

AUSTRALIAN HEALTHCARE AND HOSPITALS ASSOCIATION

RHEUMATOLOGY NURSES: ADDING VALUE TO ARTHRITIS CARE



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Executive Summary

Internationally, models of care involving rheumatology nurses for people with severe and inflammatory forms of arthritis are considered best practice.

Evidence shows that rheumatology nurse care for people with these conditions is effective and cost-effective and results in: better education and improved psychosocial support for patients; reduced delays in access to specialist care; improved care coordination and continuity of care; reduced health system costs in primary and secondary care; and improved patient outcomes and satisfaction with care.

Around 1.7 million Australians live with chronic, inflammatory forms of arthritis. These painful and debilitating conditions include rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis, gout and juvenile arthritis. These conditions are a leading cause of disease burden and cost the health system around \$2.8 billion in 2015. They are also among the most common causes of disability and early retirement due to ill health in Australia.

Yet most people with inflammatory arthritis do not receive adequate education and support to help them deal with the physical and emotional impact of their condition and its often complex management.

Early diagnosis and urgent access to specialists for treatment (ideally within 12 weeks of symptom onset) are critical for many of these conditions to avoid or delay irreversible joint damage, deformity and disability. Yet delays are common and access to rheumatologists is limited in many parts of Australia, especially in rural and remote areas, with lengthy waiting lists for appointments. Access issues will be compounded in the future as a result of a growing shortage of rheumatologists and demographic trends.

Increasing utilisation of rheumatology nurses in Australia can help to address these issues and support improved care and better outcomes for people living with severe and inflammatory forms of arthritis.

However, the current rheumatology nurse workforce in Australia is small and their role is poorly defined and recognised.

Research and modelling for this report found that:

- There are only an estimated 50 rheumatology nurses, or 39 full-time equivalent rheumatology nurses, practising in Australia to support the 1.7 million Australians with inflammatory arthritis.

- Rheumatology nurses practise predominantly in outpatient clinics in the public hospital sector. However, around 80% of rheumatology practice takes place in the private sector, with the result that most people with inflammatory arthritis do not have access to rheumatology nursing care.
- Only 23% of people with severe and inflammatory arthritis surveyed for this report had ever seen a rheumatology nurse as part of their care.
- People who had seen a rheumatology nurse as part of their care reported much higher rates of satisfaction across all aspects of their care than those who had not. In particular around twice as many people who had seen a rheumatology nurse compared to those who had not, reported that they were satisfied or very satisfied with:
 - the support they received for their emotional and mental wellbeing
 - the coordination of their care
 - the information and support they received for the ongoing management of their condition
 - their ability to quickly access specialist advice or treatment when they needed it.
- Economic modelling for this report compared costs and outcomes over a four year period for a rheumatologist-only public outpatient hospital clinic against a similar clinic with both a rheumatologist and rheumatology nurse. The results demonstrated that adding a rheumatology nurse to the traditional rheumatologist-only model would:
 - improve patient access to rheumatology specialist care and reduce delays in treatment. The number of patients able to be seen would increase by up to 47%. The proportion of patients seen within clinically relevant time frames would increase from 23% to 47.5% of patients.
 - result in 31.6% of patients (759 people) achieving remission at four years compared to 23.1% (377 people) in the rheumatologist-only clinic.
 - decrease the average cost of treatment over four years from \$11,373 to \$10,483 per person. However, due to the increased number of patients treated, the total cost of providing this care would increase by 35.2% (\$6.549 million).

- achieve additional benefits, such as reduced future health service utilisation, reduced disability and welfare costs and increased economic participation, although these benefits could not be modelled due to the lack of suitable evidence.
- The most commonly cited barrier to rheumatology nurses contributing to their full potential was lack of funding, in both the public and the private sector. Other barriers cited included lack of standardisation and recognition of the role, low levels of acceptance of the value of rheumatology nurses by clinicians, and limited training pathways and opportunities.

Implementing strategies to increase the rheumatology nurse workforce will help to support improved care and better outcomes for Australians living with severe and inflammatory forms of arthritis.

Recommendations to develop the rheumatology nurse workforce in Australia include:

- Define and recognise the rheumatology nurse role in collaborative team-based care for people with severe and inflammatory arthritis, including skills and competencies required for various levels of practice and education and training pathways.
- Support the introduction and optimisation of models of care incorporating rheumatology nurses in public hospitals, including increased and dedicated funding for rheumatology nursing staff.
- Support the development of models of care incorporating rheumatology nurses suitable for the private sector, and encourage implementation through the provision of case studies, the development of a business case and exploration of potential funding models.
- Support the introduction and optimisation of models of care utilising rheumatology nurse practitioners.

Background

Internationally, nurses, including advanced practice nurses and nurse practitioners, are playing an increasing role in delivering rheumatology care and services for people living with inflammatory forms of arthritis. The benefits of care provided by nurses with specific training or experience in rheumatology have been shown to include: better education and improved psychosocial support for patients; reduced delays in access to specialists; improved care coordination and continuity of care; reduced health system costs in primary and secondary care; and improved patient satisfaction (van Eijk-Hustings et al. 2012).

The *Time to Move: Arthritis* strategy, published by Arthritis Australia in 2014, recommended increasing the rheumatology nurse workforce in Australia to enhance education and support for people with inflammatory arthritis and to assist in improving timely access to rheumatologists.

There are around 1.7 million Australians living with inflammatory or auto-immune forms of arthritis who could benefit from access to rheumatology nursing care. However, there are few rheumatology nurses in Australia and limited recognition of rheumatology nursing as a specialty.

In order to better understand the existing rheumatology nurse workforce and the potential value of this role in the Australian context, Arthritis Australia commissioned the Australian Healthcare and Hospitals Association (AHHA) to assess the current and potential role, scope of activities, and value of rheumatology nurses in Australia. The study findings are summarised in this report.



Methodology

Rheumatology nurses are able to provide care to people with a broad range of inflammatory and auto-immune forms of arthritis. However, the findings and recommendations of this report draw most heavily on the role of rheumatology nurses in managing the more common forms, especially rheumatoid arthritis, which has the most robust evidence base.

The rheumatology nursing study undertaken by AHHA involved three components:

- **Literature review**

The literature review was based on wide and detailed consultation across electronic database collections related to inflammatory arthritis internationally, in nursing, medicine, health and organisational management. The majority of literature pertaining to the international context was retrieved via journal databases of medical and nursing research and the various journal publishers' online sites. Additional information was obtained through a grey literature search. Websites and links from the research and grey literature were followed into various professional associations related to rheumatology nursing, relevant government departments and other publications. Much of the data in the Australian context was sourced from the grey literature.

- **Stakeholder surveys and interviews**

Three broad online surveys were conducted over April to May 2017 to explore the views of:

- Consumers and carers. Responses from 476 consumers and carers were included in the analysis.
- Rheumatology nurses. Responses from 39 rheumatology nurses were included in the analysis. It is estimated that this reflects around 80% of the current rheumatology nurse workforce.
- Other clinicians including rheumatologists. Responses from 15 rheumatologists and 29 other clinicians were included in the analysis.

Sixteen one-on-one interviews were conducted across these stakeholder groups to further explore findings from the surveys.

- **Cost-benefit analysis**

An economic analysis was conducted to compare the costs and potential savings from two alternative models of care in a public hospital setting for those requiring ongoing treatment for inflammatory arthritis. This analysis examined the costs and benefits of a cohort of newly referred patients in a single enrolment year to a public hospital outpatient rheumatology clinic and followed the likely treatment pathways of individuals over the next four years. The analysis then compared this service to a similar service supported by rheumatology nursing care.

These models were informed by the available empirical evidence in both the peer reviewed and grey literature. A key constraint in performing this analysis was the lack of critical data to appropriately populate an economic model. The model was therefore structured around those health services that could be accurately estimated with respect to patient flow, parameter values and the cost of providing in-scope health services.

For the full methodology and findings from these pieces of work, please refer to the supplementary materials, which are available separately online at www.arthritisaustralia.com.au.

1. Arthritis in Australia

Who is affected?

There are over 100 different forms of arthritis, affecting more than 3.5 million Australians of all ages. Of these, around 1.7 million people live with inflammatory forms of arthritis and related conditions.

More than 3.5 million Australians of all ages are affected by arthritis (ABS 2015), a term referring to over 100 mostly chronic conditions affecting movable joints. Prevalence is projected to reach almost 4.4 million by 2020 and 5.5 million by 2030 (Ackerman et al. 2016). With damage to joint structures, such as articular cartilage and synovial lining, common symptoms are inflammation, pain, stiffness and decreased mobility (AIHW 2010).

Arthritis is often classified into two categories: inflammatory and non-inflammatory arthritis. Osteoarthritis is the most common form of arthritis and the main non-inflammatory arthritis although evidence increasingly indicates inflammatory processes are a major contributor. It is a degenerative joint condition affecting almost 2.1 million Australians in 2014–15 (ABS 2015), projected to reach almost 2.5 million by 2020 (Ackerman et al. 2016). While incidence increases with age, osteoarthritis is not an inevitable part of the ageing process. Management occurs typically in primary care, although complex and advanced cases may be managed in specialist and hospital environments. Up to 70% of osteoarthritis is considered preventable (Arthritis Australia 2014c).

Around 1.7 million Australians live with inflammatory forms of arthritis and related conditions (ABS 2015). These conditions include rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis, gout, systemic lupus erythematosus and juvenile idiopathic arthritis. These forms of arthritis typically require specialist management.

Rheumatoid arthritis is the second most common form of arthritis, and the most common form of inflammatory arthritis. It is a chronic, auto-immune condition affecting over 405,000 Australians (ABS 2015), and is projected to affect 473,000 people by 2020 (Ackerman et al. 2016). Around 58% of people with rheumatoid arthritis are between the ages of 25 and 64 years (Arthritis Australia 2014d). The condition varies in its presentation, severity and course. Along with joint swelling, stiffness, pain, fatigue and disability, the heart, respiratory system, nerves and eyes can also be affected (Arthritis Australia 2014d). Management typically occurs in specialist and hospital environments.

Around 6,000 Australian children under the age of 16 years are affected by juvenile idiopathic arthritis (JIA) (Ackerman et al. 2016), similar to the number of children affected by Type 1 diabetes. JIA is one of the most common and serious chronic conditions of childhood, causing disabling pain, fatigue, restrictions in physical activity and, potentially, growth abnormalities, irreversible joint damage and other complications. There are psychological, social, educational and financial impacts for children and their families. The impact continues into adulthood, with 25,000 adults estimated to be living with JIA-related disability in 2003 (Arthritis Australia 2014b).

What is the burden?

Rheumatoid arthritis and other forms of inflammatory arthritis account for 6% of the total burden and around 11.4% of the non-fatal burden of disease in Australia.

Inflammatory arthritis has a considerable impact on people living with the condition, their carers and the broader community. Physical impairments and activity limitations resulting from the pain and disability associated with rheumatoid arthritis can adversely impact mobility, capacity to perform self-care tasks and labour force participation.

Arthritis is the second leading cause of disability in Australia and the main disabling condition for 14.8% of people living with a disability (ABS 2012). It is estimated that 162,100 (25.5%) of these people have severe or profound core activity limitations (ABS 2010).

Burden of disease is a measure of the combined impact of living with illness and injury (non-fatal burden) and of dying prematurely (fatal burden). While musculoskeletal conditions in general are not a large contributor to fatal burden, in 2011 they accounted for 23% of the non-fatal burden in Australia, ranked second to mental health and substance use disorders which accounted for 24% of the non-fatal burden (AIHW 2017a).

Inflammatory forms of arthritis accounted for 6% of the total burden of disease and 11.4% of the non-fatal burden of disease in Australia. Rheumatoid arthritis alone accounted for 1.9% of the total burden of disease and 3.6% of the non-fatal burden. 'Other musculoskeletal conditions' (which includes inflammatory forms of arthritis and related rheumatic conditions) accounted for 4.1% of the total burden of disease and 7.8% of the non-fatal burden (AIHW 2017a).

The category of 'other musculoskeletal conditions' was the leading cause of total disease burden in women aged 45–64 years and the fourth leading cause of disease burden in women aged 25–44 years (AIHW 2017a).

Arthritis cost the Australian health system more than \$5.5 billion in 2015 and this is predicted to rise to \$7.6 billion by 2030. Around half of this cost (\$2.8 billion in 2015) was attributable to inflammatory arthritis. Healthcare costs for rheumatoid arthritis alone were estimated at more than \$550 million in 2015 and are predicted to rise to more than \$755 million by 2030 (Ackerman et al. 2016).

In addition, welfare costs and lost tax revenue due to arthritis (all forms) were estimated to be \$1.1 billion in 2015, rising to \$1.5 billion by 2030 (Arthritis Australia 2016).

2. Experience and evidence for the role of rheumatology nurses managing inflammatory arthritis

Internationally, predictions that the demand for rheumatology services will outstrip the supply of rheumatologists have led to the expansion of roles of non-rheumatologists such as nurses. The rheumatology nursing role is evolving rapidly, with a number of studies exploring and evaluating the contribution of nurses to care. These studies support the effectiveness and cost-effectiveness of nurses with experience and training in rheumatology providing care for people with inflammatory arthritis.

The European League Against Rheumatism (EULAR)¹ provides recommendations for the role of the nurse in the management of chronic inflammatory arthritis, based on best available evidence and expert consensus. These recommendations support the role of nurses in the following areas:

- **Education:** improving patients' knowledge of inflammatory arthritis and its management throughout the course of their disease
- **Comprehensive disease management:** detecting early arthritis, making referrals, determining necessary interventions, disease and medication monitoring and changing medications with the aims of controlling disease activity, reducing symptoms and improving patient-preferred outcomes
- **Psychosocial issues:** identifying, assessing and addressing psychosocial issues to minimise the chance of patients' anxiety and depression
- **Self-management:** promoting self-management skills so that people with inflammatory arthritis achieve a greater sense of control, self-efficacy and empowerment
- **Continuity of care:** providing nurse-led telephone services to enhance continuity of care and to provide ongoing support (van Eijk-Hustings et al. 2012).

Studies in the US and UK have identified similar roles and responsibilities for rheumatology nurses, as well as demonstrating the potential for rheumatology nurses to assist in the diagnostic process and monitoring of disease modifying anti-rheumatic drug (DMARD) therapy (Butt, Newman & Smith 2016; Hill, Ryan & Hassell 2009; Kroese et al. 2011; Kuznar 2014; Larsson et al. 2015; Mintz, Jones & Reiff 2015; Oliver 2011; Smith et al. 2017; Solomon et al. 2014).

In Australia, the *Time to Move: Arthritis* strategy examined the patient journey across the continuum

of care from wellness through to advanced disease to identify opportunities for improvement. The strategy identified a number of areas where rheumatology nurses could assist in improving care for people with inflammatory arthritis. These areas included:

- facilitating early diagnosis and treatment
- providing information, education and support for self-management
- providing psychosocial support
- providing care coordination
- supporting care in rural and remote Australia
- contributing to a sustainable model of care (Arthritis Australia 2014d).

A summary of the evidence relating to rheumatology nursing care is provided below.

Early diagnosis and treatment

There is a window of opportunity early in the disease during which aggressive treatment ... can alter the course of the disease, prevent or delay joint damage, increase the chance of achieving disease remission and improve long-term outcomes, including reduced disability.

Time to Move: Rheumatoid Arthritis.
Arthritis Australia 2014.

¹ EULAR is the organisation which represents the people with arthritis/rheumatism, health professional and scientific societies of rheumatology of all the European nations.

In rheumatoid arthritis, 75% of joint erosions occur within the first two years of the disease (van der Horst-Bruinsma et al. 1998). Delays in diagnosis and initiation of therapy are likely to result in avoidable burden of disease and disability (van der Linden et al. 2010). Therefore, early diagnosis and treatment are particularly crucial in the management and prognosis of inflammatory arthritis.

DMARD therapy, including conventional, biological and biosimilar drugs, is the cornerstone of inflammatory arthritis management (Jones, Nash & Hall 2017). These medications control symptoms, prevent or slow disease progression and joint erosion, reduce mortality and increase the chance of achieving disease remission (Jones, Nash & Hall 2017; Smolen et al. 2010).

Early initiation of DMARD therapy, ideally within 3-4 months of symptom onset, is particularly effective in managing rheumatoid arthritis and results in improved outcomes compared to later initiation of therapy. Starting therapy within this 'window of opportunity' can limit the long term impact and severity of the disease (Lard et al. 2001; Nell et al. 2004; Verstappen et al. 2003), reducing the disease burden (Bykerk & Emery 2010), and increasing the likelihood of achieving remission (Gremese et al. 2013; Möttönen et al. 2002; Nell et al. 2004; van der Linden et al. 2010). As a result remission is now a recommended and achievable goal of therapy (Sokka et al. 2008; Smolen et al. 2016).

Despite evidence that early initiation of treatment for inflammatory arthritis improves patient outcomes, international studies have shown that delays are common. Internationally, median times from symptom onset to commencement of DMARD therapy have been reported at 5-11 months (Nanji et al. 2012; Raza et al. 2011; Sokka & Pincus 2002; Tavares et al. 2012; UK National Audit Office 2009; van der Linden et al. 2010), with delays of up to 19 and 42 months in Spain (Hernández-García et al. 2000) and Korea (Cho et al. 1998) respectively.

Australian studies have reported median times to initiation of DMARD therapy of between 4.5 months and 6.4 months (Jamal et al. 2011; Reed et al. 2005; van Doornum et al. 2013), with delays of up to two years from symptom onset to rheumatologist review in some parts of rural Queensland (Roberts et al. 2012). A 2011 study found that only 23% of patients with early rheumatoid arthritis in Australia started on DMARD therapy within 3 months of symptom onset (Jamal et al. 2011).

Delays can occur at a number of points along the care pathway between:

- the onset of symptoms and seeking medical care
- review by a primary care physician and referral to a rheumatologist
- referral and review by a rheumatologist (Bykerk & Emery 2010; Royal College of Physicians 2013).

Timely access to appropriate rheumatology care can be limited due to barriers in accessing appropriate healthcare providers such as specialist rheumatologists. In 2012, it was reported that there were 195 full-time equivalent rheumatologists in Australia, or one per 118,000 Australians (Piper 2012). This falls short of international benchmarks, such as the UK where one full-time equivalent is recommended per 86,000 people (Royal College of Physicians 2013). Further, only 13% of rheumatologists in Australia live outside capital cities (Piper 2012), limiting access to appropriate specialist care for people living in rural and remote areas. This is particularly significant in relation to access to biologic DMARD (bDMARD) therapy, which can only be prescribed by specialist rheumatologists or clinical immunologists.

A future shortage of Australian rheumatologists is predicted due to the increasing prevalence of arthritic disease (Roberts et al. 2006), population growth, an ageing workforce and limited rheumatologist training positions (Arthritis Australia 2014d).

Increased utilisation of rheumatology nurses offers the potential to address workforce shortages and delays in access to specialist rheumatologist services.

Appropriately trained nurses have been shown to be able to detect early arthritis and provide triage services to streamline access to rheumatologists (Gormley et al. 2003). In the UK, nurse-led early arthritis clinics were found to reduce the time between symptom onset and first rheumatologist assessment for people with inflammatory arthritis from 16 weeks to three weeks, as well as time between symptom onset and the initiation of DMARD therapy (El Miedany, Palmer & Gaafary 2006).

Recent audits of rheumatology services in the UK found that there was a strong, statistically significant correlation between nurse staffing levels and timely initiation of treatment for patients. Services with higher rates of nurse staffing were twice as likely

to achieve timely initiation of combination DMARD treatment and 58% more likely to achieve treatment targets (British Society for Rheumatology 2016).

Information, education and support for self-management

Few people with arthritis receive appropriate education and support to self-manage their condition.

Time to Move: Rheumatoid Arthritis.
Arthritis Australia 2014.

Current Australian guidelines reflect the importance of patients' knowledge and self-efficacy in managing their arthritis (RACGP 2009). Self-management interventions can assist those with chronic conditions to improve their quality of life, equipping them with the knowledge, skills and confidence to better manage problems related to their condition. Interventions cover a broad range of areas. Addressing diet and physical activity is relevant for most chronic conditions, however, addressing symptom control and social functioning is of particular relevance for people with arthritis. Evaluations across a number of chronic conditions in Australia, have found that self-management interventions reduced the use of health services, as well as improving health outcomes and quality of life (Comm. DOH 2005).

Access to a rheumatology nurse for disease education in rheumatoid arthritis has been shown to significantly increase a patient's knowledge of the disease process, treatment strategies and self-management strategies. Patients monitored by a nurse also showed greater levels of knowledge compared to those monitored by doctors (van Eijk Hustings et al. 2011).

Comprehensive disease management

Good quality evidence supports the role of appropriately trained rheumatology nurses in comprehensive disease management for people with inflammatory arthritis. Several studies have shown that nurse-led care achieves equivalent suppression of disease activity in patients

with rheumatoid arthritis, as well as statistically significant less pain and fatigue compared to medical care (van Eijk Hustings et al. 2011).

A UK study evaluating the effectiveness and safety of nurse practitioner-led care within a rheumatologist practice found that people with rheumatoid arthritis managed by nurse practitioners experienced lower levels of pain, acquired greater levels of knowledge about their condition and its treatment and were significantly more satisfied with their care (Hill et al. 1994).

Nurse-led clinics for monitoring biological therapy have also been shown to be as effective as rheumatologist clinics in terms of disease activity outcomes for people with stable inflammatory arthritis (Larsson et al. 2014).

In addition, nurse-led telephone helplines can provide a cost-effective and timely source of advice and support for people with inflammatory arthritis (Hughes et al. 2002). These services are highly valued by patients, given the unpredictable and fluctuating nature of inflammatory arthritis, and can help to reduce consultations with GPs (Hughes et al. 2002).

Psychosocial support

A diagnosis of rheumatoid arthritis 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.

Time to Move: Rheumatoid Arthritis.
Arthritis Australia 2014.

Psychological distress for those living with rheumatoid arthritis is common with the National Health Survey (2007–08) finding that individuals living with rheumatoid arthritis were 1.7 times as likely to report

high or very high levels of psychological distress as those without the condition (AIHW 2013). Depression is two to three times more common in people with rheumatoid arthritis than it is in the general population (Rathburn et al. 2012). Even when not clinically diagnosed, depressive symptoms can negatively affect a person's ability to participate in work, social activities and relationships and their psychological well-being (Gettings 2010).

Effective psychosocial care can reduce psychological distress in people with arthritis. International (Lugmani et al. 2009; Smolen et al. 2016) and Australian guidelines (RACGP 2009) recognise the importance of providing appropriate and early multidisciplinary care to support the psychosocial wellbeing of individuals with rheumatoid arthritis at diagnosis and throughout the disease course. Psychosocial support can improve coping strategies around the condition and its impact on participation in activities of daily living, education and the workplace.

Nurse-led care can significantly reduce anxiety and depression in people with rheumatoid arthritis and can improve their ability to cope with their condition (Ryan et al. 2006; Hill et al. 1994). Cognitive behavioural interventions by nurses have been shown to significantly improve emotional wellbeing and personal coping (Sinclair et al. 1998).

Care coordination

Multidisciplinary care is a key principle for the management of rheumatoid arthritis as it allows the best possible care to be provided, reducing patients' risk of developing the complications and disability associated with the condition.

Time to Move: Rheumatoid Arthritis.
Arthritis Australia 2014.

Care coordination has been shown to both improve patient outcomes and yield economic benefits in a range of musculoskeletal and chronic conditions (Berry et al. 2013).

Care coordination provided concurrently with patient education and disease monitoring is an effective mechanism for enhancing continuity of care for individuals living with severe rheumatoid arthritis (van der Hout et al. 2003).

Rheumatology nurses are well placed to provide care coordination for people with inflammatory arthritis.

Patient satisfaction with care

Rheumatology nurse-led care is associated with significantly higher rates of patient satisfaction with information, education, communication, empathy and access to care compared to care provided by doctors or other health professionals (van Eijk Hustings et al. 2011).

Rural and Remote care

In the UK, outreach rheumatology nurse clinics have proved valuable in providing personalised care, disease management support, social and educational support, and continuity of care close to home for people with rheumatoid arthritis in a rural area (Abdelhamid et al. 2012).

In Western Australia, rural clinics supported by rheumatology nurses, such as the Albany Rheumatology Clinic, have been identified as a way of supporting effective services in rural and underserved areas. The Albany clinic is attended by rheumatologists with the support of an up-skilled nurse who triages referrals, monitors disease activity and ensures management plans are followed, thereby facilitating an efficient service (WA DOH 2009).

Cost-effectiveness

Healthcare systems must continuously innovate and adapt if they are to deliver effective complex care to many more patients within limited healthcare budgets into the future.

(Amalberti, Nicklin & Braithwaite 2016)

Rheumatology nurses can contribute to an effective and sustainable model of care for people with inflammatory arthritis by reducing delays in access to specialist care and by providing more cost-effective care.

Reducing delays in initiation of pharmacological treatment is likely to result in substantial health-cost savings due to higher rates of remission (Gremese et al. 2013; Nell et al. 2004; van der Linden et al. 2010), reduced need for expensive bDMARD therapy (Gremese et al. 2013), delayed joint replacement surgery (Moura et al. 2015), reduced medical referrals and consultations, (Ryan 1997; Sørensen et al. 2015) reduced hospital admissions (Oliver & Leary 2010) and reduced healthcare costs (Barnabe et al. 2013). There are also likely to be significant societal gains through greater social participation and productivity gains (Finckh et al. 2009; van der Hout et al. 2003).

Nurse-led clinics have been shown to provide equivalent or better outcomes to that provided by doctors, at less cost. A prospective randomised controlled trial in the Netherlands evaluated the relative cost-effectiveness of rheumatology nurse care compared with inpatient team care and day patient team care. It showed that rheumatology nurse care resulted in equivalent quality of life and utility, at lower costs (van den Hout et al. 2003).

A study in Sweden compared the costs of rheumatology care between a nurse-led rheumatology clinic versus a rheumatologist-led clinic, in monitoring patients with chronic inflammatory arthritis undergoing bDMARD therapy. It showed that patients

with low disease activity or in remission undergoing bDMARD therapy could be monitored with a reduced resource use and at a lower annual cost by a nurse-led clinic, with no difference in clinical outcomes (Larsson et al. 2015).

A multi-centre randomised controlled trial in the UK evaluated the clinical and cost-effectiveness of nurse-led care for people with rheumatoid arthritis. It showed that nurse-led care was not inferior to rheumatologist-led care at any follow-up time point. Nurse-led care was more cost-effective with respect to disease activity scores and was associated with higher general patient satisfaction with care. Firm conclusions on cost-effectiveness, however, could not be drawn due to variation between disease-specific and generic (quality adjusted life years) cost-effectiveness outcomes (Ndosi et al. 2014).

In addition, nurse-led monitoring and telephone helplines can reduce health service utilisation by decreasing the number of unnecessary doctor consultations and preventing unscheduled hospital admissions (van Eijk-Hustings et al. 2012).

3. Rheumatology nursing in Australia

Specialty nursing in Australia

In Australia, registered nurses are responsible and accountable to the Nursing and Midwifery Board of Australia (NMBA), one of the 14 National Boards that regulates health professions under the Health Practitioner Regulation National Law, as in force in each state and territory. Standards for practice (Nursing and Midwifery Board of Australia 2016b) articulate the expectations of registered nurse practice. These standards apply across all areas and contexts of nursing practice.

The NMBA does not recognise or regulate any *specialty areas* within nursing. While their primary consideration is to protect the public, they must also consider facilitating access to services provided by health practitioners and enabling the continuous development of a flexible, responsive and sustainable health workforce (AHPRA 2017a). They acknowledge that while a variety of mechanisms are employed internationally to recognise and regulate specialty practice, formal regulation of specialty groups for the purposes of registration does not reduce risk to the public or improve patient outcomes (Nursing and Midwifery Board of Australia, 2016a). They identify that organisations representing specialty nursing groups in Australia provide a sufficient means of acknowledging specialist nursing practice in Australia, and may be recognised by employers and the health industry at large (Nursing and Midwifery Board of Australia 2016a).

In Australia, the Rheumatology Health Professionals Association is the representative body for health professionals who work with people with rheumatic diseases, including rheumatology nurses and allied health practitioners.

In contrast to specialty areas, *advanced practice nursing* is regulated by the NMBA. Building on the platform of the registered nurse scope of practice, this is achieved through endorsements (e.g. as a nurse practitioner) and requires further education to a Master's degree level. Generally, endorsements are used to identify health practitioners who are authorised under Commonwealth or State legislation to do things that they would otherwise not be authorised to do (e.g. diagnosis, prescription of non-pharmacological and pharmacological interventions). The endorsement mechanism is intended to be used to extend scopes of practice, not restrict the scopes of practice of practitioners who do not hold an endorsement (AHPRA

2017b). Nurse practitioners were first authorised to practice in Australia in December 2000 (Masso & Thompson 2014).

There is limited evidence related to nurses practising in rheumatology in Australia. This is further complicated by the terminology surrounding the role. Internet searching indicates that a variety of position titles are used for these roles. However, an examination of job advertisements in Australia suggests that the range of activities performed by people in these roles is encompassed by those recommended by EULAR (see page 10).

Models of care incorporating rheumatology nurses

Models of care for inflammatory arthritis in Australia have been developed using registered nurses and/or nurse practitioners. These models suggest that the range of activities performed by rheumatology nurses in Australia generally aligns with those recommended by EULAR.

With limited publicly-available information about implementation and/or evaluation, these models include:

- Rheumatology Nurse Practitioner Model. Melbourne Health; 2014 (Melbourne Health 2014)
- Model of Care for the NSW Paediatric Rheumatology Network, NSW Agency for Clinical Innovation; 2013 (NSW Agency for Clinical Innovation 2013).
- Paediatric Rheumatology Nurse Practitioner — A Model of Care. Department of Rheumatology, Royal Children's Hospital Melbourne; 2012 (Royal Children's Hospital Melbourne 2012).
- Inflammatory Arthritis Model of Care. Western Australia Department of Health; 2009 (WA DOH 2009).

Implementing models of care with registered nurses in the private sector in primary and secondary care presents challenges. While there are MBS items for nurses in general practice to support chronic disease management, there is no similar funding mechanism to support nurses in specialist practice.

Implementing models of care with nurse practitioners also presents challenges. Despite international evidence consistently demonstrating that care by

nurse practitioners results in processes and outcomes that are either equivalent to or better than those achieved by doctors (Masso & Thompson 2014), nurse practitioners are not being used in Australia to their optimum capacity. At December 2016, there were 1,477 nurses endorsed as nurse practitioners in Australia (which includes prescribing scheduled medicines), and 1,118 who are endorsed to supply scheduled medicines (rural and isolated practice) (Nursing and Midwifery Board of Australia, 2016c). It has been estimated that approximately one quarter of nurse practitioners work in emergency departments (e.g. fast-track or minor injuries clinics), with the remainder working in a broad range of other clinical areas. This diversity impedes progression of their role, with 'activities which are uniquely the role of nurse practitioners making up so little of their time' (Masso & Thompson 2014). Implementation of models of care involving nurse practitioners needs profession and system level support.

Currently there are only two qualified rheumatology nurse practitioners in Australia.

What does the existing rheumatology nurse workforce look like?

The current rheumatology nurse workforce in Australia is small. There are only an estimated 39 full-time equivalent (FTE) rheumatology nurses to support the 1.7 million Australians with inflammatory arthritis.

Number of rheumatology nurses

There is no systematic collection of data relating to rheumatology nurses in Australia so information about the rheumatology nurse role and workforce presented in this section is drawn from the results of the rheumatology nurse survey conducted as part of this study and database and internet searches.

Variable terminology around the role complicates information gathering. However, database and open internet searching indicates that numerous hospitals, and to a lesser extent, specialist rheumatologists across Australia employ staff in a rheumatology nursing role. A search of publicly available information on rheumatology nurse positions in Australia identified 54 positions while the survey and interviews conducted by AHHA, identified 41 rheumatology nurses. There is no identifier that can be used to consistently determine the extent to which these two sources of information overlap/correlate.

In this context, an estimate of around 50 practising rheumatology nurses in Australia seems reasonable.

A comparison of the state/territory breakdown from these two sources of information is provided in Table 1, noting two respondents in the survey did not identify the state/territory in which they practise.

Most respondents (74%) reported practising in a major city, with 17% in a regional setting and the remainder in rural/remote locations.

Most rheumatology nurse respondents reported working part-time (66%). If it is assumed that those responding in the survey are reflective of the estimated 50 rheumatology nurses in Australia, the number of full-time equivalent (FTE) rheumatology nurses in Australia is 39.

Table 1 State/territory distribution of rheumatology nurses in Australia

State/territory	Number of rheumatology nurses *identified through search of publicly available information	Number of rheumatology nurses *identified through response to survey and interviews
ACT	2	6
NSW	16	10
NT	1	1
QLD	9	10
SA	7	3
TAS	2	1
VIC	13	5
WA	4	3
Not identified		2
Total	54	41

Training and qualifications

There is no formal pathway towards becoming a rheumatology nurse. An online Graduate Certificate in Musculoskeletal and Rheumatology Nursing has been available through the Australian College of Nursing since 2012. However it is not clear how many people have undertaken or completed this certificate. Twenty-four nurse survey respondents (65%) reported having completed a postgraduate qualification, of which 40% were in a musculoskeletal, rheumatology or orthopaedic area: seven reported this was the Graduate Certificate in Musculoskeletal and Rheumatology Nursing.

Practice settings for rheumatology nurses

Practice settings for rheumatology nurses include public hospital outpatient clinics, private rheumatology practices, public hospital inpatient wards, research institutions, general practice and educational institutions.

Most rheumatology nurse survey respondents reported spending their time in more than one practice setting (68%). This, together with the part-time nature of the workforce, limits any meaningful reporting of

workforce distribution across different settings from the survey data.

Table 2 describes the practice settings of survey respondents:

- Public hospital outpatient clinics are the most common practice setting for rheumatology nurses, with 68% working in this setting. Those working in this setting reported spending 66% of their time on average in public outpatient clinics, accounting for 45% of overall rheumatology nurse workforce time.
- Over half of rheumatology nurses reported working in private rheumatology practice, although the time spent in this setting was just 14% of total rheumatology nurse time. In contrast around 80% of specialist rheumatologist practice takes place in the private sector (Arthritis Australia 2014d). One in three nurses reported spending time in nurse-led clinics for a total of 14% of rheumatology nurse time. Nurse-led clinics could take place in either public or private practice.
- Rheumatology nurses spent negligible time in private hospitals (inpatient wards and outpatient clinics).

This distribution of practice settings was consistent with the survey responses from rheumatologists, with the majority (77%) identifying they had worked

with a rheumatology nurse in the context of a service offered by a public hospital. Other contexts included pharmaceutical company patient support programs (46%), as part of their own practice (31%), through nurse-led clinics (15%), through support provided by a pharmaceutical company (15%) or in research (8%).

Only one rheumatology nurse respondent was a nurse practitioner. In the interviews, rheumatology nurses reported that the benefits of pursuing endorsement as a nurse practitioner did not offset the associated costs. It was reported that with international qualifications not recognised through the endorsement process, the time and cost of pursuing education in Australia was not balanced by any additional financial benefits. If the nurse practitioner workforce is to be expanded, support needs to be provided for registered nurses to achieve endorsement as a nurse practitioner.

What activities are undertaken by rheumatology nurses?

Rheumatology nurses support patient care for all the different forms of arthritis and in many different ways. In addition, rheumatology nurses often have other roles such as coordinating clinical trials, running infusion centres, or managing bDMARD applications. Rheumatologists, consumers and carers and the nurses themselves all see that nurses could contribute more to improve patient care.

Rheumatology nurse respondents reported routinely assessing people with a wide range of rheumatology conditions in their practice. Over 70% reported routinely

assessing people with rheumatoid arthritis and psoriatic arthritis, 50% reported routinely assessing ankylosing spondylitis and osteoarthritis, while 30–40% reported routinely assessing other forms of inflammatory arthritis (e.g. systemic lupus erythematosus, scleroderma, gout, juvenile idiopathic arthritis).

Respondents to the surveys identified a broad range of activities undertaken by rheumatology nurses (Table 3).

Rheumatology nurse respondents reported seeing patients for different reasons. Those nurses seeing paediatric patients provided a more consistent service, with all stating they see patients for routine review, for urgent review (where there is a flare-up or complications) and when on bDMARD therapy. The services provided by nurses seeing adult patients varied more between nurses, possibly reflecting the greater variation in practice sites and patients within their service.

Nearly all rheumatologists and rheumatology nurse respondents reported nurses undertook the following tasks:

- telephone/email support, advice and follow up for patients
- patient education, support and counselling to improve self-management
- care coordination and liaison with other healthcare professionals.

Compared to rheumatologists’ assessment of nurse activities, rheumatology nurses were more likely to report that they were active in disease management, pharmacotherapy monitoring and teaching and training other healthcare professionals.

Table 2 Practice settings of rheumatology nurse respondents

Practice setting	% of respondents who identified working in this setting	Of those working in this setting, average % of time spent there (and range)	% of total time spent by rheumatology nursing workforce in this practice setting
Public hospital outpatient ward	68%	66% (7–100)	45%
Private rheumatology practice	58%	24% (1–100)	14%
Nurse-led clinic	32%	43% (10–100)	14%
Other			27%

Table 3 Activities undertaken by rheumatology nurses

Activities	% of rheumatology nurses who currently undertake each activity			
	As reported by rheumatology nurses	As reported by rheumatologists	As reported by the clinical workforce	As reported by consumers/carers who have seen a rheumatology nurse
Patient education, support and counselling to improve self-management	93%	92%	64%	67%
Early diagnosis of arthritis	24%	23%	29%	26%
Disease assessment and monitoring	69%	62%	57%	72%
Ordering medical imaging	10%	15%	29%	44%
Reviewing medical imaging	21%	15%	29%	
Performing physical assessment of the joints	62%	46%	50%	*
Assisting with joint aspirations	45%	31%	21%	10%
Disease management	72%	38%	57%	56%
Administration of pharmacotherapy (e.g. steroid joint injections, bDMARDs)	72%	62%	64%	45%
Monitoring pharmacotherapy	66%	38%	50%	39%
Management of pharmacotherapy	52%	31%	50%	
Medication counselling	86%	77%	71%	63%
Identifying and assessing psychosocial issues	79%	85%	79%	31%
Managing psychosocial issues	62%	62%	50%	15%
Care coordination	83%	92%	64%	42%
Telephone/email support, advice and follow-up for patients	97%	100%	71%	69%
Administrative tasks	93%	77%	71%	*
Teaching and training other health professionals	69%	31%	64%	*
Referrals to other specialists or departments e.g. physiotherapy	48%	31%	64%	*
Clinical trials	55%	38%	50%	*
Liaison with other healthcare professionals	97%	n/a	n/a	*

* Note. There is no result for these options as they were not provided to consumers or carers to respond against in the survey.

Rheumatologists reported that there is potential for rheumatology nurses to be involved in many more areas of care. Activities which were identified as not being undertaken extensively by rheumatology nurses currently, but for which there was a high level of support, included:

- pharmacotherapy monitoring and counselling
- assisting with joint aspirations
- teaching and training other health professionals
- early diagnosis
- disease assessment and monitoring
- clinical trials.

Overall, these activities are consistent with those recommended and implemented internationally through Europe, the UK and the US, and evaluated in the literature.

When asked which activities they considered appropriate for a rheumatology nurse to undertake rheumatologists and rheumatology nurses were generally in agreement. However, there were some significant exceptions, particularly:

- reviewing imaging: 62% of rheumatology nurse respondents considered this an appropriate activity for a rheumatology nurse compared to only 17% of rheumatologist respondents
- disease management (72% of rheumatology nurses compared to 33% of rheumatologists)
- management of pharmacotherapy (62% compared to 42%)
- referrals to other specialists or departments (72% of rheumatology nurses compared to 33% of rheumatologists).

Compared to consumers/carers' experience of nurse activities, rheumatology nurses were more likely across nearly all activities to report that they provided those services (Table 3). Key discrepancies relate to:

- identifying and assessing psychosocial issues: 79% of nurses reported this activity compared to only 31% of consumers/carers
- managing psychosocial issues (62% of nurses compared to 15% of consumers/carers)
- care coordination (83% of nurses compared to 42% of consumers/carers)

- providing patient education, support and counselling to improve self-management: 93% of nurses reported this activity compared to only 67% of consumers/carers
- assisting with joint aspirations (45% of nurses compared to 10% of consumers/carers).

These results suggest that nurses may be triaging the provision of services to consumers or that consumer expectations exceed the level of services provided. They also suggest that more emphasis should be placed on screening and managing consumers for psychosocial distress.

How are rheumatology nurses providing care?

Rheumatology nurses are flexible in how consultations are provided. Consumers and carers show an openness to all modes of consultation — face-to-face, telephone, email and web-enabled video.

There is great variation in how rheumatology nurses structure their time in supporting patient care.

All rheumatology nurse respondents reported conducting face-to-face consultations, which made up 37% of the nursing workforce's time overall. However, this varied between individuals from 2% to 85% of their time.

Rheumatology nurse respondents reported that consultations occurred most commonly:

- in conjunction with the patient seeing their specialist (86% of respondents)
- for follow up with the patient after seeing their specialist (83% of respondents)
- on an 'as needed' basis (62% of respondents).

Nurse consultations with new patients took 50 minutes on average, but ranged from 15 to 120

minutes. Consultations with patients for routine review were 31 minutes, on average, but ranged from 5 to 90 minutes. This means that nurses spend more time with patients than rheumatologists who typically spend 30 minutes with new and 15 minutes with review patients.

Nearly all rheumatology nurse respondents (93%) reported providing consultations by telephone, and 72% provided consultations by email. Some respondents also reported using Skype or other web-enabled video and text messaging support.

Consumers and carers responding to the survey showed openness to accessing rheumatology nurse services via all modes of consultation: face-to-face, telephone, email and skype or other web-enabled video.

What is the experience of consumers and carers?

Involvement of a rheumatology nurse substantially improved satisfaction with all aspects of care, but only 23% of respondents reported having ever seen a rheumatology nurse as part of their care.

Consistent with the literature, the majority of consumers and carers responding to the survey (70%) reported they (or the person they cared for) started experiencing symptoms before the age of 45 years. Half of respondents started experiencing symptoms before the age of 35 years, while only 4% were 65 years of older when they started experiencing symptoms. More than half reported that there was a delay of one year or more between symptom onset and diagnosis of their condition. On average, consumer respondents had to wait 12 weeks for an initial appointment with a rheumatologist, but 16% reported waiting six months or longer.

One in five respondents reported that they were unable to work or study due to their condition.

However, only 12% of those who had had access to a rheumatology nurse reported that they were unable to work or study due to their condition.

One in four consumer respondents (24%) reported that they were not managing well with their condition (i.e. they were in a lot of pain and having difficulty managing everyday activities).

As one respondent reported: *'I struggle everyday with mobility, it has affected my employment, pain affects my coping skills and concentration. I don't believe that my medical practitioner understands or others in my life understand the full extent of the pain I experience every day. This has led to severe anxiety and depression.'*

Only 20% of consumer and carer respondents felt that their arthritis (or that of the person they cared for) was well controlled or in remission. This indicates a need for improved management.

Access to rheumatology nurses

While 85% of respondents had seen a rheumatologist for their arthritis, only 23% of consumers and carers responding to the survey had seen a rheumatology nurse as part of their care. This was primarily through a service offered by their hospital (62%). The majority reported that access to a rheumatology nurse was not offered or available, or that they were not aware of such support.

Consumers or carers were more likely to have seen a rheumatology nurse as part of their care if:

- they were a paediatric patient - 56% of respondents relating to paediatric patients had seen a nurse as part of their care, compared with 22% of respondents relating to adult patients. This is consistent with paediatric care more often being provided through public hospitals, where rheumatology nurses more commonly practice. Nearly all paediatric rheumatology nursing is delivered in a public hospital environment.
- they were taking a bDMARD - 46% of respondents who were taking a bDMARD had seen a rheumatology nurse, compared with 8% of respondents who were not.

The most common services consumers reported receiving from rheumatology nurses were: disease assessment and monitoring; education, support and counselling to improve self-management; medication counselling; and telephone support, advice and follow-up.

Consumer satisfaction

Satisfaction was substantially greater across all aspects of care for consumers and carers who had seen a rheumatology nurse as part of their care (Table 4). In particular consumers who had seen a rheumatology nurse were around twice as likely to report that they were satisfied or very satisfied with the support they received for their emotional and mental wellbeing, the coordination of their care and their ability to quickly access specialist advice or treatment for their condition when they needed it.

Where does rheumatology nurse support provide the greatest value to patients?

Support from rheumatology nurses is of greatest value for patients who have been recently diagnosed, are having a flare-up of their condition, or are not coping emotionally.

Rheumatology nurses, rheumatologists and consumers and carers responding to the survey consistently identified that support from a rheumatology nurse was of greatest value for patients who:

- had been recently diagnosed
- were having a flare-up of their condition
- were not coping emotionally.

The benefits most commonly reported by consumers and carers in relation to having access to a rheumatology nurse can be grouped according to the following themes:

- **Timeliness of access.** Consumers benefit from having a single point of contact that they can go to for advice, with personalised service, at times when it is not necessary or timely to contact their specialist or the hospital emergency department. Nurses can triage patients, escalating urgent cases and providing support in between rheumatologist appointments. They can provide a 'go between' for doctors and patients. They are 'someone to call when I need advice on how to manage my condition'; can answer questions 'when the rheumatologist is away/busy'; they provide 'access to quick advice when required'. In addition, 'having a go-to for support is very empowering.'

Table 4 Patient satisfaction with care

Aspect of care	% of patients who were satisfied or very satisfied	
	Of those who had seen or had the assistance of a rheumatology nurse	Of those who had not seen or had the assistance of a rheumatology nurse
The information they received at diagnosis about their condition and its management	78%	58%
The care they received at diagnosis	87%	60%
The support they received at diagnosis	81%	44%
The information and support they received for the ongoing management of their condition	91%	54%
The support they received for their emotional and mental wellbeing	68%	30%
The coordination of the various aspects of care for their condition	82%	35%
Their ability to quickly access specialist advice or treatment for their condition (or the person they care for) when they needed it e.g. during a flare	80%	45%
The information received about their medicines	93%	65%

- **Time available for education and support.** Nurses have more time to provide education about a person's condition and its treatments. *'It's overwhelming when diagnosed and then trying the various medications and dealing with the reactions'; 'I'm able to ask questions without worrying about time pressures'; 'As doctors are really busy it's harder to get extended time to ask about day to day things'.*
- **Person-to-person care factor.** *'Knowing she is always there for my ongoing care, especially when things aren't going well, my condition unexpectedly changes or I need help'; 'the personal approach to my condition I have found very valuable to me'; 'Relationship of trust and understanding. Personal connection'.*
- **Care coordination specific to rheumatology needs.** *'I have worked in healthcare for 15 years and am quite health literate but when faced with being an advocate for another person, managing the stress of a very sick child and navigating multiple healthcare settings, new medical language, etc, it was incredibly challenging. Without any previous (or limited) exposure to public health, this process would have been overwhelming and very daunting. The nurse could play a significant role in reducing some of these anxieties'.*
- **Efficiency of care.** Nurses undertake preparations for rheumatologist appointments, ensuring test results are available and PBS application requirements for bDMARDs are met, to streamline consultations with the rheumatologist. In addition, 41% of those who reported having seen a rheumatology nurse reported that access to the nurse reduced the number of times they needed to see specialists or GPs about their condition. *'Can keep down trips to specialists and doctors'.*

These reported benefits were consistent with those perceived to be the benefits by consumers who had not had access to a rheumatology nurse.

Rheumatologist perspectives

Rheumatologist respondents reported that rheumatology nurses improved the quality of care and efficiency of processes, with the benefits drawn from their:

- **Education and support for patients.** Nurses were identified as having more time and bringing a different perspective to patient care. Respondents noted nurses 'generally have more time for

discussion', *'families [are] often more comfortable discussing issues with nurse rather than doctor'* and provide a *'more holistic and thorough experience'*. They *'bring a broader perspective on care aspects'*.

- **Access and care coordination.** Nurses are accessible, are a contact point for information and support continuity of care. They provide *'routine follow up'* and *'monitoring'*, *'streamline [the] review process'* and *'aid integration with community supports'*.
- **Psychosocial support.** One rheumatologist working in a public hospital environment spoke of a typical three-hour clinic: *'15-16 patients are seen, each only getting 10 minutes of their time. Patients might have their measures under control, but might not be attending school, or might be suicidal, but they don't tell the rheumatologist in that time. If they have contact with a rheumatology nurse, who is less rushed and more approachable, they feel they can share with them. It might not be medical, but has a big impact on patient well-being and satisfaction.'*

Rheumatologists also identified the following benefits to the health system from utilising rheumatology nurses:

- connected care
- improved patient safety and quality of care
- reduced waiting times for new patients
- reduced hospital admissions
- improved health outcomes and patient satisfaction.

Some rheumatologists expressed concerns about rheumatology nurses prescribing or ordering investigations. However, these activities would be considered extended practice integral to the role of nurse practitioners, which requires further education to a Master's degree level.

Due to the limited number of rheumatologist respondents to the survey, it is not clear how widespread these views are among all rheumatologists.

What are the barriers to rheumatology nurses contributing to their full potential?

The most commonly cited barrier to rheumatology nurses contributing to their full potential was lack of funding. In the public sector, positions in hospitals are often not permanently funded, unlike other specialist nursing roles, contributing to job insecurity and uncertainty.

In the private sector, where most rheumatology practice in Australia takes place, there are limited funding options. There is no MBS funding for nurses in secondary care, unlike nurses in primary care. In addition, as most rheumatology services are provided by solo practitioners, their capacity to fund a rheumatology nurse from practice proceeds is limited. Some rheumatology nurses in both the public and the private sector are part funded through clinical trials, but reliance on this funding means nurses spend more time on data entry than on supporting patients.

Other barriers cited include:

- lack of standardisation and recognition of the role of rheumatology nurses
- attitudes and low levels of acceptance of the value of nurses by the rheumatology medical community
- limited training pathways and opportunities
- a lack of understanding of the complexity of arthritis and connective tissue disease patients.

5. The case for rheumatology nurses in Australia from the economic perspective

Key Findings:

The addition of rheumatology nursing to the traditional rheumatologist-only model would result in improved patient access to rheumatology specialist care and reduced delays to treatment.

The number of patients able to be seen would increase by up to 47%. The proportion of patients seen within clinically relevant timeframes, resulting in delayed disease progression, would increase from 23 % to 47.5% of patients.

The average cost of treatment per patient over four years would decrease from \$11,373 to \$10,483 per person. However, due to the increased number of patients treated, the total cost of providing this care would increase by 35.2% (\$6.549 million).

Within the representative public hospital outpatient rheumatology clinic considered here, the addition of rheumatology nursing support would result in 31.6% of patients achieving remission at four years, compared with 23.1% of patients in the rheumatologist-only clinic over the same time.

There are a number of additional costs and savings that are identifiable but cannot be estimated due to the lack of suitable evidence. The analysis presented here is therefore conservative.

Numerous international studies provide evidence that rheumatology nurses can provide cost-effective care for people with inflammatory arthritis

What was modelled?

To determine the potential economic benefits of rheumatology nursing in Australia a cost benefit analysis was undertaken. This analysis examined the costs and outcomes for a rheumatologist-only public outpatient hospital clinic against a similar clinic with both a rheumatologist and rheumatology nurse. Modelling was undertaken to examine the costs and benefits associated with these pathways over a period of four years in a cohort of newly referred patients from a single enrolment year.

Why was this modelling approach taken?

Models were informed by the available empirical evidence in both the peer reviewed and grey literature.

A key constraint in performing this analysis was the lack of critical data to appropriately populate an economic model. The model was therefore structured around those health services that could be accurately estimated with respect to patient flow parameter values and the cost of providing in-scope health services. Costs and benefits included healthcare provision, and conventional and bDMARD therapy.

The four year time period was selected as longitudinal peer-reviewed evidence was available on remission rates up to 36 months for patients starting DMARD therapy early compared to those who had delayed treatment (Nell et al. 2004). The annual savings flowing from these alternative outcomes was then estimated.

Additional benefits and savings such as reduced future health service utilisation costs and improved workforce participation, as discussed in the section on limitations (pg 31), were not quantified in this analysis. While the savings would be real, they were not estimated either due to a lack of available empirical evidence on which to base the calculations or because the required economic modelling was beyond the scope of this project. Consequently this analysis provides a conservative estimate of the impact of rheumatology nurses in patient care and identifies areas that warrant further examination.

Healthcare service costs were calculated using activity based funding data from the Independent Hospital Pricing Authority (IHPA) (IHPA 2016).

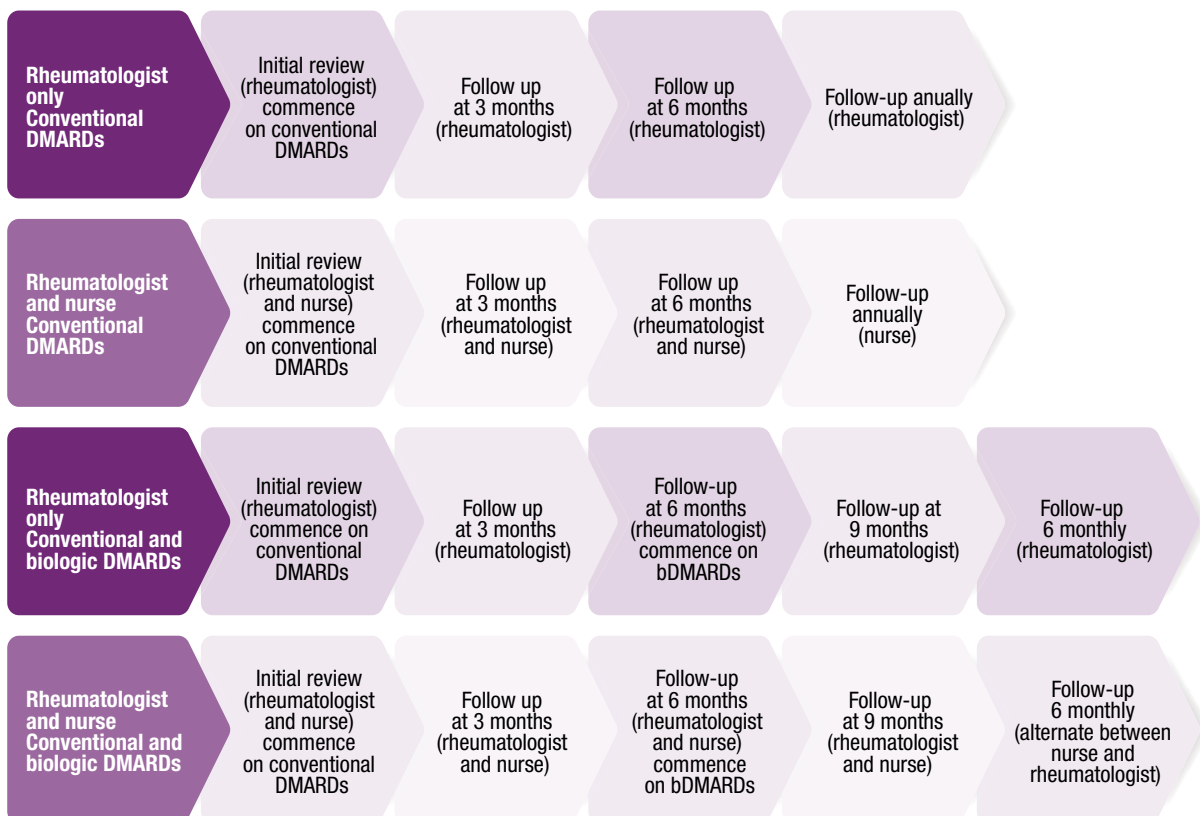
What patient treatment pathways were modelled?

Treatment for inflammatory arthritis can vary widely depending on the condition, patient factors and tolerance and response to medications. However,

for the purpose of this analysis, patient flows were modelled in three month intervals with a pattern of care based on the type of contact the patient would have in the public hospital clinic with varying assumptions on the model of care and the proportion of people that receive delayed treatment (see Figure 1).

For the purpose of the model, patients receiving delayed care received the same care as those who had early treatment, except that care was delayed by three months.

Figure 1 Patient treatment pathways for traditional and rheumatology nurse supported care for individuals requiring conventional or a combination of conventional and biologic DMARDs (Smolen et al. 2017).



How does the addition of rheumatology nursing care affect patient access?

Early access to specialist treatment for people with inflammatory arthritis, ideally within three months of symptom onset, is critical to achieving good long term outcomes. However delays in diagnosis and in access to specialist care for treatment means most Australians with inflammatory conditions do not receive specialist care within this 'window of opportunity' (Jamal et al. 2011; van Doornum et al. 2013).

Provision of rheumatology care supported by a rheumatology nurse for patients accessing public outpatient rheumatology services will improve access to rheumatology specialist care and reduce delays in receiving treatment.

Care supported by a rheumatology nurse, through shared clinics with a rheumatologist and rheumatology nurse, and rheumatology nurse-only clinics, increases the volume of patients able to access rheumatology care and hence increases annual patient throughput by 47%, or an additional 763 patients (see Figures 2 and 3).

Increased capacity to see patients allows more patients to be seen within a clinically appropriate time

frame, improving patient outcomes. Earlier initiation of treatment has been shown to improve patient outcomes and quality of life because it increases the chance of achieving remission and good disease control; it is also likely to decrease costs as it reduces the need to progress to expensive bDMARD therapy to maintain disease control (Nell et al. 2004; Gremese et al. 2013; van der Linden et al. 2010).

There are two key economic implications of the alternative model of care involving rheumatology nurses in a public hospital setting. The first is that the capacity to treat patients is expanded, i.e. a volume effect increasing the total cost of care. The second is that this expanded capacity will result in patients being examined earlier than would otherwise be the case, with patients being then placed on an appropriate pharmacological regimen to manage their condition. This brings forward the cost (or prevents the delay) of providing Pharmaceutical Benefits Scheme subsidised pharmaceuticals. However, these additional costs are offset by a number of benefits and potential savings in other areas particularly in reduced expenditure on bDMARDs and improved patient outcomes and quality of life.

Figure 2 The care pathway and patient flows for individuals accessing traditional rheumatologist-only rheumatology care in a representative public hospital rheumatology clinic.

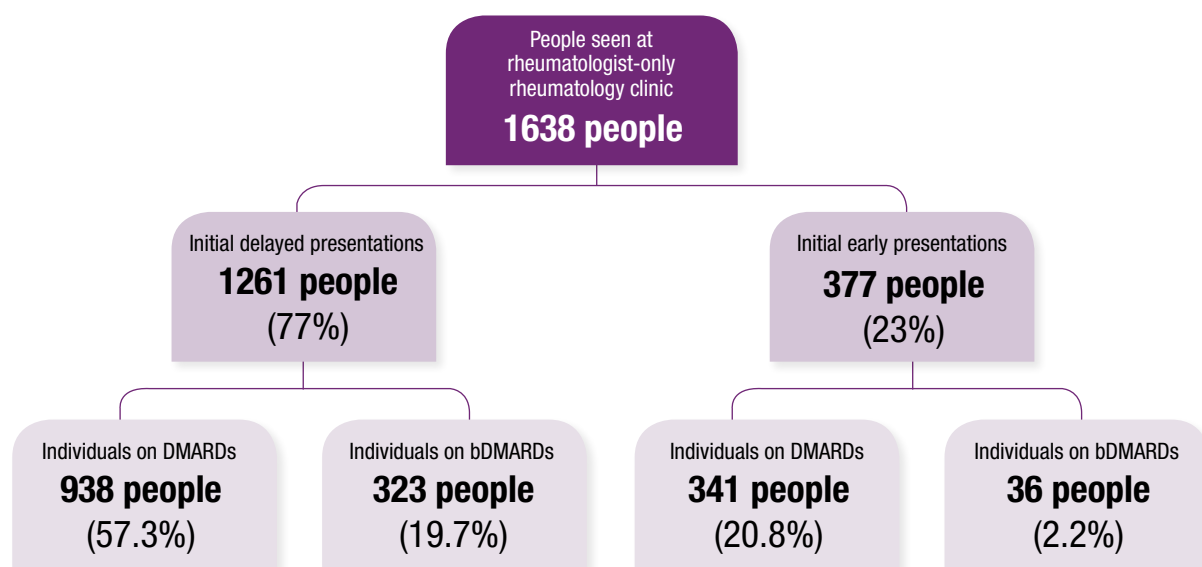
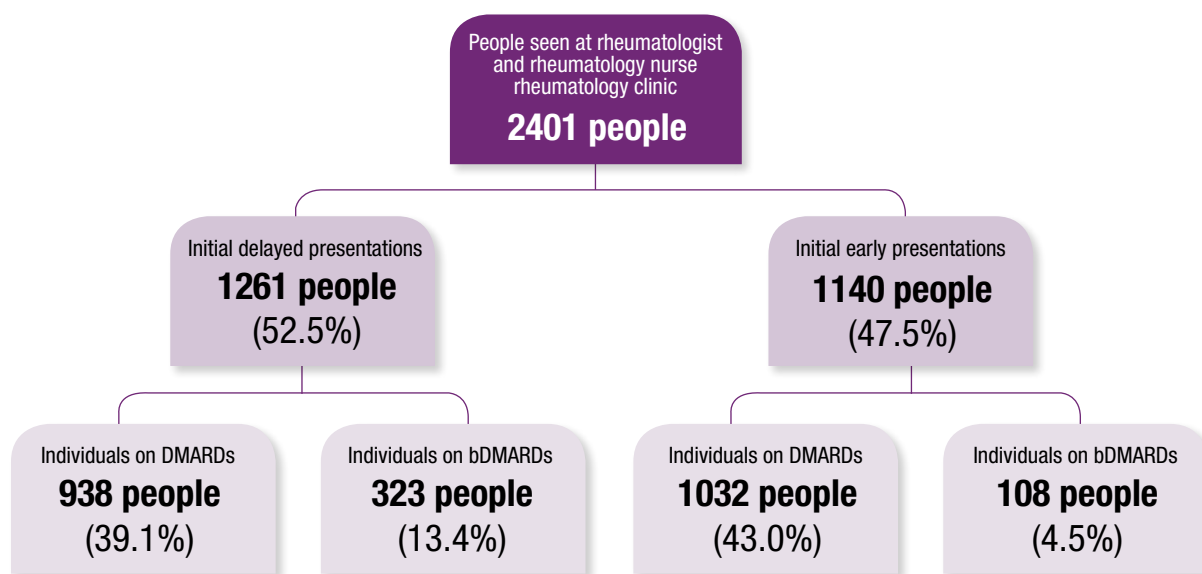


Figure 3 The care pathway and patient flows for individuals accessing rheumatology nurse supported rheumatology care in a representative public hospital rheumatology clinic.



How does the addition of rheumatology nursing change the costs of care?

The addition of rheumatology nursing to the traditional rheumatologist-only model would result in more timely access to specialist care and earlier initiation of treatment in the representative public hospital rheumatology clinic considered here. This would decrease the average costs per patient over the four years modelled, from a discounted cost of \$11,373 to \$10,483 (Table 5). However, higher patient volume due to improved service access would increase total discounted costs over the four years modelled by \$6.946 million (Table 5).

Table 5 The annual costs, total costs, average costs per patient and differences in costs for cohorts receiving either the traditional rheumatologist-only model of care or rheumatologist and rheumatology nurse model of care.

	Total Cost (\$m)					Average Cost (\$)				
	Year 1	Year 2	Year 3	Year 4	Total	Year 1	Year 2	Year 3	Year 4	Total
Rheumatologist only	\$3.673	\$5.016	\$4.777	\$5.159	\$18.625	\$2,242.87	\$3,062.89	\$2,917.04	\$3,150.43	\$11,373.23
Rheumatologist and nurse	\$6.267	\$6.421	\$6.092	\$6.394	\$25.174	\$2,609.87	\$2,674.21	\$2,536.96	\$2,662.82	\$10,483.86
Difference	\$2.594	\$1.406	\$1.315	\$1.235	\$6.549	\$367.00	-\$388.69	-\$380.08	-\$487.61	-\$889.37

How can the rheumatology nurse change patient outcomes?

Remission

Avoiding treatment delay improves remission rates in inflammatory arthritis (Gremese et al. 2013; Nell et al. 2004). The reduced proportion of patients experiencing delay in the rheumatologist and rheumatology nursing model led to higher rates of remission in this single enrolment year cohort with 31.6% (759) in remission in the fourth year, versus 23.0% (377) in the rheumatologist-only cohort, a difference of 382 patients (Table 6).

Achieving disease remission improves both patient and disease outcomes (van der Linden et al. 2010). Individuals who achieve early and sustained remission in the first year after diagnosis have lower radiographic progression and disability questionnaire scores, less missed work days and higher rates of long-term remission (Coombe et al. 2015), resulting in broader health and societal benefits.

Table 6 The number of people in remission and the percentage of cohort in remission at Year 2 and Year 4 for the rheumatologist-only model of care, or rheumatologist and rheumatology nurse model of care.

	Remission (number of people)		Remission (percentage of cohort)	
	Year 2	Year 4	Year 2	Year 4
Rheumatologist only	572	377	34.9%	23.1%
Rheumatologist and nurse	938	759	39.1%	31.6%
Difference	367	382	4.2%	8.5%

Avoiding biological DMARD therapy

Early initiation of treatment results in lower rates of bDMARD therapy utilisation (Gremese et al. 2013). This is relevant as bDMARD therapy is expensive and associated with serious side effects (AIHW 2011).

In this analysis, rates of bDMARD therapy utilisation were lower in the cohort managed by the rheumatology nurse and rheumatologist, at 13.7% in the fourth year, as a result of the reduced proportion of patients experiencing treatment delays. In comparison 17.8% of the cohort managed by a rheumatologist only progressed to bDMARDs (Table 7).

Early initiation of treatment results in lower rates of bDMARD therapy utilisation.

Table 7 The proportion of patients in the traditional rheumatologist-only model of care or rheumatologist and rheumatology nurse model of care requiring bDMARD therapy in the four years modelled.

	bDMARD utilisation (percentage of cohort)			
	Year 1	Year 2	Year 3	Year 4
Rheumatologist only	21.9%	14.7%	14.7%	17.8%
Rheumatologist and nurse	18.0%	11.6%	11.6%	13.7%
Difference	3.9%	3.1%	3.1%	4.1%

How sensitive are these findings to changes in the assumptions?

To better understand the impact and generalisability of parameters and assumptions used in the economic model taken from or based upon the academic literature, a number of sensitivity analyses were performed to assess the overall impact on the model results. These include the impact of:

- increasing clinic costs for rheumatologist medical clinics, with and without rheumatology nursing, by 20%
- reducing the cost of bDMARD therapy by 20%
- reducing the effectiveness of early treatment at preventing escalation of pharmacological treatment to bDMARD therapy by 100%
- reducing the proportion of additional patients that are seen who are early presenters by 50%.

The results of these analyses show that the economic model is minimally sensitive to changing the costs of

medical clinics, with total costs increasing slightly in both models of care across all years and the difference between groups reducing slightly. The model is moderately sensitive to reduction of bDMARD therapy costs, with total costs reducing in both models of care across all years, and the difference between groups reducing moderately due to the higher rate of bDMARD use in the rheumatologist cohort. The model is moderately sensitive to reducing the effectiveness of early treatment, with total costs increasing in both models of care across all years. Reduced delays achieved in the rheumatologist and nurse model mean that this group is more sensitive to changes in this variable, increasing the difference in total costs and average costs in each year. The model is highly sensitive to reducing the proportion of the additional patients assumed to be early presenters that otherwise would not have been treated within three months of disease onset, with total costs increasing in the rheumatologist and nurse model of care across the second, third and fourth years.

What were the limitations of the economic analysis?

A number of additional costs and savings can be identified as being associated with differences in the amount and timing of care provided to people with inflammatory arthritis in the scenarios modelled. However, these were not quantified either because the necessary data to calculate the costs and savings were not available or it was beyond the scope of this study to model the impact. These additional costs and savings include the following:

- avoided surgery e.g. hip and knee joint replacements
- avoided emergency department presentations and hospital admissions
- reduced consumption of other medicines
- other reduced healthcare costs e.g. reduced need for GP and specialist consultations
- economic benefits associated with increased workforce retention and improved labour productivity
- reduced disability and welfare costs
- improved patient quality of life from a reduced burden of disease.

Given the chronicity of inflammatory arthritis and the long-term benefits of achieving early remission, it could be argued that the four-year time frame adopted for this analysis was too brief a period. This time period was used due to the absence of longitudinal empirical evidence regarding the costs and benefits associated with early or delayed access to treatment and accessing rheumatology nursing care.

It is also likely that as the role of rheumatology nurses has not been widely standardised or optimised, there may yet be greater benefits realised with better definition and recognition of the role.

Consequently, the analysis presented does not fully capture the future benefits and cost savings associated with improved access to care by those with inflammatory arthritis.

An additional limitation of this economic analysis is that much of the empirical evidence utilised for assumptions relating to care models, pharmaceutical costs and patient outcomes has been limited to studies examining rheumatoid arthritis, a subset of

inflammatory arthritis. Although rheumatoid arthritis is the most prevalent form, this approach may not adequately reflect variations in care and service provision for those with other forms of inflammatory arthritis.

These limitations point to the need for more robust data collections and trials to be conducted to better understand the impact of alternative inflammatory arthritis care pathways on associated longer term consumption of healthcare services and other economic impacts.

6. Conclusions

Internationally, models of care involving rheumatology nurses for people with severe and inflammatory forms of arthritis are considered best practice.

Evidence shows that rheumatology nurse care is effective and cost-effective and results in: better education and improved psychosocial support for patients; reduced delays in access to specialists; improved care coordination and continuity of care; reduced health system costs in primary and secondary care; and improved patient satisfaction.

The research and modelling undertaken for this report show that rheumatology nurses also provide these benefits in the Australian context. However, the current rheumatology nurse workforce in Australia is small and their role is poorly defined and recognised.

Implementing strategies to increase the rheumatology nurse workforce will help to support improved care and better outcomes for Australians living with severe and inflammatory forms of arthritis.

7. Recommendations for action

1. Define and recognise the rheumatology nurse role

- Rheumatology nurses in Australia currently have a varied range of responsibilities, meeting diverse needs in different circumstances, but their role is poorly defined and recognised.
- The range of activities performed by rheumatology nurses in Australia is consistent with international recommendations, encompassing education, chronic disease management, psychosocial issues, support for self-management and continuity of care.
- Basic, advanced and extended roles for rheumatology nurses should be defined, noting that the skills and competencies required will vary depending on the activities performed. The majority of the role and activities can be undertaken by appropriately qualified and experienced registered nurses without requiring additional regulation (i.e. do not require endorsement as a nurse practitioner)
- Roles and activities should align with the standards of practice for registered nurses except for those activities considered to be extended scopes of practice and requiring nurse practitioner endorsement, which should align with the standards of practice for nurse practitioners.
- Guidance should be provided to service providers and health professionals, e.g. through a template role or position description or the development of protocols and guidelines, to understand the spectrum of potential roles and activities a rheumatology nurse could perform. These templates should allow sufficient flexibility to adapt to local service needs.
- An education and training framework for rheumatology nurses should be developed, recognising that competencies and skills required will vary depending on the role and activities to be performed. The framework should:
 - map education and training requirements against the skills and competencies set out in template role descriptions developed for rheumatology nurses
 - reflect the contribution that both courses and on-the-job training under the supervision/guidance of a rheumatologist could provide

- identify existing training courses as well as education and training gaps and how these gaps can be addressed.

- The Rheumatology Health Professionals Association is well placed to lead activities to define and support the recognition of the rheumatology nurse role, in consultation with key stakeholders.

2. Support the introduction and optimisation of models of care including rheumatology nurses in public hospitals

- State and territory health departments should support increased staffing levels for rheumatology nurses in recognition of the improved patient outcomes and economic benefits that could be achieved from providing rheumatology nurse care for people with inflammatory arthritis in public hospitals.
- Models of care should be collaborative and team-based, with the primary focus on areas identified to provide the greatest value by consumers and carers, rheumatologists and rheumatology nurses:
 - people who have recently been diagnosed
 - people having a flare-up of their condition
 - people who are not coping emotionally.
- Timely access to a health professional they know is important to consumers and carers. Care delivery methods should be flexible, with consumers and carers indicating they are open to telehealth consultations (telephone, email, skype or other web-enabled video).
- Rheumatology departments in public hospitals may be supported to best utilise rheumatology nurses through:
 - understanding the spectrum of potential roles and activities registered nurses and nurse practitioners could have, together with their training pathways
 - case examples of public hospital models of care (outpatient and nurse-led clinics) that: reflect varying patient cohorts and geographical coverage; focus on areas where nurses can provide the greatest value; effectively and efficiently use telehealth in models of care and; demonstrate budgets feasibility.

3. Support the development of models of care including rheumatology nurses in the private sector

- Most rheumatology practice in Australia takes place in the private sector, whereas rheumatology nurses currently work predominantly in public hospitals.
- There is a need to identify and develop models of care, including funding models, that support increased utilisation of rheumatology nurses in the private sector.
- Developing the business case for rheumatology nursing in the private sector may encourage increased utilisation of nurses by rheumatologists in private practice. The business case should include case examples which highlight the spectrum of rheumatology nurse roles and activities and identify practice improvements that can be achieved.
- The potential for Primary Health Networks and Local Hospital Districts to support increased access to rheumatology nursing care for people with inflammatory arthritis within their district should be explored. This could have particular application in rural areas, where a nurse-supported clinic similar to the Albany clinic operating in Western Australia, could be established to support existing or new rheumatologist outreach clinics.

4. Support the introduction and optimisation of models of care with rheumatology nurse practitioners

- The Commonwealth Department of Health and state/territory health departments should recognise the potential for nurse practitioners to address the care needs of patients with inflammatory arthritis:
 - Current challenges in meeting care needs in rural and remote areas are expected to worsen in future due to a growing workforce shortage of rheumatologists, projected increases in arthritis prevalence, an ageing workforce and changes in work practices.
 - Despite international evidence consistently demonstrating that care by nurse practitioners results in processes and outcomes that are either equivalent to or better than those achieved by doctors, nurse practitioners are not being used in Australia to their optimum capacity.

The diversity of nurse practitioner roles is impeding progression of their role overall. Implementation of models of care involving nurse practitioners needs profession and system level support.

- A rheumatology model of care outside the hospital environment needs to be developed that utilises the skills that are unique to nurse practitioners (i.e. the extended role beyond registered nurse roles). Opportunities through various settings should be explored, including public hospital outreach services and primary care, linking with the needs analyses of Primary Health Networks and Local Hospital Districts, and work being undertaken at regional levels on condition-specific HealthPathways.
- It was reported that pursuing endorsement as a nurse practitioner in Australia could be onerous and expensive, creating a disincentive for nurses to seek these additional qualifications. If the nurse practitioner workforce is to be expanded, support needs to be provided for registered nurses to achieve endorsement as a nurse practitioner.

Glossary

The following descriptors have been developed from the information sheets available from Arthritis Australia at www.arthritisaustralia.com.au

Term	Descriptor
Ankylosing spondylitis	Ankylosing spondylitis is a chronic systemic inflammatory condition affecting predominantly joints and ligaments of the spine. As acute inflammation settles, calcium is laid down where the ligaments attach to the vertebrae, making the back less flexible, eventually resulting in fusion of vertebrae. Inflammation and calcification of joints results in pain and difficulty moving.
bDMARD	Biological DMARDs (bDMARDs) are a specific group of DMARDs that block certain substances in the blood and joints that cause inflammation.
DMARD	A range of medicines that are known as disease-modifying anti-rheumatic drugs. These drugs help to reduce joint damage and relieve symptoms.
Fibromyalgia	Fibromyalgia is a chronic condition commonly causing muscular pain, joint pain and fatigue. Fibromyalgia is not inflammatory or degenerative meaning that it does not cause permanent damage to the muscles, bones or joints.
Gout	Gout is a common and painful condition in which small crystals form in and around a joint, causing inflammation, pain and swelling. These crystals are made of one of the body's normal waste products, uric acid.
Inflammatory arthritis	Inflammatory arthritis is a group of conditions characterised by inflammation of the joints, or synovium. Joint inflammation results in pain, functional impairment and disability and can cause permanent joint damage.
Juvenile idiopathic arthritis	Juvenile idiopathic arthritis describes a variety of subtypes of arthritis that are diagnosed before the age of 16. Juvenile idiopathic arthritis can result in severe activity limitation with long lasting impacts due to its effects during growth and development.
Osteoarthritis	Osteoarthritis is a condition affecting the cartilage or surfaces within joints. This damage results in the cartilage breaking down, causing pain, swelling and difficulty moving the joints. Although often referred to as "wear and tear" arthritis, osteoarthritis is a disease and not an inevitable part of the ageing process.
Psoriatic arthritis	Psoriatic arthritis is an auto-immune disease that causes painful inflammation in and around the joints and usually affects people who already have psoriasis.
Rheumatoid arthritis	Rheumatoid arthritis is an auto-immune disease in which the immune system attacks the body's own tissues, causing inflammation of the joints. It is the most common inflammatory arthritis condition and also the most common auto-immune disease.
Scleroderma	Scleroderma affects the connective tissues of the body (tissues that hold together joints, muscles, blood vessels and internal organs). The connective tissues of people with scleroderma have too much collagen, causing hardening and tightening of the affected area.
Sjögren's syndrome	Sjögren's syndrome is a chronic auto-immune condition that mainly causes dryness of the mouth and eyes. Sjögren's disease can cause inflammation in other areas of the body including the joints, leading to pain and fatigue.
Systemic lupus erythematosus (SLE)	Systemic lupus erythematosus (SLE) often known just as lupus, is an auto-immune disease in which the immune system attacks the body's own tissues, causing inflammation. This can affect various parts of the body including the joints, leading to pain and fatigue.

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