



Australian Healthcare and Hospitals Association

Literature Review

Rheumatology nurses: Adding value to arthritis care

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Executive Summary

The purpose of this literature review is to assess the evidence relating to the value and benefits of rheumatology nurses for consumers, health care practitioners and the health system. It provides the background for a report by the Australian Healthcare and Hospitals Association on the scope, activities, benefits and costs of rheumatology nurses in the management of chronic inflammatory arthritis in Australia.

The review is based on a search of academic databases and grey literature conducted during January and February 2017 to retrieve articles related to rheumatology nursing.

The results of the literature review indicate that around 1.7 million Australians are living with chronic inflammatory forms of arthritis and related conditions (Ackerman et al. 2016). The research also demonstrates that nurses with specific training or experience in rheumatology have an important role to play in improving care outcomes for people living with these conditions.

The benefits of care provided by rheumatology nurses have been shown to include: better patient education; 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 economic impact of inflammatory arthritis is considerable. Rheumatology nurses working in expanded roles have been shown to provide cost effective models of care.

In recent years, models of care, scope of practice descriptions, standards of practice and educational requirements for rheumatology nurses have become established internationally, but the rheumatology nurse role is new and in the early phases of development in Australia.

Inflammatory arthritis usually requires specialist care but access to rheumatologists is limited in many parts of Australia, especially in rural and remote areas and waiting lists for appointments can be lengthy.

There is considerable scope for rheumatology nurses to assist in addressing these workforce issues, especially around their role in early assessment, timely diagnosis, and cost effective service delivery.

Rheumatology nurses can play a crucial role in how the health outcomes of people with chronic inflammatory arthritis in Australia are managed and can make a considerable impact on the rheumatology workforce of the future.

1. Overview

1.1 Introduction

The [*Time to Move: Arthritis*](#) strategy recommends increasing the rheumatology nurse workforce in Australia to enhance education and support for people with inflammatory arthritis, including in rural and regional areas, and to assist in improving timely access to rheumatologists.

While the benefits of rheumatology nurses overseas are well documented, little is known about the rheumatology nurse workforce in Australia and its value in this context.

This literature review identifies evidence for the potential benefits of increasing the rheumatology nurse workforce from the perspective of consumers, rheumatologists and general practitioners as well as the health system more broadly.

It provides the background and academic context for a report on the scope, activities, benefits and costs of rheumatology nurses in the management of chronic inflammatory arthritis in Australia.

1.2 Background

There are several forms of chronic, inflammatory arthritis. These painful and debilitating conditions include rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis, gout, juvenile arthritis, and lupus. These conditions cause fatigue, stiffness, reduced mobility, joint damage and deformity. They are among the most common causes of disability (Ackerman et al. 2016; Australian Bureau of Statistics, 2015) in Australia.

Early diagnosis and timely access to specialists for treatment (ideally within 12 weeks of symptom onset) are paramount for many of these conditions to prevent or delay irreversible joint damage, deformity and disability (Lukas et al. 2011; van der Linden et al. 2010). Yet access to rheumatologists is limited in many parts of Australia, especially in rural and remote areas, and waiting lists for appointments can be lengthy (Ackerman et al. 2016).

Treatment for inflammatory arthritis is complex and the medication can cause major side effects which require careful monitoring. In addition, many people are diagnosed with the condition whilst they are relatively young. Many struggle with the prospect of life with a painful, progressive and potentially disabling condition. Many people with inflammatory arthritis do not receive adequate education and support to help them deal with the physical and psychological impact of their condition and its complex management.

Internationally, rheumatology nurses are playing an increasing role in delivering care, with benefits including improved patient outcomes, faster access to specialists and reduced costs in both primary and specialist care (van Eijk-Hustings et al. 2012; van den Hout et al. 2003).

In Australia, however, it is estimated that there are only about 50 rheumatology nurses.

1.3 Aims

The aim of the desktop review is to provide a synthesis of published and grey literature that assists with identifying the value and benefits of rheumatology nurses for consumers, health care practitioners and the health system, and the implications of these findings for the Australian context.

1.4 Definitions

Inflammatory arthritis is a group of conditions involving inflammation of the joints and often other tissues. Many forms of inflammatory arthritis are auto-immune conditions. This review focused on the major forms of inflammatory arthritis that contribute most to the total disease burden in Australia, including rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis and juvenile idiopathic arthritis (JIA) (Department of Health Western Australia [DHWA] 2009).

1.5 Limitations

For arthritis and other musculoskeletal conditions, prevalence data are often reported under the broader category of musculoskeletal conditions, rather than the specific conditions themselves. Due to small sample sizes, it is generally not possible to obtain reliable data estimates for the less common forms of inflammatory arthritis, including ankylosing spondylitis and psoriatic arthritis.

There may be inconsistencies regarding the classification of inflammatory conditions in some consumer surveys cited. This may have an impact on the quality of the outputs. The use of rheumatism, a catch-all term that means different things to different people, may cause confusion and influence participant reporting.

1.6 Methods

This literature review is 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 Medline, CINAHL, and the various journal publishers' online sites.

Titles and abstracts of publications identified through the search strategy were reviewed to select material relevant to the research questions. Particular weighting was given to studies such as major reviews and evaluations, systematic reviews and to studies deemed widely cited and influential.

Database titles and abstracts were reviewed and articles were excluded if they did not relate to inflammatory arthritis or were opinion articles that did not make significant scholarly contributions.

Specific rheumatology journals were consulted. These included Arthritis and Rheumatology Journal, Annals of the Rheumatic Diseases, Rheumatology, Arthritis Care and Research, Best Practice and Research in Clinical Rheumatology and Paediatric Rheumatology. European League Against Rheumatism (EULAR) and American College of Rheumatology abstracts were also reviewed.

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, related government departments and other publications. Much of the data in the Australian context was sourced from the grey literature.

Open Google searching, a hand search of the literature and investigation of social media uncovered further information.

1.7 Organisation

This review is organised around key research themes and questions, and the implications the results may have for service provision.

The key research questions are:

- What is the prevalence of inflammatory arthritis across Australia? What is the distribution by geographical location, age and population groups?
- What are the trends in inflammatory arthritis morbidity and mortality in Australia?
- What is the economic impact of inflammatory arthritis in Australia?
- What are the models of care, scope of practice, standards of practice and educational requirements for rheumatology nurses in Australia?
- What are the models of care, scope of practice, standards of practice and educational requirements for rheumatology nurses internationally?
- What is known about the number and characteristics of rheumatology nurses and their distribution across Australia?
- What is the evidence relating to the benefits of rheumatology nursing care for people with arthritis?
- What evidence exists for nurses in extended roles in other disciplines?

2. Results

2.1 Inflammatory arthritis in Australia

What is the prevalence of inflammatory arthritis across Australia? What is the distribution by geographical location, age and population groups?

There are several types of inflammatory arthritis, including rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis and JIA. Rheumatoid arthritis is the most common form of inflammatory arthritis, and the most common autoimmune disease in Australia (Australian Institute of Health and Welfare [AIHW] 2005).

Prevalence

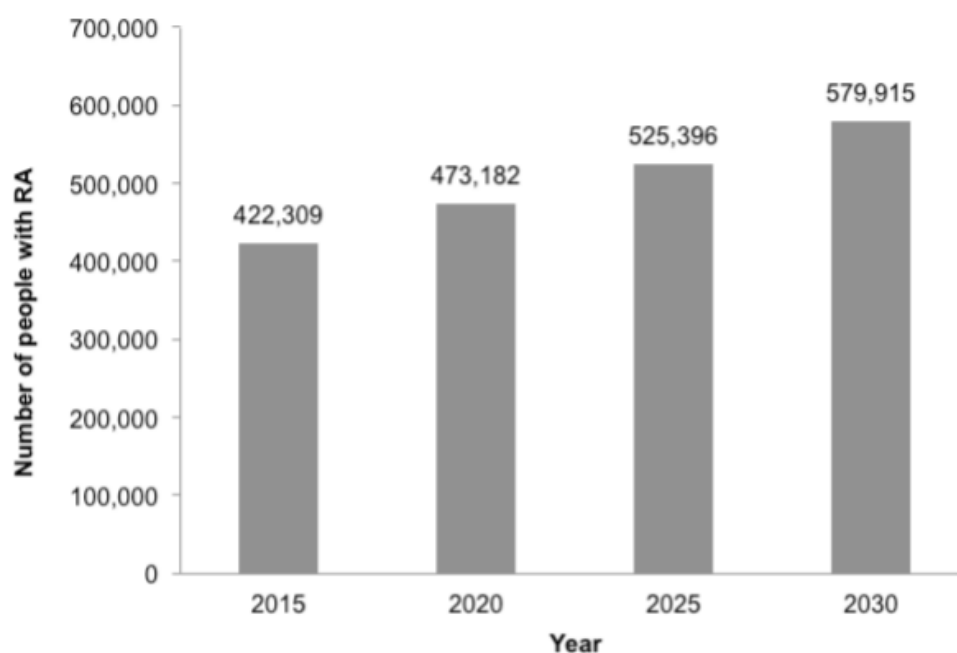
The Australian Institute of Health and Welfare (AIHW) reports that about 407,900 Australians (2% of the total population) have rheumatoid arthritis, based on self-reported data from the ABS 2014–15 National Health Survey (NHS) (AIHW 2016).

There are approximately 1.7 million Australians with various inflammatory forms of arthritis, such as ankylosing spondylitis, psoriatic arthritis and juvenile arthritis. There has been little reported change in the prevalence of these conditions over the past 10 years (Ackerman et al. 2016). However Australian prevalence data for specific types of inflammatory arthritis, other than rheumatoid arthritis, are not available.

The main factors influencing prevalence are population ageing and exposure to risk factors (AIHW 2008b). The prevalence of arthritis (including osteoarthritis, rheumatoid arthritis and other forms of arthritis) increases steadily across life stages (from less than 1% in children aged 0–15 to 19% in people aged 35–64 and 51% in those aged 80 or over) (AIHW 2014a).

6,000 Australian children are estimated to have JIA (Ackerman et al. 2016). There are no established national data about the incidence of juvenile arthritis in Australia and because of the absence of a disease registry, determining the exact prevalence of the condition is difficult (AIHW 2008a).

The prevalence of rheumatoid arthritis in Australia is projected to increase from 422,309 people to 579,915 people between 2015 and 2030 (Figure 1) (Ackerman et al. 2016).

Figure 1 Projected national prevalence of rheumatoid arthritis to 2030 (Ackerman et al. 2016)

The number of children affected by JIA is expected to increase by 22% between the years 2015 and 2030, with an additional 1,328 children and adolescents with JIA in Australia by 2030.

Geographical distribution

While Australians living in rural and remote areas generally experience poorer health than their major city counterparts, variation in the prevalence of rheumatoid arthritis across urban, regional and remote location is not statistically significant (AIHW 2010a).

All states and territories of Australia will experience an increase in the number of people with rheumatoid arthritis between 2015 to 2030, and the projected distribution by state or territory is shown in Table 1.

Table 1 Projected prevalence of rheumatoid arthritis to 2030, by state or territory (Ackerman et al. 2016)

State	2015	2020	2025	2030	Difference (2015-2030)	% change (2015-2030)
ACT	7,166	7,992	8,779	9,639	2,473	34.5%
NSW	29,633	33,289	37,127	41,125	11,492	38.8%
NT	3,177	3,684	4,158	4,646	1,469	46.2%
QLD	96,786	109,839	122,991	136,790	40,004	41.3%
SA	40,493	43,260	45,783	48,495	8,002	19.8%
TAS	18,879	20,071	20,858	21,731	2,852	15.1%
VIC	133,628	150,448	167,683	187,273	53,645	40.1%
WA	31,428	36,130	40,909	47,132	15,704	50.0%

Indigenous Australians, of whom 70% live outside Australia's capital cities, are 1.92 times more likely to have rheumatoid arthritis than non-Indigenous people (National Rural Health Alliance 2014).

Age

The onset of rheumatoid arthritis most frequently occurs between the ages of 35–64 (Table 2).

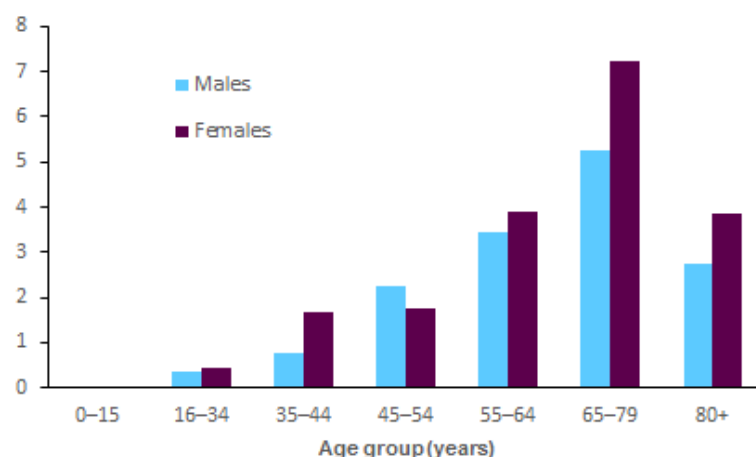
Table 2 Age when first diagnosed, 2004-05 (AIHW 2009)

(% of people diagnosed with rheumatoid arthritis in each age bracket)

Age group	Males	Females
0–14	1.3	3.2
15–24	6.1	8.4
25–34	8.9	14.1
35–44	22.4	22.8
45–54	21.8	22.3
55–64	24.3	20.1
65–74	11.4	7.0
75 and over	3.4	2.2

The prevalence of rheumatoid arthritis increases with age (AIHW 2010a); a feature common to many chronic diseases. While young people can be affected by rheumatoid arthritis, and the condition can develop at any age, it is more common in the older population (less than 1% in people aged 16–34 compared with 6% in people aged 65 or over) (AIHW 2014a). It is least common among those aged 0–15 (Figure 2).

Figure 2 Prevalence of rheumatoid arthritis by age and sex, 2014-15 (AIHW 2016)
Per cent

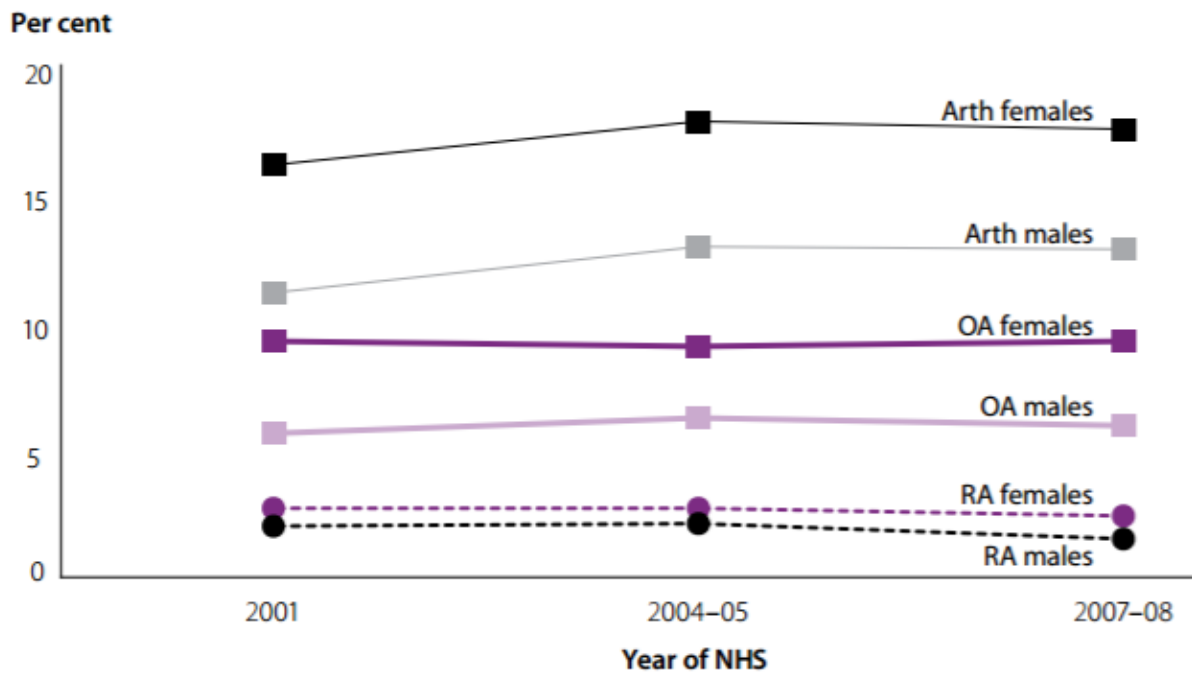


Source: AIHW analysis of ABS Microdata: NHS, 2014–15 ([Data table](#)) (AIHW 2014b).

Sex

Arthritis occurs more commonly in females than males, with the exception of the 45-54 age group (Figure 3) (AIHW 2005). Gender has an influence on the development of inflammatory arthritis (Ngo et al. 2014). Female androgen deficiency and prolactin excess may explain its higher incidence in females, and the postpartum period can be a high-risk time for developing first symptoms (AIHW 2005).

Figure 3 Trends in the prevalence of arthritis by sex, 2001 to 2007–08 (AIHW 2010a)

**Notes**

1. Based on self-reports of having a doctor's diagnosis of the type of disease.
2. OA, osteoarthritis; RA, rheumatoid arthritis; Arth, arthritis (all types).

Source: AIHW analysis of ABS National Health Survey CURFs.

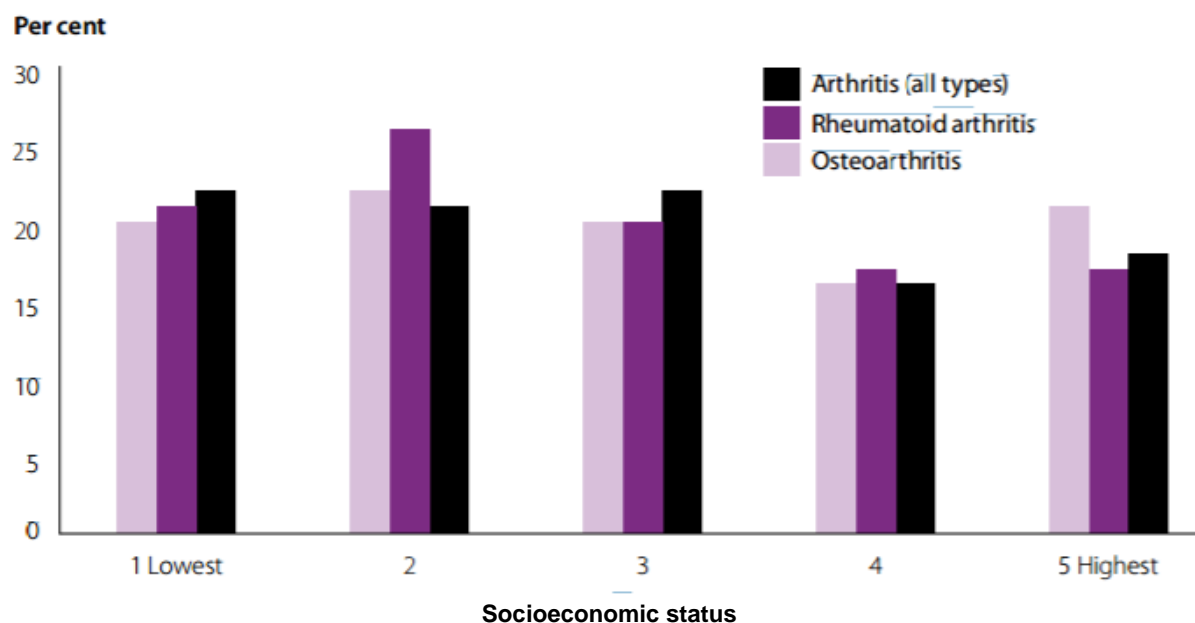
Socioeconomic status

Lower socioeconomic status (SES) is associated with a higher prevalence of chronic disease and its associated risk factors (AIHW 2010a), and there is evidence that some socioeconomic factors influence the prevalence of arthritis (Bates et al. 2014).

Individuals of lower SES have a lifestyle that is less protective against all forms of arthritis. This includes reduced levels of physical activity, higher levels of obesity, and a greater likelihood of smoking (Bates et al. 2014).

Figure 4 demonstrates the higher prevalence of all forms of arthritis for those living in low SES areas in 2007–08 (AIHW 2010a).

Figure 4 Prevalence of arthritis by socioeconomic status, 2007–08



Note Socioeconomic status based on the ABS Index of Relative Socioeconomic Disadvantage (ABS 2009b).

Source: AIHW analysis of ABS 2007–08 National Health Survey CURF.

Note: The x-axis label has been corrected from the original source.

Burden of disease

Burden of disease analysis measures the combined impact of living with illness and injury (non-fatal burden) and 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, ranked second to mental health and substance disorders which account for 24% of the non-fatal burden (AIHW 2017a).

Rheumatoid arthritis accounted for 1.9% of the total burden of disease and 3.6% of the non-fatal burden of disease in Australia. Further, '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 of disease in Australia (AIHW 2017a).

Rheumatoid arthritis alone accounted for 16% of the non-fatal burden attributed to musculoskeletal conditions. In 2011 it resulted in 81,036 years of life lived with disability (AIHW 2017a). 'Other musculoskeletal conditions' (which includes inflammatory forms of arthritis and related rheumatic conditions) accounted for 34% of the non-fatal burden attributed to musculoskeletal conditions. In 2011 these resulted in 173,106 years of life lived with disability (AIHW 2017c).

The category of 'other musculoskeletal conditions' is the leading cause of total disease burden in women aged 45–65 years and the fourth leading cause of disease burden in women aged 25–44 years (AIHW 2017a).

Risk factors

In the context of risk factors, arthritis includes osteoarthritis, rheumatoid arthritis and other arthritic conditions as self-reported in the Australian Bureau of Statistics (ABS) NHS 2011–12 (AIHW 2015).

According to the NHS, people with arthritis were more likely to be current smokers, physically inactive and obese, compared to those without arthritis.

Non-modifiable risk factors include age, gender and genetic predisposition.

Cigarette smoking

Smoking is the main modifiable risk factor associated with rheumatoid arthritis specifically. 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 rheumatoid arthritis. Smoking cessation appears to reduce the risk of developing the condition over time (AIHW 2015).

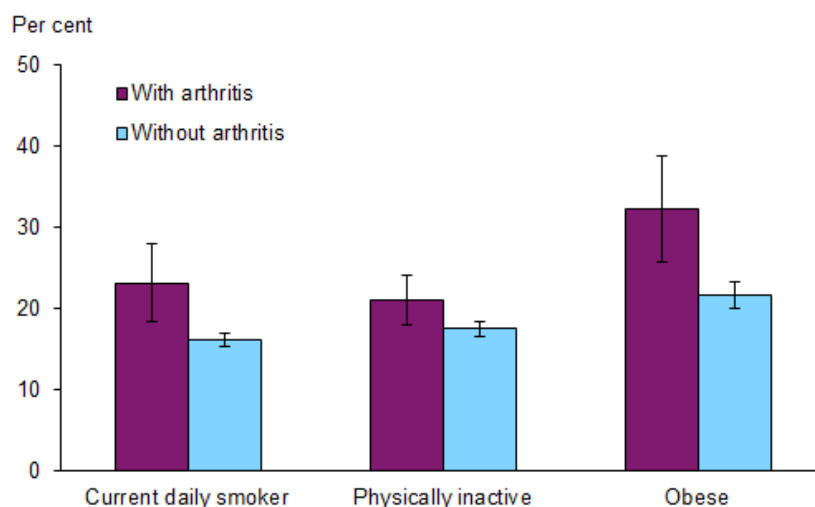
Body mass index

Obesity is a risk factor for development of arthritis and body mass index (BMI) is linearly positively associated with rheumatoid arthritis risk (Feng et al. 2016), particularly for women (AIHW 2015).

Physical inactivity

People with arthritis, including osteoarthritis, rheumatoid arthritis and other arthritic conditions are less likely than people without arthritis to report engaging in recommended levels of moderate or vigorous physical activity (AIHW 2015). Physical activity can help minimise pain, improve function and reduce disability associated with all forms of arthritis. Additionally, physical activity can help people with arthritis manage other chronic conditions such as diabetes, heart disease, and obesity (AIHW 2015).

Figure 5 Prevalence of risk factors in people with and without arthritis, 2011–12 (AIHW 2015)



Notes:

1. Rates are age-standardised to the Australian population as at 30 June 2001.
2. The thin vertical lines attached at the end of each bar are 95% confidence intervals. We can be 95% confident that the true value is within this confidence interval.

Source: AIHW analysis of unpublished ABS 'Australian Health Survey, 2011–12 (National Health Survey Component). [Source data](#)

Few studies that addressed compliance with reducing modifiable risk factors in people with inflammatory arthritis in Australia were found (Commonwealth Department of Health [CDH] 2010).

Patient self-management

People with arthritis and musculoskeletal conditions are major users of complementary and alternative medicines, with around 60% of people trying a range of products in an effort to gain relief from pain. Of these, around 60% take omega-3 fish oils and glucosamine while about 13% take chondroitin (Arthritis Australia 2014).

What are the trends in inflammatory arthritis morbidity and mortality in Australia?

There are limited Australian data on morbidity and mortality related to specific forms of inflammatory arthritis other than rheumatoid arthritis. Consequently most data presented in this section focus on rheumatoid arthritis.

Mortality

In Australia, arthritis is not commonly recorded as a cause of death. For the almost 148,000 deaths in Australia in 2013, lupus, rheumatoid arthritis and gout/inflammatory conditions were identified as the underlying cause in 245, 194, and 45 deaths, respectively (AIHW 2016a).

Rheumatoid arthritis and its treatments increase the risk of premature mortality. The survival rate for people with rheumatoid arthritis is estimated to be lower than for those without the disease. While the condition is not commonly the direct cause of death, it is a contributing cause of death (AIHW 2005).

There is excess mortality in patients with rheumatoid arthritis, but no long term cohort data is noted (Lassere et al. 2013).

Although rheumatoid arthritis has a much lower prevalence in the population than osteoarthritis, it contributes relatively more to mortality. The systemic nature of the disease accounts for these increased contributions (AIHW 2010a).

Table 3 demonstrates that in 2013, inflammatory forms of arthritis were associated with over 3,000 deaths. Rheumatoid arthritis was listed as an associated (but not primary) cause of death in 723 cases while gout and other inflammatory arthropathies were associated with 485 deaths and lupus and other connective tissue disorders with 450 deaths.

Table 3 Top 6 musculoskeletal conditions reported as associated causes of death, 2013 (AIHW 2016a)

Associated cause of death	Number	% ^(a)
Osteoporosis	1,689	29
Osteoarthritis	1,558	27
Rheumatoid arthritis	723	13
Back problems	512	9
Gout and other inflammatory arthropathies	485	8
Lupus and other connective tissue disorders	450	8
Other musculoskeletal conditions	1,252	22
Total deaths with musculoskeletal conditions listed as an associated cause^(b)	5,782	100

(a) Proportion of all musculoskeletal deaths listed as an associated cause of death.

(b) The total number of deaths where one or more musculoskeletal conditions were listed as an associated cause of death.

Note: Components will not sum to total, as one death can have more than one musculoskeletal condition as an associated cause of death.

Source: AIHW National Mortality Database.

Morbidity

Inflammatory arthritis is a chronic, inflammatory condition that can cause considerable morbidity, joint damage, early disability and premature mortality. Disability associated with inflammatory arthritis is substantial, and can have a serious impact on quality of life (AIHW 2005). The AIHW notes the difficulty in quantifying morbidity related to specific musculoskeletal conditions (for example, arthritis compared with other musculoskeletal conditions) (AIHW 2014b).

Inflammatory arthritis has a major impact on quality of life, with pain, fatigue, joint damage and loss of function affecting a person's mobility and ability to undertake daily activities. While specific figures for inflammatory arthritis are not available, arthritis is the second most common cause of disability in Australia (Arthritis Australia 2014).

Early assessment and diagnosis

Early treatment is central to the current treatment paradigm. Early diagnosis and medical intervention is critical to improving outcomes in people with inflammatory arthritis (AIHW 2009). Early treatment with disease modifying therapy can reduce joint damage, slow disease progression and improve long-term outcomes. However, specialised clinical and diagnostic skills are needed to identify early rheumatoid arthritis (CDH 2010).

Education

Education to help people self-manage their inflammatory condition plays an important role in achieving optimal outcomes (AIHW 2009). Patient education is an effective component of disease management (AIHW 2009).

With self-management for chronic illness increasingly being seen as an important component of primary care, evidence from controlled clinical trials suggests that self-management programs are more effective than information-only patient education in improving clinical outcomes (Arthritis and Osteoporosis Victoria [AOV] 2015).

Treatment delay

A treatment delay of more than 12 weeks from symptom onset can negatively affect treatment response in rheumatoid arthritis. Assessment in less than 12 weeks is associated with reduced joint destruction and a higher chance of achieving remission as compared with a longer delay in assessment (van der Linden et al. 2010).

Inadequate disease control

Advances in diagnosis and management have not occurred consistently across all types of arthritis. For ankylosing spondylitis, as compared with rheumatoid arthritis for example, there are no current treatments that have been shown to lead to disease remission or to halt the progression of the bony ankyloses that causes the major morbidity associated with the condition. However, improved diagnostic methods and management have led to major benefits for patients, with marked improvements in quality of life. The authors highlight the role of specialist rheumatology nurses and nurse practitioners in the management of this condition, including patient education and monitoring of disease activity and impact on activities of daily living (Brown & Bradbury 2017).

A cross-sectional assessment of a large cohort of Australian rheumatoid arthritis patients found a large proportion remain in moderate or high disease activity despite receiving therapy (Littlejohn et al. 2013).

Physical activity

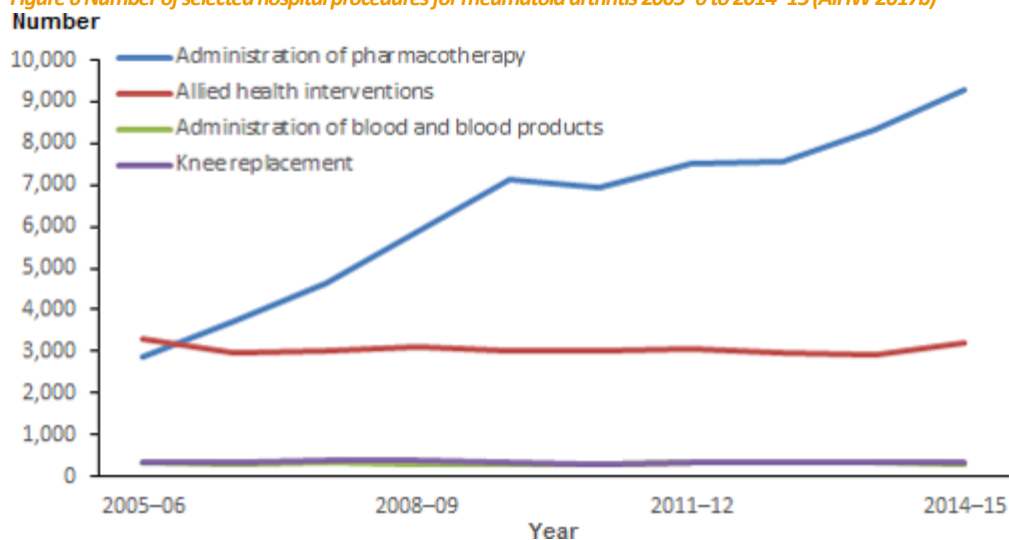
Exercise is crucial in maintaining joint movement and muscle strength for people with arthritis (AIHW 2009). Exercise programs can achieve statistically and clinically important improvements in pain and physical function in people with inflammatory conditions.

The activities do not need to be targeted to a particular type of arthritis in order to be effective (Arthritis Australia 2014). Therapies such as strength training, massage and water-based exercise have been found to be beneficial in reducing joint pain and swelling (AIHW 2009).

Hospitalisation

In 2014–15, a total of 19,037 procedures and other interventions were recorded for people who had a principal diagnosis of rheumatoid arthritis. There were more procedures than hospitalisations, as a person may have more than one procedure performed during their hospital stay. Most procedures (49%) were for administering drug treatments, which rose by over 200% between 2005–06 and 2014–15, followed by allied health interventions such as physiotherapy, occupational therapy or dietetics (17%) (Figure 6) (AIHW 2017b).

Figure 6 Number of selected hospital procedures for rheumatoid arthritis 2005–6 to 2014–15 (AIHW 2017b)

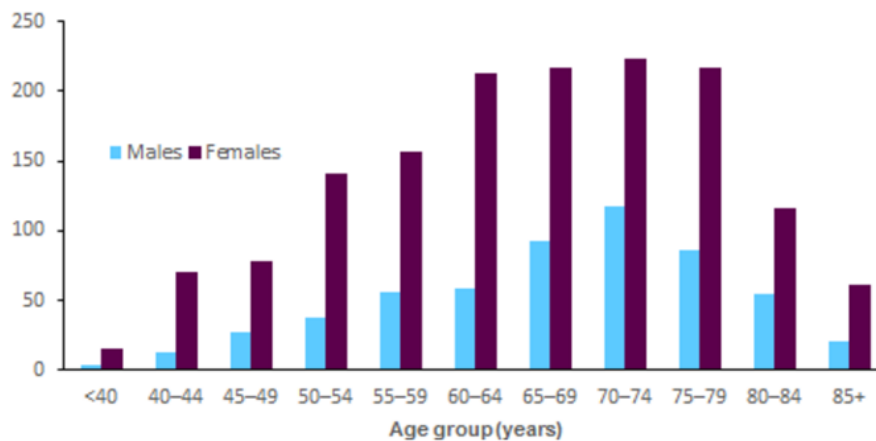


Source: AIHW National Hospital Morbidity Database ([Data table](#)).

Data from the AIHW National Hospital Morbidity Database show that, in 2014–15:

- there were 11,982 hospitalisations with the principal diagnosis of rheumatoid arthritis
- the hospitalisation rate for females (76 per 100,000 population) was 3 times that of males (25 per 100,000)
- the hospitalisation rate increased with age until the age of 70–74 (Figure 7).

Figure 7 Rate of hospitalisation for rheumatoid arthritis, by sex and age, 2014–15
Hospitalisations per 100,000 population



Non-inpatient hospital care

There is a lack of hospital outpatient and private practice data available which reliably captures the use of all rheumatology services because most accurate data relates only to inpatient care and arthritis is most commonly treated in the outpatient setting or private practice clinics (DHWA 2009).

Economic impact

What is the economic impact of inflammatory arthritis in Australia?

The economic impact of arthritis is reported to be substantial by all studies reviewed, particularly in terms of morbidity, long-term disability and cost.

Arthritis and other musculoskeletal conditions constitute a major public health concern, placing a high economic burden on the community (AIHW 2014a). In terms of the health and welfare systems, arthritis costs Australia more than \$6.6 billion annually, and this is projected to rise to \$9.1 billion annually by 2030 (Ackerman et al. 2016). Healthcare costs for rheumatoid arthritis alone are estimated at more than \$550 million annually and are predicted to rise to more than \$755 million by 2030 (Arthritis Australia 2016). This equates to \$1,303, on average, for every person with the condition (Ackerman et al. 2016). A substantial share of this expenditure is accounted for by prescription medicines (\$273.6 million or 86% of the total) (AIHW 2010a).

The main bearers of arthritis costs are the people with the condition. It is estimated that they bear 61% of the total cost. The Federal Government is the second biggest cost bearer, a consequence of funding health system expenditures on arthritis and also bearing the lost taxation revenues associated with the considerable productivity losses which arise (Access Economics 2007).

Arthritis affects society in numerous ways, including reduced workforce participation, increased costs of managing the condition, and increased impacts on carers. Arthritis is the second leading cause of early retirement due to ill-health in Australia. The associated cost of additional welfare payments and lost tax revenue in 2015 were estimated at \$635 million and \$458 million respectively (Schofield, Shrestha & Cunich 2016).

Work disability associated with rheumatoid arthritis is extensive and costly (Shanahan et al. 2008b). It occurs relatively early in the disease and is associated with several identifiable variables, many of which may be amenable to intervention. Many studies note that people with arthritis may reduce

their work hours or change their employment arrangements to accommodate their condition. Others leave the workforce entirely if their condition is severe. All of these scenarios translate to lost income over the lifespan.

A cross-sectional study of 497 working age people with rheumatoid arthritis found that when standardised, the income of the cohort was 66% that of the average income of the Australian population. Overall, one third relied principally on the social security system, and more than 75% estimated they had lost greater than \$10,000 per annum in personal income as a result of their disease. Individuals with rheumatoid arthritis who were not working had annual incomes on average of more than \$20,000 less than those who continued to work. The personal income loss in Australia is of enormous significance (Shanahan et al. 2008a).

There is a considerable financial burden from the cost of GP and specialist visits, diagnostic tests, pharmaceuticals, dietary supplements or natural therapies and consultations with allied health professionals. In severe cases, people may require high level residential aged care services and hospital services. There can also be substantial indirect costs (AIHW 2009).

There may also be a financial impact on family members, as people often require the daily assistance of a carer (AIHW 2009).

The costs of healthcare for rheumatoid arthritis are expected to increase in all states, in concert with population growth. As shown in Table 4, the largest absolute increase in healthcare costs for rheumatoid arthritis is forecast for Victoria (increase of \$82 million), followed by Queensland (increase of \$61 million) (Ackerman et al. 2016).

Table 4 Projected healthcare costs for rheumatoid arthritis to 2030, by state or territory (Ackerman et al. 2016)

State	2015	2020	2025	2030	Difference (2015-2030)	% change (2015-2030)
ACT	10.92	12.18	13.38	14.69	4	34.5%
NSW	45.15	50.72	56.57	62.66	18	38.8%
NT	4.84	5.61	6.33	7.08	2	46.3%
QLD	147.48	167.37	187.41	208.44	61	41.3%
SA	61.70	65.92	69.76	73.89	12	19.8%
TAS	28.77	30.58	31.78	33.11	4	15.1%
VIC	203.62	229.25	255.51	285.36	82	40.1%
WA	47.89	55.05	62.34	71.82	24	50.0%

*All costs reported in \$000,000.

While the advent of biological disease modifying anti-rheumatic drugs (bDMARDs) has changed the management of inflammatory arthritis, these first-line treatments that can alter the disease course and reduce joint erosion are costly. Taking into account the costs for bDMARDs, healthcare costs for rheumatoid arthritis are projected to rise to over \$755 million by the year 2030 (AOV 2013).

In 2012-2013, the Australian Government paid \$6.39 million in pharmaceutical benefits for biologics used to treat JIA (AOV 2013). The total cost to the health system of treating all children with JIA according to a best practice model of care equates to approximately \$40.3 million dollars per year. By 2030 (with an estimated 7,334 children affected by JIA), this will equate to a cost of nearly \$49.2 million per year (Ackerman et al. 2016).

2.2 Models of care for inflammatory arthritis in Australia

What are the models of care, scope of practice, standards of practice and educational requirements for rheumatology nurses in Australia?

Data collection regarding rheumatology nursing in Australia is scarce. AIHW National Health Workforce Data Sets about workforce status and principal role do not collect specific information about nurses working in rheumatology.

However, database searching and open internet searching indicates that some hospitals, and to a lesser extent, specialist rheumatologists across Australia employ staff in a rheumatology nursing role. Variation in the implementation of this role is evident and scope of practice appears to differ across contexts.

General practitioners

GPs are usually the first point of contact with the health system for people with chronic conditions, and their role in the diagnosis and early management of rheumatoid arthritis and other inflammatory forms of arthritis is critical.

It is being increasingly recognised that disease modifying antirheumatic drug therapy should be commenced early to arrest progressive disease and joint destruction (Ndosi 2010). Appropriate early referral from the GP to a specialist rheumatologist is also essential.

However, there is currently no nationally consistent primary health care data collection monitoring provision of care by GPs (AIHW 2017d). Bettering the Evaluation and Care of Health (BEACH) data from April 2011 to March 2013 indicates that rheumatoid arthritis was managed by GPs at a rate of four in every 1000 encounters, and made up 0.2% of all problems managed (Charles et al. 2013).

More than 4 out of 10 people in Australia with rheumatoid arthritis reported that they consulted a GP or a specialist for their condition in the 12 months before the 2007–08 National Health Survey. This equated to an estimated 186,000 people seeking treatment (AIHW 2010b).

There are insufficient GPs, particularly in outer metropolitan and country areas, and patients have difficulty seeing them promptly. Poor access to GPs and the need for a primary care referral to access specialists make it difficult for patients to access appropriate specialist expertise (DHWA 2009).

With GPs bearing a considerable burden in making timely, rapid diagnoses and referrals, there may be scope for specialised rheumatology nurses to undertake tasks around the initiation of multidisciplinary care and provide patient and information support.

In addition, GPs may be less familiar with biologic DMARDs for inflammatory arthritis as they are unable to prescribe these medications, so rheumatology nurses can provide a contact point for information and advice about the management of these medicines.

Specialist rheumatology physicians

The Royal Australasian College of Physicians describes rheumatologists as specialist physicians with particular expertise in the diagnosis and holistic management of diseases that affect joints, muscles, and bones. Their training curriculum covers all forms of arthritis, autoimmune connective tissue disease, spinal and soft tissue disorders and certain metabolic bone disorders, such as osteoporosis

and chronic musculoskeletal pain syndromes. Key aspects of their clinical practice are the management of pain, reduction of inflammation, and preservation of musculoskeletal function (The Royal Australasian College of Physicians 2013).

The Royal Australian College of General Practitioners (RACGP) recommends that patients with symptoms indicative of inflammatory arthritis that persist beyond 6 weeks be referred to a rheumatologist to enable early initiation of DMARD therapy. It is noted that ideally, DMARD therapy should be initiated by a rheumatologist rather than a GP (Royal Australian College of General Practitioners 2009).

Despite these recommendations many people in Australia face long delays to see rheumatologists. This is particularly evident in Queensland and rural and remote areas, as well as in public practice.

In 2012, a survey of Australian rheumatologists found that half of all patients had to wait more than six weeks for an urgent initial consultation with a rheumatologist. A report by the Australian Rheumatology Association identified shortages in the rheumatologist workforce and found that only 13% of the rheumatology workforce lived outside capital cities. The report found that there were 195 full-time-equivalent (FTE) rheumatologists in Australia or around one for every 118,000 people, which compares unfavourably to international benchmarks. 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 and changes in work practices (Arthritis Australia 2014).

Stakeholder consultations undertaken as part of the development of the *Time to Move: Arthritis* strategy highlighted lack of access and long waiting times to see rheumatologists as a critical issue. Some people reported attending the hospital emergency department in response to flares because they could not get appointments with their rheumatologists at short notice. Expanding the roles of non-rheumatology clinicians including nurses, GPs and allied health professionals could support improved care for people with arthritis in underserviced areas (Arthritis Australia 2014).

A survey of paediatric rheumatologists examined the paediatric rheumatology workforce in Australia and New Zealand and found a shortfall of 68% based on minimum requirements and a shortfall of 225% based on an ideal scenario. The authors noted the need for an increase in resource allocation to clinical service and speciality training to overcome this disparity (Cox et al. 2016).

Role and scope of rheumatology nurses

There is limited evidence relating to nurses practising in rheumatology in Australia. This is further complicated by the terminology surrounding the role. The terms rheumatology clinical nurse, advanced nurse practitioner, clinical nurse specialist and other titles are often used without clear descriptions of the level of expertise or responsibility associated with each role (Dewing et al. 2010). While some articles reference specialist nursing, the term specialist is a restricted professional title not allowed by the Australian Health Practitioner Regulation Agency (AHPRA) or the Nursing and Midwifery Board (Australian Health Practitioner Regulation Agency 2017).

In Australia, rheumatology nursing is a young and evolving field. An examination of job advertisements suggests that rheumatology nurses in Australia participate in a range of clinical activities including patient education and counselling, providing advice about management,

monitoring drug therapy and coordinating aspects of care. However, no core competencies for rheumatology nurses in Australia are apparent, and their exact role remains unclear.

Nurse practitioners are advanced practice nurses endorsed by the Nursing and Midwifery Board of Australia (NMBA), typically within an area of specialisation. Requirements for endorsement include nurses demonstrating significant experience and successful completion of an approved program of study. Their practice is characterised by increased complexity of clinical reasoning and increasing levels of autonomy in decision-making and practice. They also extend their practice by incorporating new practices not typically considered to be the norm or practices previously undertaken by other health professionals (Masso & Thompson 2014).

Nurse practitioners were first authorised to practice in Australia in December 2000 (Masso & Thompson 2014). 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) (NMBA 2016). It has been estimated that approximately a quarter 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 in roles 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). 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 present there are two qualified rheumatology nurse practitioners in Australia and two nurses currently undertaking the requisite study to qualify as rheumatology nurse practitioners.

EULAR represents people with arthritis/rheumatism, health professionals and scientific societies of rheumatology of all the European nations. Their recommendations for the role of the nurse in the management of inflammatory arthritis have enabled a homogenisation of rheumatology nursing care across Europe (van Eijk-Hustings et al. 2012), but no equivalent recommendations exist in Australia.

Models of care

With the prevalence of chronic musculoskeletal conditions expected to rise considerably in coming decades and extensive systemic and sector-wide changes in health service delivery and funding, changes in the way health professionals are trained and provide care are imperative.

A review of models of care for musculoskeletal pain conditions, osteoarthritis, rheumatoid arthritis, osteoporosis and musculoskeletal injuries found a range of successful health system and local implementation strategies that improve consumer outcomes. Consistent features were observed across the models reviewed, including the importance of primary and secondary prevention, care coordination, access to a multidisciplinary team, self-management support, leveraging digital technologies and inclusive care planning (Speerin et al. 2014).

In Australia, evidence-informed models of care for particular life stages are an important facilitator of these change processes (Briggs & Towler 2014).

Several current models of care for inflammatory arthritis have been developed in Australia and are described below.

Melbourne Health Rheumatology Nurse Practitioner model

The Melbourne Health Rheumatology Nurse Practitioner model was developed to address identified gaps in the management of rheumatology patients.

As the number of patients and their complexity increases, the model aims to build the capacity and capability of the multidisciplinary team to improve patient outcomes with prompt, appropriate treatment and management. The model is based on the principles of chronic disease management and patient centred care, and aims to improve quality of life, prevent disease progression, and avoid hospitalisation. The rheumatology nurse practitioner is a registered nurse who works both autonomously and collaboratively in an advanced, extended clinical role, performing tasks including the direct referrals of patients to other health care professionals, prescribing medications and ordering diagnostic investigations. The rheumatology nurse is based in the hospital and works with outpatients, biologics clinic, specialist clinics, inpatient wards and day units, among others.

As this is a new model, its success and sustainability has not yet been evaluated.

WA Model of Care for Inflammatory Arthritis

The model takes a holistic approach to the provision of services for people with inflammatory arthritis in Western Australia. It aims to ensure patients receive high-level, evidence based continuing care. It makes recommendations in support of the role of rheumatology nurse specialists and their value, including in co-ordinating and conducting assessments, monitoring medication toxicity, scheduling reviews, performing audits, and ensuring continuity of Pharmaceutical Benefits Scheme (PBS) funded therapy. The model recommends that rheumatology nurse specialists/practitioners should receive training in patient education, care coordination, clinical metrology and chronic disease management (DHWA 2009).

Model of Care for the NSW Paediatric Rheumatology Network

This model aims to provide international best practice standards and meet the needs of families and children affected by paediatric rheumatic disease.

A goal is for all core team members to be specifically trained in the care of children with rheumatic diseases. A clinical nurse consultant will provide care coordination of all services, targeted and specific child and family education, ongoing family support and nursing care for the child (Agency for Clinical Innovation Musculoskeletal Network 2013).

Examples of practice

Rheumatologists in south western Sydney have developed an award-winning drug monitoring and surveillance system for DMARD therapy. Patients' blood test results are reviewed by a nurse and dose adjustments communicated to patients and their health providers (DHWA 2009).

The Albany Rheumatology Clinic is supervised by a nurse with additional qualifications who triages referrals and monitors disease activity. It is expected that the nurse will assist in monitoring DMARD therapy through specialised software used to communicate with GPs and pathology providers (DHWA 2009).

Consumer experience

Feedback from people with inflammatory arthritis has provided useful insight into the patient experience and the barriers and enablers of quality, appropriate health care, primarily around access

to care, quality of care and cost of care. An Australian survey undertaken in 2013 of people with arthritis found that two in three were not coping well with their condition, and that poor access to specialists, GPs and allied health professionals was a key factor in how they were faring (Arthritis Australia 2014).

Access to care

Survey respondents reported considerable delays between onset of first symptoms and diagnosis. Two thirds of respondents reported delays of longer than 12 months to receive a diagnosis. Of these, half were not diagnosed until five or more years after first symptoms presented (Bates et al. 2014).

Effective arthritis management usually requires a team of health care professionals. However, accessing such teams can be difficult and expensive. Participants also reported that health services were complex and fragmented and that they experienced difficulties navigating services and finding an appropriately skilled provider that met their needs (Bates et al. 2014).

Quality of care

The quality of treatment provided to people with arthritis varied from no treatment to comprehensive treatment, either by a GP, specialist or both. The quality of information provided about their disease and its treatment also varied widely. Participants reported that pain and fatigue were overlooked in the treatment of their arthritis and few were offered advice on symptom management.

Living with arthritis adversely affected psychological wellbeing for patients and their carers, and this was often ignored in their treatment plan (Bates et al. 2014).

Cost of care

The cost of medications used to treat inflammatory arthritis and relieve symptoms was reported to be high, both in terms of the cost of medications and the number of different medications and supplements required, not all of which are subsidised under the PBS (Bates et al. 2014).

The financial consequences of arthritis are due both to the added costs associated with living with the disease (e.g., medical care and regular medication) and the loss of income from reduced capacity to work. Two thirds of participants reported that they suffered financially because of their arthritis, while one in five reported that they struggled to meet their expenses or needed financial support due to the financial impact of their arthritis. Many participants reported compromising their ongoing health care and other basic needs to meet the cost of medication. Government support for ongoing medical expenses was identified as a high priority, particularly given the chronic nature of arthritis and the high cost of medication and treatment (Bates et al. 2014).

It is noted in *Time to Move* that many aspects of care for inflammatory arthritis are not adequately covered by Medicare, and patients without private health insurance often bear the cost of allied health services. This forms a considerable barrier to care for many patients. While Medical Benefits Scheme (MBS) benefits are available to patients with Chronic Disease Management Plans, these are limited to five occasions per year (Arthritis Australia 2014).

Standards of practice

The Department of Health's national service improvement framework for osteoarthritis, rheumatoid arthritis and osteoporosis does not make specific reference to standards of practice for

rheumatology nurses (CDH 2010). No other formal standards of practice or frameworks in Australia were identified.

Nurse education and competencies

Nursing education in Australia has expanded to include postgraduate qualifications and specialisations. 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, is expected to help build the rheumatology nursing workforce (Arthritis Australia 2014). The program addresses bone and connective tissue disorders with an emphasis on assessment and management. It aims to enhance the nurse's application of knowledge and skills for the intervention and prevention of worsening disease states and the facilitation of client self-management related to non-inflammatory joint diseases and connective tissue diseases. Credit transfer to a master's degree is available.

A number of Australian universities and organisations offer postgraduate programs in chronic care for nurses, a selection of which are described below.

The University of Queensland offers a graduate certificate in nursing chronic disease and palliative care (University of Queensland n.d.), and a graduate certificate in chronic condition management is available at Flinders University (Flinders University 2016). Areas of study include management of chronic conditions, implementing change, educating patients, and management of specific conditions. The graduate certificate in chronic health conditions at Queensland University of Technology recognises the growing need for health professionals to be able to lead interdisciplinary healthcare teams working in the areas of chronic disease, chronic illness and disability (Queensland University of Technology 2017). Edith Cowan University offers a chronic disease management specialisation (Edith Cowan University 2016) which provides registered nurses with the knowledge to develop expertise in the management of chronic illness and disease in the acute and community setting.

2.3 Models of care for inflammatory arthritis internationally

What are the models of care, scope of practice, standards of practice and educational requirements for rheumatology nurses internationally?

Internationally, rheumatology nursing is evolving rapidly as demand for services increases and new complex medications require trained providers to administer and manage them.

Role and scope of rheumatology nurses internationally

Rheumatology nurses in the United States

A gradual increase in the scope of activities for nurses in rheumatic disease has occurred since the 1990s in the US, more so in Europe and Canada with a focus particularly on rheumatoid arthritis (Kuznar 2014).

In 2012, the American Nurses' Association Board of Directors recognised rheumatology nursing as a new specialty, and approved a scope of practice statement. This scope includes as core duties patient education and injection teaching, physical assessment, medication monitoring, coordination of care, and psychosocial support and assistance (Kuznar 2014). The scope of practice varies between states.

A recent workforce study notes that during the next several decades, the demand for rheumatology services will outstrip the supply of rheumatologists in the US and that nurse practitioners and physician assistants may be able to alleviate projected shortages. The rheumatology nurses in the study were asked to identify their key responsibilities.

These included substantial patient care responsibilities and monitoring disease activity measures. The results suggest that rheumatology nurses may help to address the impact of shortages in the rheumatology workforce (Solomon et al. 2014).

Other studies have noted the ability for rheumatology nurses and/or physician assistants to increase the rheumatology workforce. While the two roles have different formal education, they are both able to augment the workforce and improve access to care (Smith et al. 2017).

A study of the use and education of nurse practitioners in paediatric rheumatology found that due to the shortage of speciality physicians in the US, there is an increasing need to add mid-level practitioners to specialty practices (Solomon et al. 2014). The current scope of practice and job profile appears to be broad with an average workload ranging from 3 to 8 half-day clinics. There does not appear to be consistency about the length of training and educational plan. The authors note that a formalised training program for nurse practitioners is necessary (Mintz et al. 2015).

Roles of rheumatology nurses in the United Kingdom

A survey about the work and activity profile of nurses working in the rheumatology field explored nurses' qualifications, training needs, self-reported perceptions of competency and work productivity. Highlights of the information collected include:

- the rheumatology nurse workforce is ageing (mean age 48 years)
- one third held a teaching qualification while 22% held a Masters qualification
- 26% were nurse prescribers
- almost half were carrying out administrative, non-clinical tasks
- the majority of nurses ran between 4-5 clinics per week
- nurses ran telephone support advice lines for between 3-10 hours per week
- nurses were managing an increasing number of day cases
- the range of tasks undertaken by nurses were broad, and included injections, cognitive behavioural therapy and biomechanical assessments
- nurses played a key role in educating trained nurses, student nurses and allied health care professionals. Approximately half (49%) also trained medical students (Hill et al. 2009).

In the UK, rheumatology nurses may work in a rheumatology ward or clinic or have roles as infusion nurses, specialised outpatient support and chronic care nurses. Challenges in demonstrating the cost effectiveness of these activities is noted, together with the limited data available about numbers of patients seen and duration of appointments. The authors note the different nursing titles in use in different care settings, the lack of consensus about roles and responsibilities, and the difficulty in obtaining information that accurately reflects the breadth and value that rheumatology nurses provide (Hill et al. 2009).

Rheumatology workforce

A workforce of adequate volume and competencies is critical for effective and sustainable implementation of effective models of care. Several studies have noted the need for effective, efficient care for people with inflammatory arthritis, which addresses workforce shortages by

drawing on the skills of various health professionals in the multidisciplinary team, including nurses with extended scopes of practice (Speerin et al. 2014).

In Canada, there are regional disparities in access to specialist rheumatologist care, and the rheumatology workforce is ageing. To address these capacity issues, better data are needed including information on clinical full-time equivalents, delivery of care to remote communities, and use of different models of care to increase clinical capacity (Brophy et al. 2016).

Although the rheumatology workforce in the US has increased between 2012 and 2015, the number of rheumatology professionals is still insufficient to meet demand, particularly in the care of children and those in rural areas (Reveille et al. 2016).

A survey by the British Society for Rheumatology found recruitment gaps across all professions working in rheumatology services, and extensive global workforce shortfalls are anticipated (British Society for Rheumatology 2015).

A systematic literature review of the rheumatology workforce has been suggested as a way of agreeing upon an international approach to formulating reliable estimates of workforce requirements in rheumatology (Dejaco et al. 2016).

Frameworks

A number of local and international guidelines, recommendations and standards of care for rheumatology nurses are evident.

UK Department of Health Musculoskeletal Services Framework

This framework outlines a model of care through its multidisciplinary musculoskeletal clinics. These act as the interface between primary care and hospital care, offering assessment, diagnosis, and treatment or referral. The focus is holistic care. Episodes of care during the period in which the framework was piloted increased by 62% but overall expenditure dropped and the average cost for an episode of care fell by 41%. While the pilot was well received, broader implementation has been limited (Arthritis Australia 2014).

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 European Union countries, and which has developed best-practice evidence-based standards of care for rheumatoid arthritis and osteoarthritis (Arthritis Australia 2014). The ten recommendations on the role of the nurse in the management of chronic inflammatory arthritis provide a basis for optimising rheumatology nursing care to contribute to a more standardised level of professional nursing across Europe (van Eijk-Hustings et al. 2012).

National Institute for Health Care Excellence (NICE) rheumatoid arthritis guideline

This guideline notes the key role specialist nurses play in the UK as members of the multidisciplinary team providing care to people with rheumatoid arthritis (Hennell 2009).

The literature recognises that an evidence-based, integrated framework for the care of rheumatoid arthritis would be of benefit. Definitive care delivery pathways are needed and further research is required to refine appropriate frameworks and educational needs as well as better understand the factors that contribute to delays in care at the early stage of the disease (Li et al. 2008).

Standards of practice

Rheumatology Nursing: Scope and Standards of Practice

In the US, rheumatology nurses are integral members of the healthcare team who treat patients with rheumatic diseases. They often manage healthcare teams that integrate patient care and education with professional expertise and research. The rheumatology scope and standards of practice define rheumatology nursing, the areas in which rheumatology nurses work and the unique skill set needed to care for patients with rheumatic disease (Rheumatology Nursing Society and the American Nurses Association 2013).

Nurse education and competencies

There is little evidence of consistency across the nursing profession globally in terms of the level of formal education needed to work as a rheumatology nurse. Various levels of nursing courses and certifications exist globally, at bachelor or postgraduate level, including graduate diploma and master's levels. Some specialty organisations do not specify any formal postgraduate qualifications. Internet searching uncovered a lack of criteria for assessing the availability or academic quality of courses with a focus on specialist areas of practice (Ashley 2014). Disparities exist among European countries regarding rheumatology nurse activities and qualifications (van Eijk-Hustings et al. 2012). This lack of specific training has been noted by numerous authors.

2.4 Benefits of rheumatology nursing care

What is the evidence relating to the benefits of rheumatology nursing care for people with arthritis?

Effectiveness of rheumatology nurses

There is growing evidence supporting the value of the rheumatology nurse role, and the benefits associated with it.

EULAR recommendations

EULAR provides recommendations for the role of the rheumatology nurse (van Eijk-Hustings et al. 2012) in managing inflammatory arthritis, based on evidence and expert consensus. of evidence-based (van Eijk-Hustings et al. 2012). The Taskforce which developed the guidelines found high quality (Level 1A or 1B) evidence to support the effectiveness of rheumatology nurses in the following areas:

- Participation in comprehensive disease management to control disease activity, to reduce symptoms and to improve patient-preferred outcomes
- Patient education to improve knowledge of inflammatory arthritis and its management throughout the disease course
- Improved communication, continuity and satisfaction with care
- Identifying, assessing and addressing psychosocial issues to minimise the risk of patient depression and anxiety
- Interventions and monitoring as part of comprehensive disease management to achieve cost savings (van Eijk-Hustings et al. 2012).

Diagnosis

A randomised controlled trial to evaluate the substitution of specialised rheumatology nurses for

rheumatologists in diagnosing fibromyalgia found that such substitution is a trustworthy and successful approach that can assist early diagnosis through saved waiting time (Kroese et al. 2011).

Timely initiation of treatment

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).

Treatment outcomes

A trial to compare treatment outcomes from a nurse led rheumatology clinic and a rheumatologist clinic for patients undergoing therapy with low disease activity or in remission showed equivalent outcomes for patients at the nurse led clinic to those obtained by rheumatologist-led clinic at 12 month follow-up (Larsson et al. 2015).

A randomised controlled trial found that patients with stable chronic inflammatory arthritis undergoing biological therapy could successfully be monitored by a nurse led rheumatology clinic, rather than a rheumatologist, without difference in disease outcome (Oliver 2011).

Rheumatology nurse telephone advice and consultations

The results of a pilot study in Singapore found that patients with rheumatoid conditions have a need for clinical advice about disease flares and medication side effects. This can be effectively provided by a rheumatology nurse advice line in the outpatient setting. Similar interventions may play a role in encouraging adherence to therapy, preventing major flares, promoting self-management in patients, and improving patient satisfaction (Yee et al. 2015).

In the US, a nurse scheduled telephone visit was trialled as a way of improving patient experience, minimising cost burdens and increasing access to care. It was well accepted by the patients and providers as an efficient resource in a busy clinic setting. It improved access to care and reduced costs for patients (Butt et al. 2016).

Nurse led injection clinic

A study to determine satisfaction with a nurse led steroid injection clinic in Canada noted the gap between patients who need care and the capacity of the system to deliver it. Several models of team-based care were developed with trained rheumatology nurses, including a nurse managed injection clinic treating patients with inflammatory arthritis. The clinic allows immediate access and assessment of patients with flares or potentially needing steroid injections, and it administers nearly 100 injections per week. The results showed that the clinic was valued by patients for pain and inflammation management. Patients exhibited a high degree of satisfaction and noted that without the clinic, they would seek treatment through GPs, specialists or hospitals, adding to the existing burden on the health system (Saldanha et al. 2013).

Nurse led urate-lowering treatment (ULT) clinic

A number of studies have identified that providing increased education to patients with gout results in more patients adhering to treatment. A 2013 observational study found a nurse-led intervention achieved recommended treatment targets in 9 out of 10 patients (Rees et al. 2013). A 2016 UK study found that following a 1 year initial nurse-led program to provide personalised interactive education about gout resulted in improved long-term persistence on ULT even after the responsibility of

prescribing ULT is handed over to the patients' own GP. This concurred with the findings a systematic review undertaken in the same study which concluded that patient education improves medication adherence (Abhishek et al. 2016).

Consumer experience

People with rheumatoid arthritis in Australia have reported that they are left to navigate and coordinate services for themselves, with minimal direction from health care professionals. This is especially problematic for people who lack the health literacy or language skills to do this effectively (Arthritis Australia 2014). The issue of service fragmentation is exacerbated in the private system, where access to multidisciplinary teams is limited or non-existent. Around 80% of rheumatology practice takes place in private practice (Arthritis Australia 2014). Stakeholder consultations have also highlighted the lack of adequate information and support for people with arthritis at the time of diagnosis (Arthritis Australia 2014).

Patients' experiences of a nurse led rheumatology clinic

A study from Sweden about patients' experiences of a nurse led clinic for those undergoing biological therapy concluded that the nurse led rheumatology clinic provided added value to patient care. Participants reported that their consultations with a nurse created security, familiarity and a feeling of inclusion. Replacing every second visit to a rheumatologist with a consultation with a nurse added value to patient care, making it more complete. Nurses and rheumatologists complemented each other, as they approached patients from different perspectives. This study suggests that a nurse led rheumatology clinic adds value to the quality of care for patients in rheumatology units (Larsson et al. 2012).

A nurse led rheumatology clinic intervention based on person-centred care found that biological therapy follow-up care can be effectively performed by a nurse led clinic (Larsson et al. 2014).

Communication

Discussion with a rheumatology nurse in a clinic may add value in terms of improving patients' perceived ability to cope with arthritis (Ryan et al. 2006). The opportunity to attend a nurse led clinic soon after a diagnosis provides a valuable opportunity for patients to discuss practical and self-management issues and receive emotional support (Hehir et al. 2008).

A study of traditional funding models for public paediatric rheumatology care found that there is a need expressed by patients and families for out-of-clinic communication with care providers. Traditional funding models may not meet this need. The communication and support needs of patients with chronic inflammatory conditions, and their families, are greater than those which can be provided in the clinic setting. It was recommended that funding for paediatric rheumatology services allows for staffing to meet this need (Fitzgerald 2015).

Funding/cost effectiveness

A multicentre randomised controlled trial of the outcome and cost-effectiveness of nurse led care in people with rheumatoid arthritis found robust evidence to support the suitability of nurse led care in the management of rheumatoid arthritis. The study found that the nurses provided patient education and psychosocial support more frequently than rheumatologists, and their patients had fewer unplanned hospital admissions or visits to accident and emergency units. Additionally, several

clinical benefits of nurse led clinics were identified, including general satisfaction and disease-specific outcomes (Ndosi et al. 2014).

The evidence suggests that shared care and nurse care appear to cost less but provide broadly similar health outcomes compared with rheumatologist led outpatient care (Sørensen et al. 2015).

A cost analysis of substitution of specialised rheumatology nurses for specialists in the care of patients with fibromyalgia found total societal costs were lower for nurse led patients when compared with rheumatologist-led care (Kroese et al. 2011).

A randomised controlled trial of a nurse-led rheumatology clinic versus a rheumatologist-led clinic in monitoring of patients with arthritis undergoing biological therapy found that patients with low disease activity or in remission could be monitored at less cost by a nurse-led clinic with no difference in clinical outcome. The annual saving per patient was calculated to be €2167.2, representing a 13% reduction in costs (Larsson et al. 2015).

2.5 Rheumatology nurses in Australia

What is known about the number and characteristics of rheumatology nurses and their distribution across Australia?

The literature review did not identify any systematic collections of data relating to rheumatology nurses in Australia. The wide variety of titles used to describe specialist nurses and diverse models of care means existing data is limited and comparisons are difficult.

However, information provided by Arthritis Australia indicated that there are an estimated 50 rheumatology nurses in Australia. There are two qualified rheumatology nurse practitioners in Australia and two nurses currently undertaking the requisite study to qualify as rheumatology nurse practitioners.

While the role of rheumatology nurses is extending and expanding, and new models of practice are emerging in the literature, there is minimal information about the practice environment, current service structure, patient load or the extent to which new models and variations in practice already exist.

2.6 Specialised nurses in Australia

What evidence exists for nurses in extended roles in other disciplines?

Nurses in extended roles and specialised roles

The value of the specialist nurse in providing supportive and clinical care in extended roles is widely recognised, and the Australian health system has made provision for specialist nurses for a range of diseases (Sykes et al. 2015). However, there are very few quality evaluations and data about numbers is limited. No agreed standards of practice or mandatory educational requirements were identified.

A South Australian study sought to explore the major components of nurse specialist roles in the state and to develop a framework for their evaluation. Clinical work, educational, professional development, management and research were identified as key components of the nurse specialist

role. The results highlighted the diversity within the role for and the need for a comprehensive range of evaluation tools (Dunn et al. 2006).

Mental health nurses

In 2015, about one in 15 nurses employed in Australia (6.9%) indicated they worked principally in mental health (AIHW, 2016c). Mental health nurses work in hospitals, community mental health services, residential mental healthcare services, welfare and aged care facilities, correctional services and the community.

Mental health nurses have roles in promoting optimal physical and mental health, prevention of physical and mental illness, and providing therapeutic interventions and treatment to support the physical and mental health preferences and needs of individuals, communities and population groups (ACMHN, 2017).

Cancer nurses

There are over 1,000 cancer nurses in Australia (Oncology News, 2015), although workforce figures tend to be reported in terms of sub-specialties, e.g. breast care or prostate cancer nurses.

Breast care nurses

There have been several Australian studies on breast care nurses (BCNs) in Australia. A 1997 survey found that care provided by BCNs involved consultations preoperatively, postoperatively and at follow-up. The study found that women who were treated in public hospitals were more likely to receive care from a BCN (Campbell 2010). A study around the BCN workforce in Australia in 2010 noted the presence of 213 BCNs in 160 public and 53 private hospitals, but the study was unable to consider the complexity of caseloads nor determine the optimal caseload for these specialist nurses (Koschel 2010). Specialist BCN models have been developed.

BCNs adopt a holistic approach to a psychosocial and physical health during breast cancer. They provide patients with support, education, counselling, advice, resources, advocacy and management. BCNs provide coordination, continuity and personalised care (McGrath Foundation 2010).

Prostate cancer nurses

The Prostate Cancer Foundation of Australia has implemented a structured prostate cancer specialist nursing service in 12 hospitals, in which the nurse works as a member of the multidisciplinary care team. An evaluation of the program found that having a defined service model enabled the prostate cancer specialist nurse (PCSN) to facilitate a flexible common practice model that was implemented with a degree of flexibility to meet client need. The research found that models of care are necessary to guide service delivery and ensure standards of care are fulfilled. It also concluded that consideration should be given to ways to expand the scope of the PCSN's practice through new models including nurse led clinics. Importantly, it was noted that the role of the PCSN should be on expert nursing consultation functions, rather than administrative tasks (Sykes et al. 2015).

Diabetes educators

Credentialed Diabetes Educators (CDEs) are healthcare practitioners qualified to provide a client-centred approach to diabetes education and care, empower patients and assist 1.7 million Australians in dealing with daily self-management. A number of health disciplines are eligible for recognition as a CDE, of which registered nurses are one (ADEA, 2015). There are currently over 1,300 CDEs in Australia (ADEA, 2017), of which 90% are registered nurses (ADEA, 2016).

Inflammatory bowel disease nurses

A nurse led irritable bowel disease (IBD) patient advice line at Liverpool Hospital, NSW, offered a phone and email service for patients with IBD who needed acute advice. A specialist nurse reviewed and triaged patients, then initiated a collaborative review with a specialist. A care plan was formulated and discussed with the patient.

An audit of the service demonstrated that over four months, 111 calls were received. Of these, 34 avoided GP consultation and 70 avoided outpatient clinic presentations. 34 emergency department presentations were avoided, and there were no unplanned hospitalisations. The projected annual net cost saving was \$111,061. The findings highlight the importance of a proactive multidisciplinary approach in optimising patient care (Sechi et al. 2016).

Parkinson's disease nurses

Six Parkinson's specialist nurses (PSN)s are funded by the Western Australian Department of Health to provide home visits and assist patients with self-management in Perth and the south west region while patients continue with their regular therapy services. Where PSNs have been in place, the increase in health costs has been lower than those in a control group. It is expected that access to PSNs reduces the need for unnecessary hospitalisation, outpatient appointments and GP visits, and may ultimately delay admission to aged care facilities. All participants who had access to a PSN reported an improved sense of well-being (Parkinson's Australia 2014).

Primary health care nurses

Primary health care nurses (PHCN)s are enrolled nurses, registered nurses and nurse practitioners eligible for registration by AHPRA, whose competence is specific to the primary health care context (Australian Primary Health Care Nurses Association [APNA] 2016c).

PHCNs play a considerable role in managing chronic disease in Australia. Recent research within the general practice setting describes the functions of PHCNs as carers, organisers, quality controllers, problem solvers, educators and agents of connectivity (APNA 2016c). The Australian Primary Health Care Nurses Association (APNA) notes evidence that a coordinated and consistent approach to specific diseases helps primary care more effectively prevent and manage chronic conditions (APNA 2016b).

A comprehensive international literature review (which included Australia) examined nurse led primary healthcare interventions with a focus on chronic and complex conditions and hard to reach populations. It found that such interventions provided effective care and had high patient satisfaction and that patients were more likely to comply with nurse instructions than GP instructions. Further, it found that PHCNs can provide care equivalent to that delivered by doctors provided it is within their scope of practice. Lifestyle interventions provided by PHCNs were shown to be effective for cardiac care, diabetes care, smoking cessation and obesity.

The research concluded that PHCNs can offer appropriate, cost-effective and high-quality chronic disease care in the primary care context (Parkinson & Parker 2013).

Nurse practitioners

NPs work at an advanced level in a range of clinical practice contexts, delivering diabetes care, wound management, rural and remote health, men's health, mental health, community health, pain management, orthopaedics, chronic heart failure, cardiology, and oncology (Australian Nursing Federation 2012).

Notably, access to MBS and PBS is available to nurse practitioners working in a private capacity. This is significant for the greater access to health professionals available to the community and is particularly important for people unwilling or unable to access mainstream health care services (Australian Nursing Federation 2012).

A census of Australian NPs found that professional support is essential if the NP role is to be fully utilised, and that currently, NPs were not being used to their optimum capacity despite growing pressure on the health system (Middleton et al. 2011).

Nurse educators

A nurse educator (NE) is generally a registered nurse who plans, delivers and evaluates nursing education. There is a lack of clarity about their scope of practice, in part due to the multifaceted nature of the role and the context of practice (Sayers et al. 2010). The NE role in the Australian hospital setting has been poorly described (Sayers et al. 2010). One cross-sectional online survey of NEs in acute care found that NEs reported that role ambiguity and confusion had a negative impact on job satisfaction. The need to clarify nurse educator roles in Australia was highlighted (Davidson et al. 2015).

Enhanced nurse clinics

APNA's Enhanced Nurse Clinics project is an innovative initiative across various metropolitan, rural and remote locations. Nurse led clinics form the basis of the model of care at 11 sites. The project will be completed in 2018, after which there will be an extensive evaluation. Outcomes, recommendations, resources and tools will be made available to other primary health organisations wishing to implement nurse led clinics themselves (APNA 2016a). The Enhanced Nurse Clinics are as follows:

Community Owned Health Service, Diabetes

The diabetes clinic will incorporate education and multidisciplinary care for people with diabetes. Nurses will also complete the Annual Cycle of Care for patients with type 2 diabetes.

General Practice, Wound Clinic

The wound clinic aims to increase the practice's capacity through a wound-specific consultation space which will enhance the skills of staff to deliver care. Information systems will be developed, and marketing to the local community will occur.

General Practice, Cardiovascular

Bluestone Family Medical centre commenced a nurse led cardiovascular clinic.

Community Health Service, Dementia

The Memory Health Support Service within a general practice in Ballarat is a nurse enhanced model of care designed to improve psycho-social and medical care planning for people presenting with cognitive decline and their carers.

General Practice, Teen Health

The clinic is a free service for teenagers within the Bega Valley region. Teenagers can talk with a registered nurse about medical and non-medical issues, including mental health and sexual health concerns.

Community Health Service, Hepatitis C

The clinic will provide accessible, timely and appropriate treatment to people with hepatitis C,

support clients to access new treatment (where appropriate), and prevent further complications and disease progression.

Not-for-Profit Community Organisation, Hepatitis B

The Healthy Liver Clinic will screen, diagnose, monitor, educate and treat refugees and asylum seekers with chronic hepatitis B.

Correctional Services, Men's Health

The Men's Health and Wellbeing Clinic features a collaborative, nurse run model which addresses priority health and wellbeing issues for male prisoners. Nurses are guided by evidence-based protocols, in partnership with the multidisciplinary health care team.

Aboriginal Development Organisation/General Practice, Diabetes

A diabetes clinic will provide Indigenous Australian patients with access to a multidisciplinary and culturally appropriate collaborative model of care.

Aged Care, Healthy Ageing

The Primary Health Nursing Clinic for Older People targets older people with complex care requirements and health needs, providing pathways and nurse led education to support wellness.

General Practice, Mental Illness and Chronic Disease

The SKIP into Life Clinic aims prevent and manage chronic mental illness. It offers person centred assessment, change management support, wellbeing education, care planning, and early referral to specialist services.

Credentialing

Internationally, credentialing for nurses is common, but in Australia, nurse registration occurs through statutory regulation. Quality health care and patient safety are assured through the National Registration and Accreditation Scheme, under the Health Practitioner Regulation National Law Act 2009. Initial registration occurs after successful completion of an accredited education program. Program entry requires graduates to meet minimum standards as specified by the Nursing and Midwifery Board of Australia (NMBA). Once registered, nurses are listed on AHPRA Public Register for health practitioners (Fitzgerald 2015).

Other types of accreditation or certification are offered by professional organisations. These private credentialing arrangements are not recognised under the national regulatory framework or AHPRA. The Australian Nursing and Midwifery Federation states that the requirements for continuing professional development for nurses, and the broad range of post graduate education programs, is sufficient (Australian Nursing and Midwifery Federation 2009).

As an example of such private credentialing, five specialty nursing organisations in Australia have collaborated to develop a consistent, evidence-based credentialing program for specialist nurses (Credentialing for Nurses 2016).

The five organisations are:

- Australian College of Children and Young People's Nurses
- Australian College of Mental Health Nurses
- Cancer Nurses Society of Australia
- College of Emergency Nursing Australasia

- Palliative Care Nurses Australia (Credentialing for Nurses 2016)

A review of the literature in 2014 failed to identify any other credentialing models and processes for achieving credentialed status in Australia (Ashley 2014).

Technology

New technologies offer an opportunity to improve the way in which health professionals deliver care, and may streamline processes for meeting demand.

The use of digital technologies both in the delivery of health services and in enabling self-management is becoming increasingly recognised as an effective strategy to overcome care disparities because of geographic location. It provides a means of supporting patients to be more active participants in their care. Emerging evidence suggests that network-based models of engagement and collaboration for clinicians, consumers and other stakeholders such as managers and policymakers are a key enabler to effective models of care. The importance of this collaborative approach to care was noted by numerous sources examined for this review (Speerin et al. 2014).

Technologies in telemedicine like videoconferencing are increasingly being used for multidisciplinary meetings and patient consultations, with particular benefits for patients in rural locations. Other benefits include the ability to provide consultations to patients in their home, the ability to provide urgent medical input without patients having to travel great distances, and the ability to accommodate the needs of Indigenous people. It has been reported that while information and communication technology is currently used on a discretionary basis, the future workforce will require universal uptake (Health Workforce Australia 2013).

Telehealth and telecare technologies and services for the management of chronic disease at home or in the community have been demonstrated to deliver cost-effective, timely and improved access to quality care. They have been widely embraced in the United States. However, experience with deployment in Australia is limited. Australian research published in 2016 shows a telehealth model to manage patients suffering from a wide range of chronic conditions utilising a nurse as a Clinical Care Coordinator can deliver significant benefits at lower cost and with a high level of acceptance by patients and their carers (Celler et al, 2016).

In 2013, the Nursing and Midwifery Telehealth Consortia published Telehealth Standards to provide telehealth education and support specifically for registered nurses (Nursing and Midwifery Telehealth Consortia, 2013).

3. Conclusion

Inflammatory arthritis is a chronic condition which requires long term, expert care from an appropriately skilled multidisciplinary team. It results in considerable morbidity and cost, both to individuals and the wider community. People with inflammatory arthritis may experience delays in diagnosis, difficulty in accessing services, fragmented care and a heavy financial burden.

The benefits of rheumatology nurses overseas are well documented internationally. Rheumatology nurses provide a range of support for people with inflammatory arthritis and can facilitate timely access to treatment. They commonly work as members of multidisciplinary teams in general practices, hospitals, outpatient clinics and the community setting. Broadly, their principal responsibilities include ongoing patient support and education, care coordination, drug monitoring and facilitating care planning. They can also contribute to primary prevention activities such as smoking cessation programs.

Rheumatology nurses have been shown to make an important contribution to improving patient outcomes, improving accessibility to appropriate care and reducing costs. Nurse led models of care are effective, safe and associated with increased patient satisfaction.

The rheumatology nurse workforce in Australia is small, and there are no formal standards of practice. However, the international example highlights numerous potential benefits of increasing the rheumatology nurse workforce in Australia, for consumers, the rheumatology workforce and the health system more broadly.

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