand C, Sundararajan V, Ajani AE, Wicks IP, 2010. Rheumatoid arthritis patients receive less frequent acute reperfusion and secondary prevention therapy after myocardial infarction compared with the general population. *Arthritis Research and Therapy* 2010; 12 (5): R183; doi:10.1186/ar3151
- ⁹² Cush JJ, Kay J, Dao KH. Does rheumatoid arthritis or biologic therapy increase cancer risk? *Drug Safety Quarterly*, ACR Drug Safety Committee, August 2012; 4(2)
- ⁹³ Raaschou P, Simard JF et al., 2013. Rheumatoid arthritis: anti-tumour necrosis factor therapy and risk of malignant melanoma: nationwide population based prospective cohort study from Sweden. *BMJ* 2013; 346: f1939
- ⁹⁴ National Health and Medical Research Council, 2013. *Clinical practice guidelines for the management of overweight and obesity in adults, adolescents and children in Australia*. Melbourne: National Health and Medical Research Council
- ⁹⁵ Hurkmans E, van der Giesen FJ, Vliet Vlieland TPM, Schoones J, Van den Ende ECHM. Dynamic exercise programs (aerobic capacity and/or muscle strength training) in patients with rheumatoid arthritis. *Cochrane Database of Systematic Reviews* 2009, Issue 4. Art. No.: CD006853. DOI: 10.1002/14651858.CD006853.pub2
- ⁹⁶ Han A, Judd M, Welch V, Wu T, Tugwell P, Wells GA, 2004. Tai Chi for rheumatoid arthritis (Review) *Cochrane Database of Systematic Reviews* 2004; Issue 3, Art no: CD004849. doi: 10.1002/14651858.CD004849
- ⁹⁷ Ward L et al. Yoga for Functional Ability, Pain and Psychosocial Outcomes in Musculoskeletal Conditions: A Systematic Review and Meta-Analysis. *Musculoskeletal Care* 2013
- ⁹⁸ Munneke M et al. Effect of a high-intensity weight-bearing exercise program on radiologic damage progression of the large joints in subgroups of patients with rheumatoid arthritis. *Arthritis and Rheumatism* 2005; 53(3): 410-417
- ⁹⁹ Kelley GA et al. Effects of community-deliverable exercise on pain and physical function in adults with arthritis and other rheumatic diseases: a meta-analysis. *Arthritis Care and Research* 2011; 63(1): 79-93
- ¹⁰⁰ van den Berg MH, Ronday HK, Peeters AJ, le Cessie S, van der Giesen FJ, Breedveld FC, Vliet Vlieland TP, 2006. Using internet technology to deliver a home-based physical activity intervention for patients with rheumatoid arthritis: A randomized controlled trial. *Arthritis Rheum* 2006, Dec 15; 55(6): 935-45
- ¹⁰¹ Callahan LF, Mielenz T, Freburger J, Shreffler J, Hootman J, Brady T, Buysse K, Schwartz T, 2008. A Randomized Controlled Trial of the People with Arthritis Can Exercise Program: Symptoms, Function, Physical Activity, and Psychosocial Outcomes. *Arthritis and Rheumatism*; 59(1): 92-101
- ¹⁰² Andersson MLE, Bergman S, Soderlin M, 2012. The effect of stopping smoking on disease activity in rheumatoid arthritis (RA). Data from BARFOT, a multicentre study of early RA. *The Open Rheumatology Journal* 2012; (6): 303-300
- ¹⁰³ Hyrich KL, Watson KD, Silman AJ, Symmons DP, 2006. Predictors of response to anti-TNF-alpha therapy among patients with rheumatoid arthritis: results from the British Society for rheumatology biologics register. *Rheumatology (Oxford)* 2006, Dec; 45(12): 1558-65
- ¹⁰⁴ Abhishek A, Butt S, Gadsby K, Zhang W, Deighton CM, 2010. Anti-TNF-alpha agents are less effective for the treatment of rheumatoid arthritis in current smokers. *J Clin Rheumatol* 2010, Jan; 16(1): 15-8
- ¹⁰⁵ Maska LB, Sayles HR, O'Dell JR, Curtis JR, Bridges SL Jr, Moreland LW, Cofield SS, Mikuls TR, 2012. Serum cotinine as a biomarker of tobacco exposure and the association with treatment response in early rheumatoid arthritis. *Arthritis Care Res (Hoboken)* 2012, Dec; 64(12): 1804-1810
- ¹⁰⁶ Australian Institute of Health and Welfare, 2008. *Arthritis and osteoporosis in Australia 2008*. Arthritis series no 8. Cat no PHE 106. Canberra, AIHW
- ¹⁰⁷ Lacaille D, White MA, Backman CL, Gignac MAM, 2007. Problems faced at work due to inflammatory arthritis: new insights gained from understanding patients' perspective. *Arthritis and Rheumatism*; 57(7): 1269-1279



- ¹⁰⁸ Lacaille D, Sheps S, Spinelli JJ, Chalmers A, Esdaile JM, 2004. Identification of modifiable work-related factors that influence the risk of work disability in rheumatoid arthritis. *Arthritis & Rheumatism*; 51(5): 843-852
- ¹⁰⁹ Bishop FL, Yardley L, Lewith GT. A systematic review of beliefs involved in the use of complementary and alternative medicine. *J Health Psychol* 2007; 12: 851-67
- ¹¹⁰ Australian Institute of Health and Welfare, 2010. *Use of health services for arthritis and osteoporosis*. Arthritis series no 14. Cat no PHE 130. Canberra, AIHW
- ¹¹¹ Proudman SM, James MJ et al. Fish oil in recent onset Rheumatoid arthritis: a randomised, double-blind controlled trial within algorithm-based drug use. *Annals of Rheumatic Disease* 2013; 0: 1-7; doi: 10.1136/annrheumdis-2013-204145
- ¹¹² Armstrong AR, Thiebaut SP, Bron LJ, 2011. Australian adult use complementary and alternative medicine in the treatment of chronic illness: a national study. *ANZJPH* 2011; 35(4): 384-390
- ¹¹³ Arthritis Research UK, 2012. *Complementary and alternative medicines for the treatment of rheumatoid arthritis, osteoarthritis and fibromyalgia*
- ¹¹⁴ National Collaborating Centre for Chronic Conditions. *Rheumatoid arthritis: national clinical guideline for management and treatment in adults*. London: Royal College of Physicians, February 2009
- ¹¹⁵ Clement ND, Breusch SJ, Biant LC, 2012. Lower limb joint replacement in rheumatoid arthritis. *Journal of Orthopaedic Surgery and Research* 2012; 7:27, doi:10.1186/1749-799X-7-27
- ¹¹⁶ Leon L, Abasolo L, Carmona L et al., 2013. Orthopedic surgery in rheumatoid arthritis in the era of biologic therapy. *J Rheumatol* 2013; 40: 1850-1855
- ¹¹⁷ AIHW, 2013. Hospital performance: waiting times for elective surgery. <http://www.aihw.gov.au/haag10-11/hospital-performance-elective-surgery-wait>, viewed 4/7/2013
- ¹¹⁸ Kim SJ, Jung KA, 2007. Arthroscopic synovectomy in rheumatoid arthritis of wrist. *Clin Med Res* 2007, Dec; 5(4): 244-250
- ¹¹⁹ Simmen BR, Bogoch ER, Goldhahn J, 2008. Surgery insight: orthopaedic treatment options in rheumatoid arthritis. *Nat Clin Pract Rheumatol* 2008, May; 4(5):266-73
- ¹²⁰ Arthritis Australia, 2011. *The Ignored Majority: The Voice of Arthritis 2011*
- ¹²¹ Royal College of Physicians. *Consultant physicians working with patients*. London, UK, 2005
- ¹²² <http://www.health.gov.au/internet/main/publishing.nsf/Content/work-spec>, viewed 28/11/2013
- ¹²³ Kepler A. The Future is here: the role of nurse practitioners in rheumatology. *The Rheumatologist* 2012, Nov. http://www.the-rheumatologist.org/details/article/3038891/The_Future_is_Here_The_Role_of_Nurse_Practitioners_in_Rheumatology.html, viewed 22/10/2013
- ¹²⁴ American College of Rheumatology, 2013. The Rheumatology Health Care Team. http://www.rheumatology.org/Practice/Clinical/Patients/Healthprofessionals/The_Rheumatology_Health_Care_Team/, viewed 22/10/2013
- ¹²⁵ Health Policy Analysis, 2011. Evaluation of the Medical Specialist Outreach Assistance Program and the Visiting Optometrists Scheme – Final report. Volume 1. Department of Health and Ageing, Canberra
- ¹²⁶ Abelhamid AS, Mooney J, Walker AA, Barton G, MacGregor, Scott DGI, Watts RA, 2012. An evaluation of rheumatology practitioner outreach clinics – a qualitative study. *BMC Health Services Research* 2012; 12:119. <http://www.biomedcentral.com/1472-6963/12/119>
- ¹²⁷ Davis P, 2003. The application of telehealth to rheumatology. *Clinical Rheumatology* Sep 2003; 22:168-172
- ¹²⁸ Moffat JJ, Eley DS, 2010. The reported benefits of telehealth for rural Australia. *Australian Health Review* 2010; (34): 276-281
- ¹²⁹ Smith AC, Gray LC. Telemedicine across the ages. *MJA* 2009; 190: 15-19
- ¹³⁰ Thaker DA, Monypenny R, Olver I, Sabesan S, 2013. Cost savings from a telemedicine model of care in northern Queensland, Australia. *MJA* 2013; 199: 414-417
- ¹³¹ Department of Health, UK, 2006. *The musculoskeletal services framework. A joint responsibility: doing it differently*. London, 2006
- ¹³² Arthritis Care UK 2011 *Get a grip: Making the case for a national strategy for musculoskeletal disease*
- ¹³³ Wilkes G 2013. Modernising the musculoskeletal pathway. Health Services Journal 1 May 2013 <http://www.hsj.co.uk/home/innovation-and-efficiency/modernising-the-musculoskeletal-pathway/5057531.article#.UvRbBqPNu73> viewed 7/2/12014



References

¹³⁴ <http://www.eumusc.net/>, viewed 18/11/2013

¹³⁵ Leary A, Oliver S, 2010. *Clinical nurse specialists: adding value to care*. Royal College of Nursing Rheumatology Nursing Forum, UK

¹³⁶ Warmington K, 2011. The early impact of Advanced Clinician Practitioner in Arthritis Care program-trained extended role practitioners on the Ontario healthcare system: a system-level evaluation. <http://www.stmichaelshospital.com/pdf/programs/acpac-executive-summary.pdf>, viewed 16/11/2013

¹³⁷ Inala Chronic Disease Management Service: a new model of care for the management of diabetes. http://www.health.qld.gov.au/qhafe/docs/020_icdms.pdf, viewed 16/11/2103



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