



Australian Healthcare and Hospitals Association

Stakeholder surveys and interviews

**Rheumatology nurses:
Adding value to arthritis care**

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Table of Contents

Background	1
Methodology	1
1. Who is in the rheumatology nursing workforce in Australia? Who do they work with and who are their patients?	3
Highlights.....	3
Background from literature review.....	3
Rheumatology nurse survey respondents	3
Age and gender of respondents	3
Geographical settings of respondents	4
Practice settings of respondents	5
Rheumatologist survey respondents.....	6
Age and gender of respondents	6
Geographical settings of respondents	6
Practice setting of respondents.....	6
Experience of working with a rheumatology nurse	7
Other clinical workforce survey respondents	8
Professions of respondents.....	8
Geographical settings of respondents	8
Practice setting of respondents.....	9
Focus on patients with inflammatory forms of arthritis	10
Experience of working with a rheumatology nurse	10
Consumer and carer survey respondents	10
Age and gender of patients.....	10
Geographical settings of respondents	11
Experience with care from a rheumatology nurse.....	12
2. What are the roles and scope of activities for rheumatology nurses in Australia?	13
Highlights.....	13
Background from literature review.....	13
Position titles for rheumatology nurses	14
Range of conditions seen in rheumatology practice	14
Activities undertaken by rheumatology nurses	16
Skills required by rheumatology nurses	20

Pathways and training for rheumatology nurses	21
3. What models of care incorporate rheumatology nurses into care in Australia?.....	23
Highlights.....	23
Background from literature review.....	23
Models of care with rheumatology nurses	24
Types of reasons for seeing patients	24
Nurse involvement in the patient’s journey	25
A breakdown of how the workforce’s time is spent	26
How rheumatology nurse roles are funded	26
4. What is the perceived and actual value of rheumatology nurses? 28	
Highlights.....	28
Background from literature review.....	28
The patient’s experience	28
Timeliness of care.....	28
Understanding of their condition and treatment	29
How they are coping with their condition	30
Access to treatment	30
Satisfaction with care	32
Additional support	33
Impact on life	34
When nursing support is of greatest value	35
Rheumatology nurse survey results	35
Rheumatologist survey results	36
Clinical workforce survey results.....	37
Consumer and carer survey results	38
Rheumatology nurses contributing to their full potential	40
Rheumatology nurse survey results	40
Rheumatologist survey results	40
Clinical workforce survey results.....	41

Background

Introduction

The Australian Healthcare and Hospitals Association (AHHA), on behalf of Arthritis Australia, is undertaking a study to assess the current and potential role, scope of activities and value of rheumatology nurses in Australia.

Overview

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.

A literature review has been undertaken to identify 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 qualitative research with stakeholders, through both targeted online surveys and interviews, to further explore the current and potential role, scope of activities and distribution of rheumatology nurses in the management of chronic inflammatory arthritis in Australia.

This paper summarises the results of the qualitative research with stakeholders.

The results of the above research activities, together with a cost-benefit analysis has also been undertaken to determine the feasibility of funding rheumatology nurse positions from the perspective of the service provider and the wider health system, will be collated into a report which will include a range of recommendations to advance the proposal to build the rheumatology nurse workforce, including potential funding options.

Methodology

Online survey

In order to better explore the actual current and potential future role, scope of activities and distribution of rheumatology nurses in the management of chronic inflammatory arthritis in Australia, three broad online surveys were undertaken. The online survey method was chosen as a cost effective way to reach largest potential audience and gather their experience and opinion.

Each survey targeted a different reference group being:

- Rheumatology nurses
- Other clinicians including rheumatologists
- Consumers and carers

The surveys were developed with input from Arthritis Australia and two experienced rheumatology nurses and aimed to explore the issues from a number of angles, but also while keeping each survey to a manageable length to encourage completion.

The survey period was 20 April 2017 to 31 May 2017 and was promoted by both AHHA and Arthritis Australia through a broad range of channels including:

- By directly contacting relevant professional and consumer bodies such as the relevant arthritis bodies and also including:
 - Pain Australia
 - Allied Health Professions Australia
 - Australian Rheumatology Association
 - Australian College of Nursing
 - The Royal Australasian College of Physicians
 - The Consumers Health Forum of Australia
 - Rheumatology Health Professionals Australia
 - Royal Australian College of General Practitioners
 - Australian Primary Health Care Nurses Association
- Through social media, including Twitter, Facebook and LinkedIn
- In AHHA's twice weekly eNewsletter
- At conferences including
 - A Nurse masterclass at RASoR
 - Australian Rheumatology Association/RHPA Conference

Interviews

The surveys noted to respondents that AHHA were seeking volunteers for an in-depth interview for case studies, and asked whether they were willing to be contacted.

Interviews were held over May to July 2017 with:

- 8 rheumatology nurses
- 3 rheumatologists
- 1 social worker involved with paediatric rheumatology
- 1 person involved in the management of rheumatology nursing services
- 2 patients with arthritis
- 1 carer for a paediatric patient with arthritis.

Each interview lasted between 20 and 45 minutes.

A smaller number of patients/carers were interviewed because the patients and carers generally provided much more detailed written comments in the survey, lessening the need to ask additional questions.

1. Who is in the rheumatology nursing workforce in Australia? Who do they work with and who are their patients?

Highlights

- There are approximately 50 rheumatology nurses practising in Australia. Less than one-third of this workforce work full time, with an estimated 39 full time equivalent rheumatology nurses in Australia.
- The most common practice setting for rheumatology nurses was in public hospital outpatient clinics.
- Less than one-quarter of patients with arthritis had seen a rheumatology nurse as part of their care. Paediatric patients were more likely than adults to have seen a rheumatology nurse, probably because a larger proportion of paediatric rheumatology clinics are in public hospitals compared with adult services.

Background from literature review

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. Terminology around the role further complicates gathering information about the role. 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.

Rheumatology nurse survey respondents

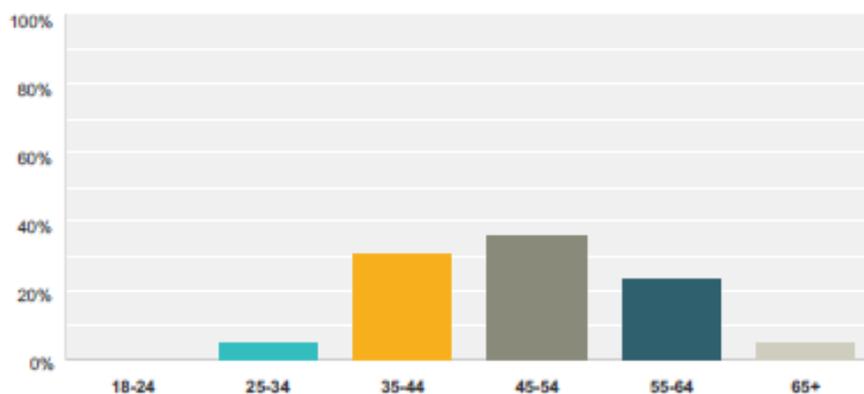
Age and gender of respondents

52 respondents to the survey identified as a rheumatology nurse. Following exclusion of responses with no useful data, 39 were suitable for inclusion for further analysis. Interviews were conducted with eight rheumatology nurses, two of which had not responded to the survey, bringing the total respondents in this study to 41.

While there is no systematic collection of data relating to rheumatology nurses in Australia, 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 this publicly available information identified 54 rheumatology nurse positions in Australia. It is believed this approximately reflects the size of the workforce, and while there is no identifier that can be used to consistently determine the extent to which survey respondents' overlap/correlate with the nurse positions identified, there is confidence that responses have been captured from approximately 80% of the rheumatology nurse workforce.

The majority of respondents were female (97%) and aged in the 45-54 age group (see Figure 1). 79% of respondents saw adult patients and 21% saw paediatric patients.

Figure 1: Age distribution of rheumatology nurse respondents



Geographical settings of respondents

Respondents were most commonly located within a major city: 51% identified spending all of their time working in this location, with another 8% spending 75-80% of their time working from within a major city.

27% identified spending all of their time working within regional centres/large towns.

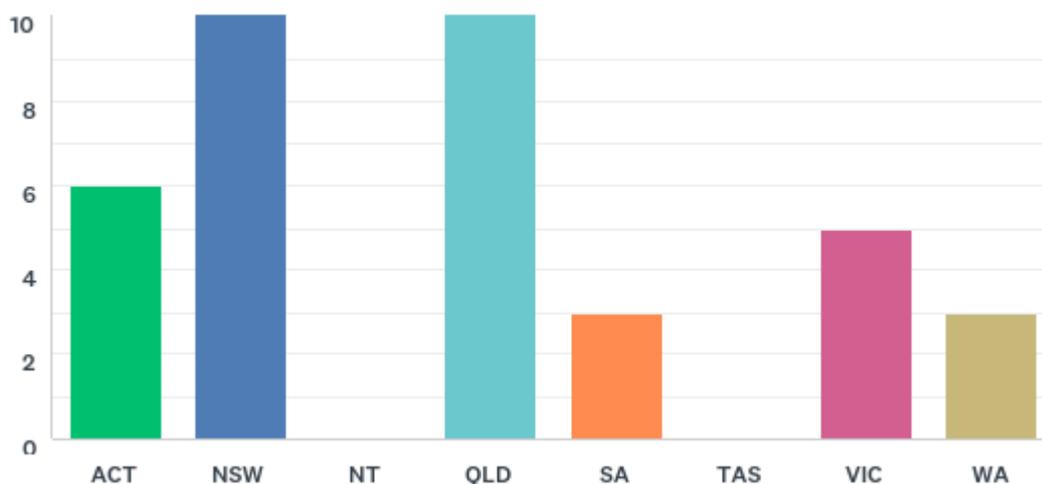
5% identified spending all of their time working within a rural location, of which half were telehealth services and half were permanent practices/clinics.

Table 1 describes the geographic location of where rheumatology nursing occurs. Figure 2 identifies the states/territories where respondents primarily practised.

Table 1. Geographical locations of where rheumatology nursing occurs

% of total time dedicated to rheumatology nursing spent in these locations	
Major city	63%
Regional centre/large town	31%
Rural location	6%
Remote location	0.3%

Figure 2. States/territories where rheumatology nurse respondents practice (number of respondents)



Practice settings of respondents

The most common practice setting for respondents was in public hospital outpatient clinics: 68% identified working in this setting. Of those working in this setting, an average of 66% of their time was spent there (range 7-100%).

Table 2 describes the practice settings of respondents. Only 32% of respondents spent their time in a single practice setting. Only 34% worked full time, the remaining working part-time (an average of 22.5 hours per week, range of 1.5 to 34 hours). If it is assumed that the 39 respondents are reflective of the estimated 54 rheumatology nurses in Australia, the number of full time equivalent (FTE) rheumatology nurses in Australia is 39.

15% of rheumatology nurse respondents identified that they worked with paediatric patients.

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%
Research institution	54%	23% (10-50)	6%
Public hospital inpatient ward	51%	17% (1-70)	9%
Nurse led clinic	32%	43% (10-100)	14%
General practice	8%	63% (10-100)	5%
Private hospital outpatient clinic	5%	70 (50-90)	neg
Educational institution	3%	100 (100)	3%
Private hospital inpatient ward	3%	6 (6)	neg

Rheumatologist survey respondents

Age and gender of respondents

15 respondents identified as a rheumatologist; all responses were considered suitable for inclusion in further analysis.

There were approximately an even number of male and female respondents, with the majority aged in the 45-54 age group (73%).

Geographical settings of respondents

Respondents were most commonly located within a major city: 54% identified spending all of their time working in this location, with another 38% spending 80-98% of their time working from within a major city.

15% identified spending all of their time working within regional centres/large towns.

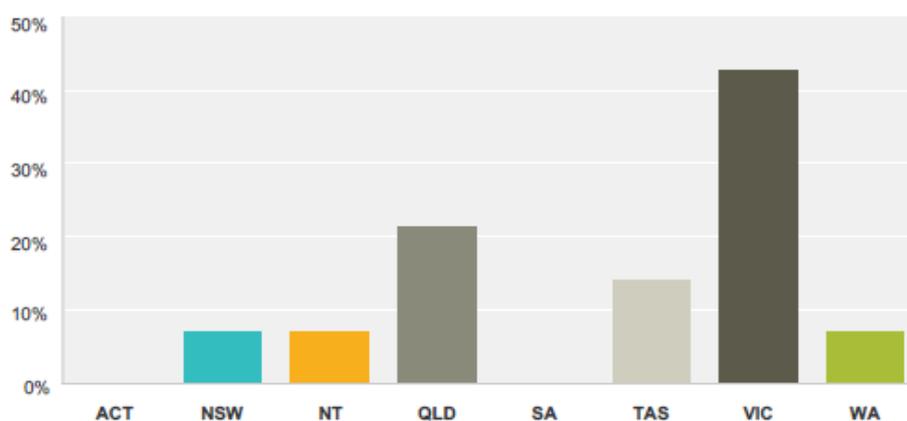
One respondent identified spending all of their time working within a remote location.

Table 3 describes the geographic location of where respondents practised. Figure 3 identifies the states/territories where respondents primarily practised.

Table 3. Geographical locations of where rheumatologist respondent practice occurs

	% of total time dedicated by the rheumatologist workforce in these locations
Major city	74%
Regional centre/large town	17%
Rural location	1%
Remote location	8%

Figure 3. States/territories where rheumatologist respondents practice (% by number of respondents)



Practice setting of respondents

Table 4 describes the practice settings of respondents. The practice settings of respondents does not align with what is known about rheumatology practice in Australia, where 80% has been reported to occur in

private practice. As such, respondents are more likely to have been exposed to models of care involving rheumatology nurses.

Table 4. Practice settings of rheumatologist respondents

Practice setting	% of respondents who identified working in this setting	Of those working in this setting, average % of time spent there (and range)
Public hospital outpatient ward	85%	33% (14-70)
Private rheumatology practice	38%	47% (20-100)
Research institution	31%	38% (20-80)
Public hospital inpatient ward	92%	21% (1-70)
Nurse led clinic	8%	18% (18)
Private hospital outpatient clinic	8%	25 (25)
Educational institution	46%	34 (1-85)
Private hospital inpatient ward	0%	0 (0)

One respondent also identified working in a bulk-billing rural clinic.

Experience of working with a rheumatology nurse

All rheumatologists responding to the survey had worked with a rheumatology nurse.

The majority had worked with the nurse in the context of a service offered by the hospital (77% of respondents). Other contexts included:

- Through referral of patients to the 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%)
- In research (8%).

One respondent had worked with rheumatology nurses in the United Kingdom.

Other clinical workforce survey respondents

Professions of respondents

29 respondents identified as a part of the clinical workforce (but not as a rheumatologist or rheumatology nurse); all responses were considered suitable for inclusion in further analysis.

The professions reported by respondents are provided in Table 5.

Table 5. Clinical workforce respondents in rheumatology care

	% of respondents in this profession
Physiotherapists	38%
Registered nurse or midwife (not rheumatology)	21%
Social worker	7%
Other	34%

Other respondents included a clinical psychologist, general practitioner, chronic pain physician, audiologist, specialist sonographer, rheumatology trainee, occupational therapist, coordinator, research assistant and health educator specialist.

Geographical settings of respondents

Respondents were most commonly located within a major city: 59% identified spending all of their time working in this location, with another 7% spending 80-90% of their time working from within a major city.

19% identified spending all of their time working within regional centres/large towns.

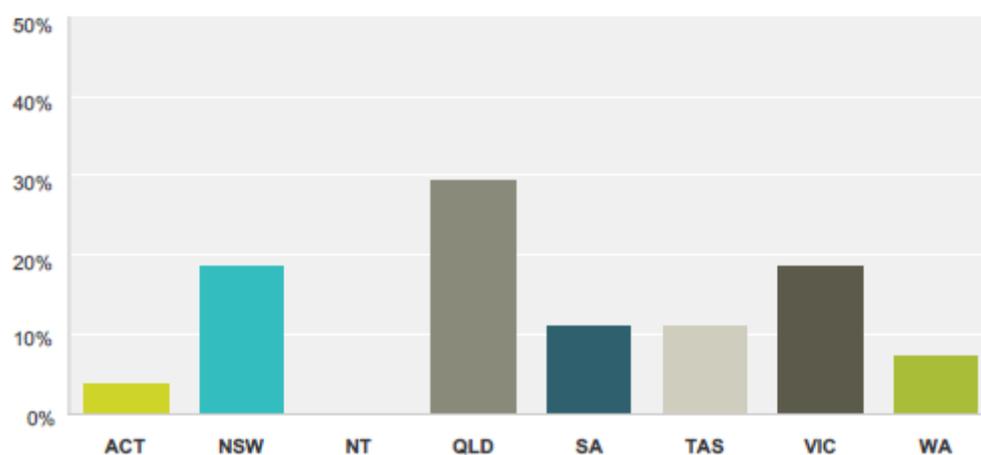
One respondent identified spending all of their time working within a remote location.

Table 6 describes the geographic location of where respondents practised. Figure 4 identifies the states/territories where respondents primarily practised.

Table 6. Geographical locations of where clinical workforce respondents practice

	% of total time dedicated by the clinical workforce in these locations
Major city	71%
Regional centre/large town	23%
Rural location	6%
Remote location	neg

Figure 4. States/territories where clinical workforce respondents practice (% by number of respondents)



Practice setting of respondents

Table 7 describes the practice settings of respondents.

Table 7. Practice settings of clinical workforce respondents

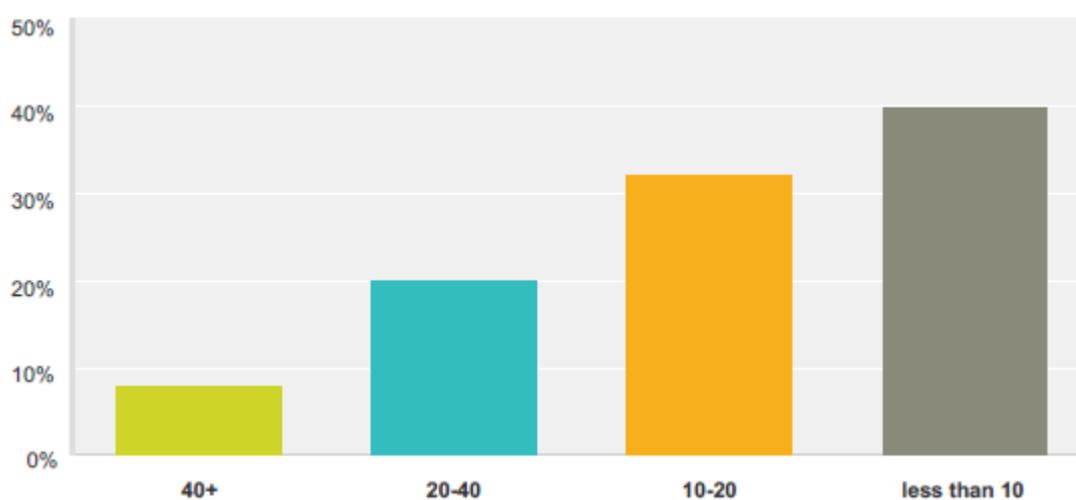
Practice setting	% of respondents who identified working in this setting	Of those working in this setting, average % of time spent there (and range)
Public hospital outpatient ward	56%	60% (15-100)
Private rheumatology practice	20%	68% (18-100)
Research institution	12%	43% (20-80)
Public hospital inpatient ward	44%	24% (5-80)
General practice	20%	56% (1-100)
Nurse led clinic	8%	60% (20-80)
Private hospital outpatient clinic	8%	63 (25-100)
Educational institution	4%	40 (40)
Private hospital inpatient ward	1%	10% (10)

Other practice settings included a not-for-profit charity specialising in autoimmune illness, community services, own private practice, a hospital liaison role, and the emergency department.

Focus on patients with inflammatory forms of arthritis

The number of hours per week clinical workforce respondents spent focused on assisting patients with inflammatory forms of arthritis is displayed in Figure 5.

Figure 5. Hours per week that clinical workforce respondents spend focused on assisting patients with inflammatory forms of arthritis



Experience of working with a rheumatology nurse

60% of the clinical workforce responding to the survey had worked with a rheumatology nurse. The majority had worked with the nurse in the context of a service offered by the hospital (79% of respondents). Other contexts included:

- As part of their own practice or team (57%)
- Through nurse-led clinics (14%)
- Through referral of patients to the pharmaceutical company patient support programs (7%)
- Through education to assist in providing services for a rural area (7%).

For those who had not worked with a rheumatology nurse, the reason was primarily because one did not work within the service/practice of the respondent or within their networks.

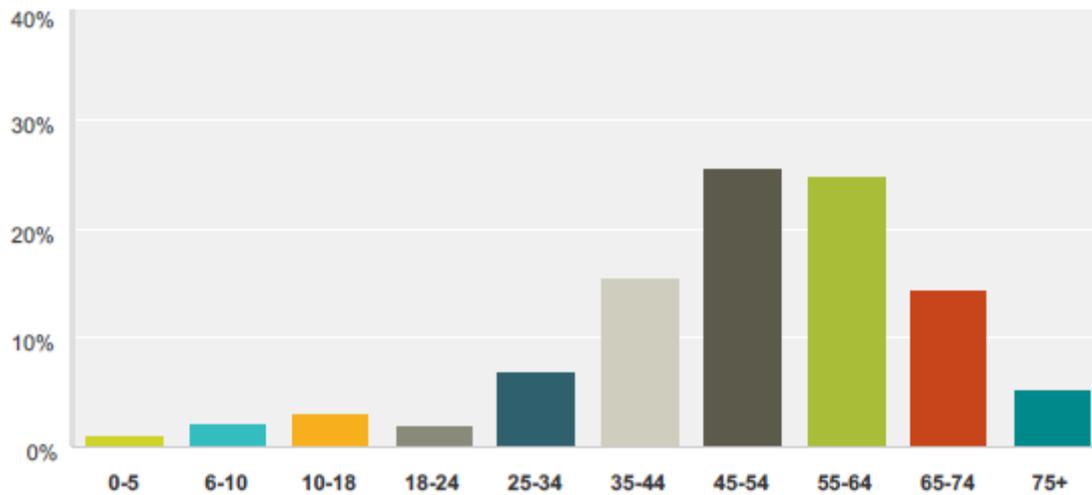
Consumer and carer survey respondents

Age and gender of patients

476 respondents identified as having arthritis (91%) or being a carer for someone with arthritis (9%). Following exclusion of responses with no useful data, 439 were suitable for inclusion for further analysis.

The majority of respondents were female (81%), and the majority of patients aged less than 55 years (56%; see Figure 6).

Figure 6: Age distribution of patients with arthritis within the survey responses



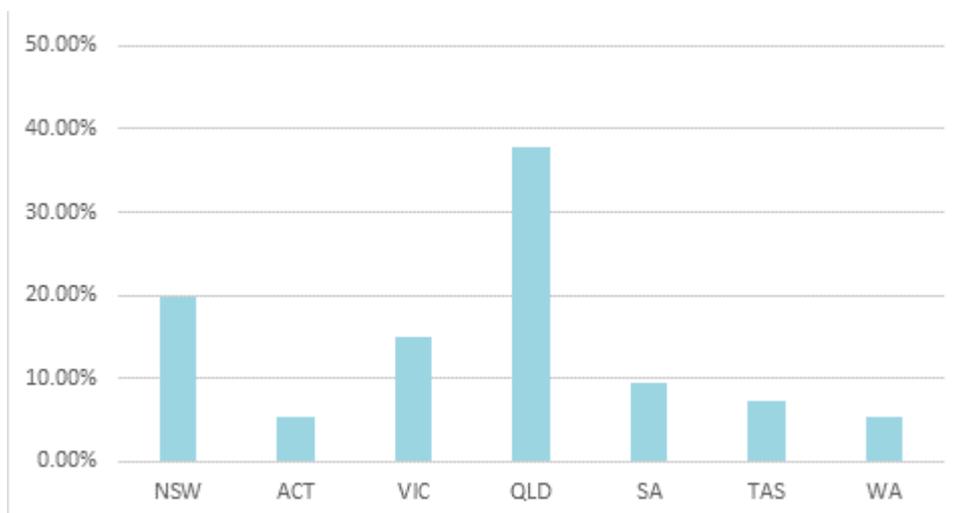
Geographical settings of respondents

Table 8 describes the geographic location of where respondents live. Figure 7 identifies the states/territories where respondents live.

Table 8. Geographical locations of patient and carer respondents

% living in these locations	
Major city	68%
Regional centre/large town	24%
Rural location	5%
Remote location	3%

Figure 7. States/territories where patient and carer respondents live (% by number of respondents)



Experience with care from a rheumatology nurse

While 85% of respondents have or are seeing a rheumatologist for their arthritis, only 23% of respondents have seen a rheumatology nurse as part of their care. This was primarily through a service offered by their hospital (62%). Other responses included at their specialist practice (34%), at a support program provided by a pharmaceutical company (5%), at a nurse-led clinic (1%) or a service provided by their general practice (1%).

Paediatric patients were more likely to have seen a rheumatology nurse as part of their care (56% of respondents), primarily through a service offered by their hospital (92%), with the remainder having seen them at their specialist's practice. This may reflect that a larger proportion of paediatric rheumatology clinics are in public hospitals compared to adult services.

Of those who had not seen a rheumatology nurse, the reasons provided were:

- The service wasn't offered (38%)
- They don't know if there is one (37%)
- No nurse is available at their specialist (12%)
- One was not required (8%)
- They have seen the practice nurse at their general practice (6%).

The medicines prescribed appears to influence whether care from a rheumatology nurse is more likely.

- 39% of respondents reported that they were taking a biologic medicine (ie Actemra, Brenzys, Cimzia, Enbrel, Humira, Inflectra, Orenzia, Remicade, Simponi, or Xeljanz). Of these, 46% had seen a rheumatology nurse, compared with only 8% of patients who were not taking a biologic medicine. This may reflect the complexity of the medicines and the fact that many are given by infusion or injection, where nursing support is required (e.g. with dedicated biologic nurses).
- 42% of respondents reported taking methotrexate. Of these, 22% had seen a rheumatology nurse, similar to those patients who were not taking methotrexate (24%).

2. What are the roles and scope of activities for rheumatology nurses in Australia?

Highlights

- Rheumatology nurses routinely see patients with a broad range of conditions.
- Patients with these conditions start experiencing symptoms when they are young. More than half of patients started experiencing symptoms before the age of 35 years, with 70% experiencing symptoms before the age of 45.
- Only one in five patients considered their condition well-controlled or in remission; most identified they still required some level of improvement in the management of their condition.
- Rheumatology nurses undertake a broad range of activities. Rheumatologists, the clinical workforce and consumers/carers support an even greater contribution.
- There is no formal pathway towards becoming a rheumatology nurse. There is general support that this should involve both 'on-the-job' training and formal courses or qualifications.

Background from literature review

General practitioners 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 is critical. It is being increasingly recognised that disease modifying anti-rheumatic drug (DMARD) therapy should be commenced early to arrest progressive disease and joint destruction. Ideally DMARD therapy should be initiated by a rheumatologist, so appropriate early referral from the GP to a specialist rheumatologist is essential.

However, with the current number and distribution of rheumatologists, people in Australia face long delays in accessing specialist care. In 2012, half of all patients had to wait more than the recommended period for an urgent initial consultation with a rheumatologist.

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 development of the rheumatology nursing role is in its infancy but evolving rapidly, with studies exploring and evaluating their contribution to care.

The European League Against Rheumatism (EULAR) provides recommendations, based on best evidence and expert consensus, for the role of the nurse in the management of chronic inflammatory arthritis. Recommendations for the contribution of nurses to care and management related to:

- **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 in order that patients might 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.

Studies in the US and UK have identified similar roles and responsibilities for rheumatology nurses, as well as demonstrating the potential of using rheumatology nurses in the diagnostic process and the monitoring of DMARD therapy.

Position titles for rheumatology nurses

Rheumatology nurse survey results

Consistent with the wide range of terminology found in the literature, position titles varied considerably:

- 21% of titles reflected the focus of the role (e.g. Biologics, Clinical Trials, Paediatric, Scleroderma, Research)
- 13% of titles reflected the coordination aspect of the role (e.g. Clinical Nurse Coordinator, Nurse Care Coordinator)
- 13% of titles reflected the advanced nature of the role (e.g. Advanced Practice Nurse)
- 10% of titles reflect the specialist nature of the role (e.g. Clinical Nurse Specialist)
- 8% of titles reflected the setting in which services were provided (e.g. Telehealth, Outpatient Clinic).

Range of conditions seen in rheumatology practice

Respondents reported routinely assessing, or having, a wide range of rheumatology conditions in practice, with rheumatoid arthritis and psoriatic arthritis most commonly seen by rheumatology nurses (see Table 9).

Table 9. Conditions being routinely assessed in rheumatology practice

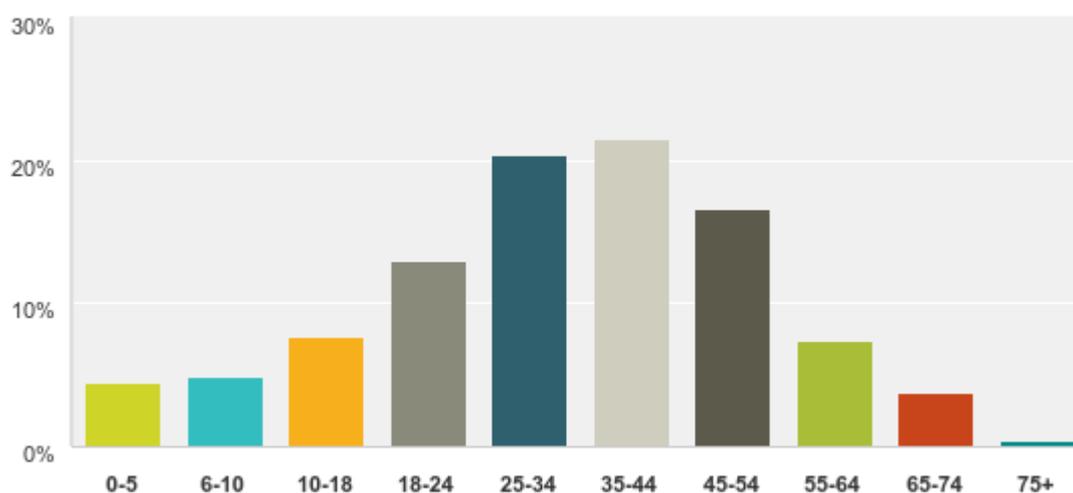
Condition	Conditions			
	% of rheumatology nurses reporting it is routinely seen	% of rheumatologists reporting it is routinely seen	% of clinical workforce reporting it is routinely seen	% of consumers and carers reporting they (or the person in their care) have it
Rheumatoid arthritis	71%	64%	76%	47%
Psoriatic arthritis	71%	86%	68%	10%
Ankylosing spondylitis	50%	71%	68%	15%
Systemic lupus erythematosus	32%	86%	64%	3%
Osteoarthritis	50%	71%	68%	39%
Osteoporosis	39%	71%	56%	7%
Scleroderma	36%	79%	60%	1%
Juvenile Idiopathic arthritis	32%	79%	48%	7%
Gout	39%	79%	44%	2%

Other conditions reported to be seen by rheumatologists and the clinical workforce, and had by consumers, included soft tissue, chronic pain, vasculitis, juvenile dermatomyositis, fibromyalgia, PMR, GCA, hypermobility syndrome, Sjogren's connective tissue disorders and various other auto-inflammatory and non-inflammatory musculoskeletal conditions in children.

Consumer and carer survey results

Half of patients for whom responses relate started experiencing symptoms before the age of 35 years, with 70% experiencing symptoms before the age of 45. Only 4% were 65 years or older when they started experiencing symptoms (see Figure 8).

Figure 8. Age when patients started experiencing symptoms of arthritis



Consumer respondents reported being at varying stages of arthritis (see Table 10). Only one in five respondents considered their condition well-controlled or in remission; most identified they still required some level of improvement in the management of their condition.

Table 10. Stage of arthritis of patients in which responses relate

Stage of arthritis	% of respondents
I have had my condition for more than a year and although it is not completely controlled, it is manageable	51%
I have had my condition for more than a year and I am not managing i.e. I am in a lot of pain and have difficulty managing everyday activities	24%
I have had my condition for more than a year and it is well controlled	17%
I have recently been diagnosed (less than 1 year)	5%
My condition is in remission	3%
It is suspected I have inflammatory arthritis but I have not yet been formally diagnosed	1%

Activities undertaken by rheumatology nurses

Respondents identified a broad range of activities undertaken by rheumatology nurses in their practice. Table 11 identifies the proportion of respondents who reported rheumatology nurses *currently* undertake each type of activity, along with whether they thought nurses *could* undertake each activity. The activities most commonly reported by rheumatology nurses were:

- Telephone/email support, advice and follow-up for patients
- Liaison with other health care professionals
- Patient education, support and counselling to improve self-management
- Administrative tasks.

Table 11. Activities undertaken by rheumatology nurses

Activities	% of rheumatology nurses who currently undertake each activity				% of respondents who think each activity would be appropriate for a rheumatology nurse to undertake			
	As reported by rheumatology nurses	As reported by rheumatologists	As reported by the clinical workforce	As reported by patients/carers who have seen a rheumatology nurse	As reported by rheumatology nurses	As reported by rheumatologists	As reported by the clinical workforce	As reported by all patients/carers
Patient education, support and counselling to improve self-management	93%	92%	64%	67%	93%	100%	82%	77%
Early diagnosis of arthritis	24%	23%	29%	26%	41%	42%	41%	10%
Disease assessment and monitoring	69%	62%	57%	72%	79%	83%	73%	71%
Ordering medical imaging	10%	15%	29%	44%	41%	25%	27%	34%
Reviewing medical imaging	21%	15%	29%		62%	17%	32%	
Performing physical assessment of the joints	62%	46%	50%	*	86%	83%	55%	*
Assisting with joint aspirations	45%	31%	21%	10%	72%	67%	45%	14%

Disease management	72%	38%	57%	56%	72%	33%	68%	66%
Administration of pharmacotherapy (such as steroid joint injections, biologic therapies)	72%	62%	64%	45%	76%	67%	55%	38%
Monitoring pharmacotherapy	66%	38%	50%	39%	79%	75%	59%	43%
Management of pharmacotherapy	52%	31%	50%		62%	42%	36%	
Medication counselling	86%	77%	71%	63%	83%	92%	73%	56%
Identifying and assessing psychosocial issues	79%	85%	79%	31%	79%	83%	82%	58%
Managing psychosocial issues	62%	62%	50%	15%	69%	75%	64%	29%
Care coordination	83%	92%	64%	42%	79%	83%	91%	63%
Telephone/email support, advice and follow-up for patients	97%	100%	71%	69%	90%	100%	82%	61%
Administrative	93%	77%	71%	*	83%	92%	64%	*

tasks								
Teaching and training other health professionals	69%	31%	64%	*	79%	75%	55%	*
Referrals to other specialists or departments e.g. physiotherapy	48%	31%	64%	*	72%	33%	68%	*
Clinical trials	55%	38%	50%	*	79%	75%	77%	*
Liaison with other health care professionals	97%	n/a	n/a	*	90%	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.

Other activities undertaken by rheumatology nurses that were identified by rheumatologists included research, service development (e.g. business plans), and development of care pathways. The clinical workforce identified that the activities performed by rheumatology nurses would depend on the patient's access to a knowledgeable GP or rheumatologist: *'If limited, need nurses to offer more.'*

Rheumatologists were asked about any activities they believed should not be undertaken by rheumatology nurses. Areas of concern reported included:

- Prescribing DMARDs, biologic and chemotherapy agents
- Ordering investigations beyond plain imaging and monitoring bloods
- Surgery.

One rheumatologist stated: *'I think the issue is what can be safely undertaken by nurses, particularly nurse practitioners, independent of the Rheumatology team and consultant supervision. I have worked with many Rheumatology nurses who function at a similar level as a registrar in assessing and managing inflammatory arthritis in an outpatient clinic, but they do not have the same skills in assessing more complex or unusual presentations, and co-morbidities. The final responsibility for the patient, as with registrars, lies with the consultant with appropriate delegation relative to competence.'*

The clinical workforce identified the following activities as inappropriate for being undertaken by rheumatology nurses:

- Aspirations and diagnosis
- Prescribing and changing medications
- Physical therapies
- Imaging
- Managing psychosocial issues.

Skills required by rheumatology nurses

Rheumatology nurses identified a broad range of skills required in their role. Table 12 identifies the proportion of respondents who think that skill is required by rheumatology nurses. The skills most commonly reported as being needed were:

- Providing psychosocial support
- Providing education to patients
- Interpreting clinical and laboratory data
- Monitoring the safety and efficacy of disease-modifying anti-rheumatic drugs (DMARDs).

Table 12. Skills required by rheumatology nurses

Skills	% of respondents who believe the skill is required (as reported by rheumatology nurses)
Performing physical assessment of the joints	89%
Interpreting clinical and laboratory data	95%
Performing joint aspiration or joint/soft tissue injection	8%
Administering medications (e.g. intramuscular injections, infusions etc)	86%
Monitoring the safety and efficacy of disease-modifying anti-rheumatic drugs (DMARDs)	95%
Pain management	81%
Physical activity prescription	62%
Diagnosing new patients	16%
Prescribing medications	8%
Assessing psychosocial health	81%
Providing psychosocial support	100%
Assessing for co-morbidities	81%
Providing education to patients	100%

Other skills identified by respondents as being needed included an understanding of Medicare/PBS requirements and criteria, skills in triaging urgency of rheumatological referrals/problems, skills in coordination of care, knowledge and skills to access appropriate community supports and skills in advocating for patients.

Some respondents also noted that some skills should be limited to nurse practitioners, e.g. performing joint aspirations, diagnosing new patients and prescribing medications.

Pathways and training for rheumatology nurses

Rheumatology nurse survey results

The majority of rheumatology nurse respondents were registered nurses (97%), with the one remaining respondent holding a non-registrable role. One of the registered nurses had endorsement as a nurse practitioner (including the prescribing of scheduled medicines) and one had endorsement to supply scheduled medicines (rural and isolated practice).

Respondents had entered their rheumatology nurse role primarily:

- Through an interest in chronic care more generally
- Following research and clinical trial positions in rheumatology

- As an extension of roles in a rural area (e.g. telehealth)
- By accident/chance... they 'fell into it.'

65% of respondents had gained post-graduate qualifications: 40% of these were in a musculoskeletal, rheumatology or orthopaedic area (seven respondents had completed the Graduate Certificate in Musculoskeletal and Rheumatology Nursing). Qualifications not related to these areas were typically in other nursing areas such as diabetes, emergency nursing, oncology, anaesthesia, sexual and reproductive health, rural and remote nursing, and primary and community care. Some were more general such as in marketing or in training and assessment.

34% of respondents had completed other training relevant to rheumatology nursing. This included hospital training (e.g. on-the-job tutorials, joint count training), online training (e.g. EULAR, Ausmed, pharmaceutical-sponsored), Rheumatology Health Professionals Association scientific meetings, pharmaceutical-sponsored conferences and self-led reading.

77% of respondents reported being a member of a nursing professional body, with the Rheumatology Health Professionals Association cited most frequently (by 70% of those who held any membership).

The majority of respondents (72%) had worked in a rheumatology nurse role for greater than five years. Respondents commonly felt that the training required to become a rheumatology nurse should involve:

- On-the-job training for 6-12 months, followed by
- A post-graduate course, with recommendations ranging from online modules and CPD requirements, to post-graduate qualifications at Certificate IV through to Master's degree level.

Rheumatologist survey results

Rheumatologists reported that experience in the area was the most important preparation for rheumatology nurses.

There were varying views on the additional education that would be required, from continuing professional development to a postgraduate diploma to a Master's qualification. Some felt that the nurse practitioner requirements were too onerous, but this may reflect the spectrum of potential roles, with one reporting: *'Nurse practitioner would be ideal to run nurse led clinic'* and *'Nurse practitioner qualification if involved in patient assessment.'*

As one rheumatologist reported: *'depends on their scope of practice – some could be up skilled without formal course – others if they want to inject joints or prescribe or order investigations have to be educated to a level where they make optimal decisions.'*

Clinical workforce survey results

Like with rheumatologists, the clinical workforce had varying views on the additional education that would be required, from continuing professional development to a postgraduate diploma to a Master's qualification (as required for a nurse practitioner role). Experience through supervised practice (e.g. for a year) was also identified by some respondents.

One respondent noted the dependence on the role: *'Some none, others nurse practitioner.'*

3. What models of care incorporate rheumatology nurses into care in Australia?

Highlights

- There is no standard model of care incorporating rheumatology nurses into care in Australia.
- The model most preferred by rheumatologists and other members of the clinical workforce is with rheumatology nurses working collaboratively with a team of clinicians.
- Consultations with rheumatology nurses may be held prior to the patient seeing their specialist, in conjunction, as follow up, or as needed.
- Consultations were most commonly held face-to-face, but consultations by phone, email or web-enabled video were also conducted. Patients showed openness to all consultation types.
- Rheumatology nurses tended to spend longer with patients than rheumatologists. On average, consultations with new patients took around 50 minutes, while consultations for routine review took around 30 minutes.

Background from literature review

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.

In Australia, models of care that have been developed include:

- A Rheumatology Nurse Practitioner model that aims to build the capacity and capability of the multidisciplinary team. The nurse practitioner is based in the hospital and works autonomously and collaboratively with outpatients, biologics clinic, specialist clinics, inpatient wards and day units, among others. They perform tasks such as the direct referral of patients, prescribing medications and ordering diagnostic investigations.
- A Rheumatology Nurse model where the nurse undertakes tasks such as coordinating and conducting assessments, monitoring medication toxicity, scheduling reviews, performing audits and ensuring continuing of PBS funded therapy.
- A Clinical Nurse Consultant model for paediatric care where a nurse provides care coordination of all services, targeted and specific child and family education, ongoing family support and nursing care for the child.
- A Rheumatology clinic model where a nurse triages referrals and monitors disease activity, also communicating with GPs and pathology providers.

There are also many other models used in Australia for nurses in extended and specialised roles in other clinical areas.

Internationally, rheumatology nurses have taken on roles to substitute for rheumatologists in the diagnostic process, monitoring biologic therapies in nurse led rheumatology clinics, providing telephone advice and consultations from clinics, as well as leading injection clinics.

Models of care with rheumatology nurses

Rheumatology nurse survey results

Rheumatology nurses work within a variety of models of care:

- 34% work collaboratively with a team of clinicians
- 34% work by themselves directed by another clinician
- 21% work by themselves under their own direction (autonomously)
- 10% work with one other clinician.

Those working within a team of clinicians identified rheumatologists primarily, but also medical practitioners (registrars, junior medical officers, advanced trainees), physiotherapists, occupational therapists, clinical psychologists, social workers, school liaison teachers, other rheumatology nurses and inpatient ward staff.

Rheumatologist survey results

Rheumatologists reported that they thought rheumatology nurses should mostly work collaboratively with a team of other clinicians (83%), with some believing they should work collaboratively with one other clinician (33%) and by themselves directed by another clinician (25%). None of the rheumatologists surveyed believed that rheumatology nurses should work by themselves under their own direction (autonomously).

Clinical workforce survey results

The clinical workforce reported that they thought rheumatology nurses should mostly work collaboratively with a team of other clinicians (91%) or with one other clinician (77%). Some believed they should work by themselves directed by another clinician (45%). Few believed they should work by themselves under their own direction (autonomously) (9%).

Types of reasons for seeing patients

Rheumatology nurse survey results

79% of respondents saw adult patients and 21% saw paediatric patients. Table 13 lists the types of reasons that respondents saw patients. The comparison between those seeing adult versus paediatric patients reflects there is much less variability when it is paediatric patients being seen.

Table 13. Reasons rheumatology nurses see patients

	Adult patients	Paediatric patients
New patients	70%	67%
Routine review patients	91%	100%
Urgent review patients – flare/complications	70%	100%
Clinical trial patients	61%	33%
Patients on biologics	87%	100%
Patients requiring education about medication or biologics	83%	100%
Patients requiring review of medication or biologics	70%	100%

Other reasons provided by respondents for seeing patients included when juvenile patients are transitioning to adult care and when wound care is required.

Nurse involvement in the patient's journey

Rheumatology nurse survey results

Rheumatology nurses 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).

Consultations may also have occurred following referral from general practice or primary care (24% of respondents), around clinical trial timetables, during admissions to hospital, and around biologic infusion schedules.

38% of respondents identified involvement in nurse-led clinics, with the number of clinic sessions held each week varying from 1 to 20.

Consumer and carer survey results

Of patients and carers who reported having seen a rheumatology nurse in their care, consultations were most commonly in conjunction with seeing their specialist (54%), prior to seeing their specialist (34%), as needed (32%) or as follow up to seeing their specialist (28%). Others reported they were 'gatekeepers' to the specialists. 53% reported that nurse appointments were routinely offered.

Of patients and carers who reported having seen a rheumatology nurse as part of their care, 61% reported that the rheumatology nurse was available at every specialist appointment.

Of the patients and carers who reported having seen a rheumatology nurse as part of their care, 92% reported that consultations were face-to-face, 65% reported consultations were by telephone and 47% reported consultations by email. However of all patients and carers responding to the survey, preferences

for how rheumatology nurses are accessed showed openness to all types of consultation types (86% face-to-face; 68% telephone; 62% email and 31% skype or other web-enabled video).

A typical clinic

A 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.'

A breakdown of how the workforce's time is spent

Rheumatology nurse survey results

All respondents conducted consultations with patients face-to-face. Consultations with new patients were allocated, on average, 50 minutes (ranging from 15 to 120 minutes). Consultations with patients for routine review were allocated, on average, 31 minutes (ranging from 5 to 90 minutes). Face-to-face consultations made up 37% of the nursing workforce's time (32% in outpatient settings; 5% in inpatient settings), although time spent by individuals ranged from 2% to 85% of their working hours.

93% of respondents provided consultations by telephone, and 72% provided consultations by email. Skype or other web-enabled video and text support was also identified by some respondents. Telephone/email support constituted 16% of the nursing workforce's time, although time spent by individuals ranged from 3% to 50% of their working hours.

48% of respondents provided support for clinical trials. This made up 12% of the nursing workforce's time, although time spent by individuals ranged from 1% to 100% of their working hours.

Clinical administration (e.g. reviewing scans) made up 8% of the nursing workforce's time. Clerical administration made up 15%. Training/education of other health professionals made up 3%, as did their own CPD.

How rheumatology nurse roles are funded

A range of funding sources were identified by respondents (see Table 14), sometimes with multiple funding sources used for a single role.

Table 14. Funding sources for rheumatology nurses

	% of respondents who receive funding from this source for rheumatology nurses		
	As reported by rheumatology nurses	As reported by rheumatologists	As reported by the clinical workforce
Public hospital	57%	77%	86%
Clinical drug trials	29%	7.7%	0%
Private practice	18%	7.7%	7%
Academic institution	14%	15%	14%
Pharmaceutical company	11%	31%	7%
Charity/NGO funded	11%	7.7%	7%
Private billing (patient pays directly)	4%	0%	0%

The seriousness of rheumatology conditions needs to be recognised for adequate funding

'At one stage, with no rheumatologists located outside Perth, an outreach program was established by the rheumatologists to meet the needs of patients in regional and rural Western Australia. The model involved clinics being held around the state. A rheumatology nurse would set up a clinic in a regional public hospital a few days before a rheumatologist would attend for consultations. Independently they could triage referrals, organise blood tests and results. They were linked with a specific rheumatologist so they could build a relationship with them.'

'The model worked well. Patients got continuity in their care with the rheumatology nurse providing support. Face-to-face consultations for those initial appointments are so important, and this way the cost for travel and being away from home was minimised. This is particularly important for people with inflammatory arthritis; travelling long distances compromises their function and they end up hospitalised. Not an ideal outcome and it affects the whole family.'

'The clinics also provided a training centre; rheumatologists would take registrars out to see cases you don't see in metro areas. It was a real team approach, with the nurse the linchpin between them all.'

'The model has since been eroded with decentralisation of funding from government. Patients are taking up hospital beds, but it is the complication of rheumatoid arthritis that is recorded rather than rheumatoid arthritis, so the stats around the seriousness of the problem are skewed.'

4. What is the perceived and actual value of rheumatology nurses?

Highlights

- More than half of patients experienced delays in diagnosis of more than a year.
- Involvement of a rheumatology nurse substantially improved patient satisfaction with all aspects of care, including the information they received at the time of diagnosis and for ongoing management; the support they received at diagnosis; and their access to care during a 'flare up'. Referral for additional support or treatment was also greater, highlighting their role in supporting multidisciplinary care.
- Patient satisfaction rates were more than double when a rheumatology nurse was involved with care for support received for their emotional and mental wellbeing and the coordination of the various aspects of care.
- The greatest value from rheumatology nurses in patient care is when patients have been recently diagnosed, are having a flare-up of their condition, or are not coping emotionally.
- Patients who had a rheumatology nurse involved in their care were less likely to identify 'Dr Google' and online forums, or their GP as the first point of contact when they had questions about managing their condition.
- Other health professionals believed rheumatology nurses increased the efficiency, effectiveness and timeliness of care for patients with arthritis.
- The greatest barrier to rheumatology nurses contributing to their full potential was funding.

Background from literature review

There is evidence from international trials that nurse led care in people with rheumatoid arthritis can achieve broadly similar health outcomes compared with rheumatologist led outpatient care, but at a reduced cost. In addition to positive results in terms of disease-specific outcomes and cost-effectiveness, patient self-management, the patient's perceived ability to cope with arthritis and patient satisfaction have been shown to be improved through this complementary role.

Studies of specialist nursing roles in Australia (but not rheumatologist nurses) have similarly identified positive outcomes in terms of both disease-specific outcomes and cost-effectiveness.

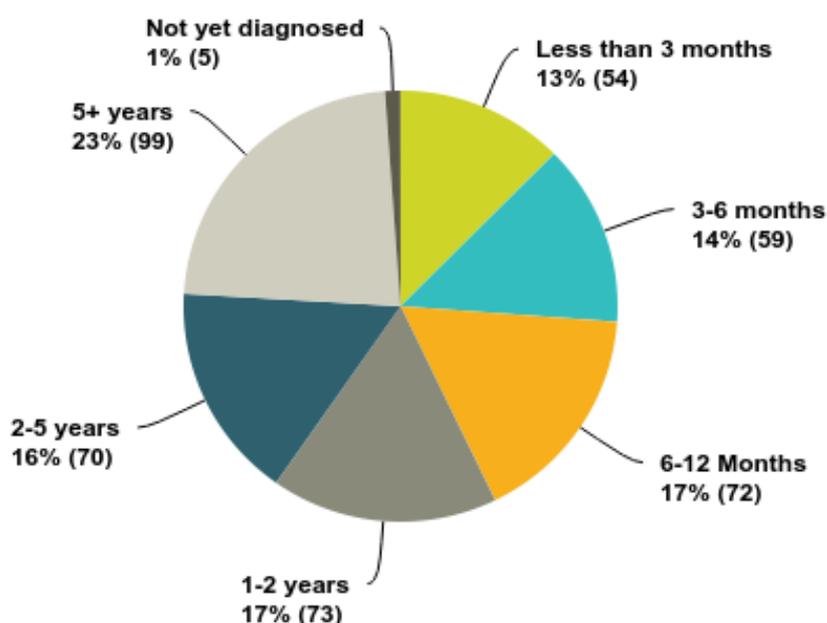
At the same time evidence in Australia has shown that people with rheumatoid arthritis have reported they have to navigate and coordinate services for themselves which is one of the key identified roles for rheumatology nurses. This is particularly problematic for people who lack the health literacy or language skills to do this effectively leading to poorer outcomes, increased health care costs and wider economic costs as people with rheumatoid arthritis are forced to reduce work hours or leave the workforce.

The patient's experience

Timeliness of care

Consumer respondents reported great variation in the time from when they first noticed symptoms to when they received their diagnosis (see Figure 9). More than half of patients experienced delays in diagnosis of more than a year. This did not vary significantly with the type of arthritis, nor whether the patient had experienced care from a rheumatology nurse or not.

Figure 9. Time between first noticing symptoms and receiving their diagnosis



For those patients who have or are seeing a rheumatologist, there was also great variation in time waited for an initial appointment. It took on average, 12 weeks for an initial appointment with a rheumatologist. 16% waited six months or longer, with one patient reporting waiting 12 years (this outlier was not included in the data average calculation). This did not vary significantly with whether the patient had experienced care from a rheumatology nurse or not.

Understanding of their condition and treatment

The majority of patients for whom responses relate reported they had quite a good understanding of their condition and its treatment, while they don't know everything, they know how to find answers if needed (see Table 15).

Table 15. Patient understanding of their condition and its treatment

Level of understanding	Perception by patients		
	Overall	Of those who have seen or had the assistance of a rheumatology nurse	Of those who have not seen or had the assistance of a rheumatology nurse
Extremely well, there is very little I don't know about my condition	19%	19%	19%
Quite well, I don't know everything but I know how to find answers if need them	58%	67%	55%
Ok, I know a bit but think there is quite a lot I don't know and it can be hard to find answers	20%	13%	22%
Not well, I have lots of questions and am not sure how to find answers	3%	1%	4%
I don't understand it at all	neg	0%	neg

How they are coping with their condition

The majority of patients for whom responses relate reported that are coping ok, but do struggle sometimes (see Table 16).

Table 16. How patients are coping with their condition

Level of coping	Perception by patients		
	Overall	Of those who have seen or had the assistance of a rheumatology nurse	Of those who have not seen or had the assistance of a rheumatology nurse
I'm coping very well	17%	28%	14%
I'm ok but I do struggle sometimes	66%	61%	67%
I'm struggling with my condition	17%	10%	19%

Of those who are struggling with their condition:

- A carer reported: *'We find it very difficult to watch our daughter struggle with the pain & depression she is having. It has affected her self confidence & social life. Financially it is difficult for all of us.'*
- A patient reported: *'I'm ok but I struggle a lot. I try and keep a positive mindset though and I'm trying to use chronic pain management techniques to manage and stay positive.'*
- A patient reported: *'And I see myself struggling further as my joints deteriorate.'*
- A patient reported: *'Over the 55 yrs that I have had RA, there have been times when it was in remission and times when it was very severe. When I was a child, there were very few children with RA so I was very alone. Then throughout my teens and twenties, I was never really informed about my disease or the side effects of drugs or my limitations or even the future. Things seemed to change over the last 20 years and doctors offer more education. I was never offered any counselling and I believe my life would have been much easier and happier if someone could have understand how traumatic this disease is for a child, a teenager and a young woman trying it deal with it.'*
- A patient 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. But I push myself to work full time, but my employment is often compromised by my condition.'*
- A patient reported: *'I still have flare ups. It has changed the person who I once was (I can't be as active and I am not as social anymore). It can impact upon my work and family when I am unwell. That is frustrating.'*

Access to treatment

The majority of patients for whom responses relate reported they have mostly or always been able to access treatment for their condition (see Table 17). Access was reported to be better by patients who have seen or had the assistance of a rheumatology nurse.

Table 17. Access to treatment when needed

Access to treatment when needed	Perception by patients		
	Overall	Of those who have seen or had the assistance of a rheumatology nurse	Of those who have not seen or had the assistance of a rheumatology nurse
Always	38%	52%	34%
Mostly	43%	44%	43%
Sometimes	15%	4%	18%
Rarely	4%	0%	4%

Concern was expressed by one patient about future access, reporting: *My rheumatologist 'is very well known in Hobart while an excellent Dr has announced his intention to retire Sept '17, although currently looking for a replacement it is not certain this can be arranged. All rheumatologists in Hobart have closed their patient list stating they do not wish to takeover any of my Rheumatologist's patients. My concern is I could left without adequate rheumatology care.'*

Who usually manages treatment?

Of those who had not seen or had the assistance of a rheumatology nurse, 55% identified their GP as one of the health professionals who usually manages their treatment. This contrasts with those who had seen or had the assistance of a rheumatology nurse, with only 34% identifying their GP as one of the health professionals who usually manages their treatment.

Who is the first point of contact when patients have questions about managing their condition, or the condition of the person they care for?

Of those who had not seen or had the assistance of a rheumatology nurse, 52% approached their GP as the first point of contact. Of those who had seen or had the assistance of a rheumatology nurse, only 25% approached their GP as the first point of contact, with 49% approaching the rheumatology nurse as the first point of contact.

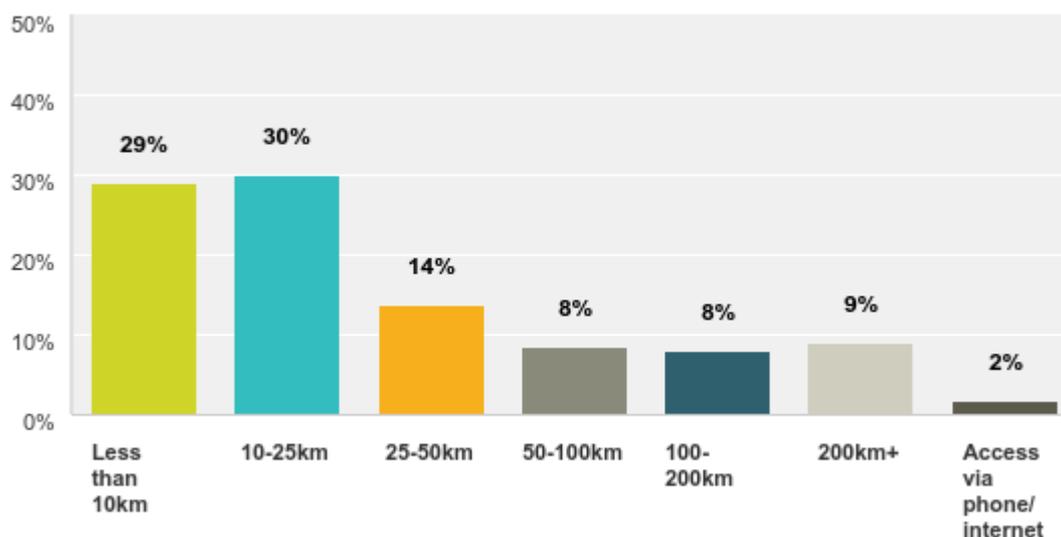
Patients also reported their own searches ('Dr Google' or online forums) as the first point of contact when they have questions about managing their condition: 3% of those who had seen or had the assistance of a rheumatology nurse, compared with 11% of those who had not seen or had the assistance of one.

First points of contact potentially vary with the patient's health literacy. At one end of the spectrum, a patient reported: *'depends on the issue - there is no one person that oversees my condition. I need to manage and to direct concerns as appropriate. This can be challenging process especially when you are unwell'*, while at the other end of the spectrum, a patient (who had not never had a rheumatology nurse involved in their care) reported: *'Gosh! I just suffer! My GP is all but useless & it takes weeks or months to see the rheumatologist.'*

How far do you have to travel to access rheumatologist treatment?

Of those who access rheumatologist care for their condition (91%), the majority of patients travel less than 50km (73%) to receive this care (see Figure 10). These results were unaffected by whether the patient had seen or had the assistance of a rheumatology nurse. One respondent who is required to travel 200km+ to see the rheumatologist stated: *'I have requested that I should be able to contact the Rheumatologist via video link so I don't have to travel to Brisbane just to get my script for the next six months.'*

Figure 10. Distance travelled to access rheumatologist care



Satisfaction with care

Patients for whom responses relate have varying levels of satisfaction with different aspects of care (see Table 18). Patient satisfaction was greater across all aspects of care in those who had seen or had the assistance of a rheumatology nurse.

Table 18. Patient satisfaction with care

Aspect of care	% of patients who were satisfied or very satisfied		
	Overall	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 your condition and its management	62%	78%	58%
The care they received at diagnosis	66%	87%	60%
The support they received at diagnosis	52%	81%	44%
The information and support they receive for the ongoing management of your condition	63%	91%	54%
The support they receive for your emotional and mental wellbeing	39%	68%	30%
The coordination of the various aspects of care for their condition	46%	82%	35%
Their ability to quickly access specialist advice or treatment for their condition (or the person they care for) when they need it e.g. during a flare	53%	80%	45%

Patients who had seen or had the assistance of a rheumatology nurse were also more likely to be satisfied or very satisfied with the information they had received about their medicines, 93% compared with 65% of patients who had not seen or had the assistance of one.

Additional support

Within the responses, 66% of patients have received additional support or treatment for their condition. However 25% indicated they were not aware of any additional support or treatment. Patients who had seen or had the assistance of a rheumatology nurse were accessing additional support or treatments more than those who were not. See Table 19.

Table 19. Additional support or treatment being received

Additional support or treatment received	% of patients who were satisfied or very satisfied		
	Overall	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
Yes – I was referred	34%	54%	28%
Yes – I found it myself	32%	24%	35%
No – I don't know of any additional support or treatment	25%	18%	27%
No – I would have like to but couldn't afford it	9%	4%	10%

Impact on life

Within the responses, 65% of patients have had their ability to undertake work or study affected by their condition (see Table 20).

Table 20. Extent of impact on ability to undertake study or paid work

Impact on work or study	% of patients reporting this impact on their ability to undertake work or study		
	Overall	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
I am unable to work or study due to the condition	21%	12%	23%
I have had to reduce my hours of work or study due to the condition	20%	22%	21%
I have had to change the type of work or study I do due to the condition	10%	12%	9%
I often have to miss days at work or study due to the condition	14%	20%	12%
The condition has not affected my ability to undertake work or study	18%	27%	16%
I am not in work or study or have reduced my hours for other reasons (eg retired)	17%	10%	19%

Within the responses, 43% of patients reported their condition had often or most of the time stopped or reduced their (or their carer's) ability to undertake social activities (see Table 21).

Table 21. Extent of impact on ability to undertake social activities

Impact on ability to undertake social activities	% of patients or their carers who report this level of impact on their ability to undertake social activities		
	Overall	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
Most of the time	14%	11%	15%
Often	28%	28%	29%
Sometimes	48%	46%	49%
Never	9%	16%	7%

A number of respondents identified that the most significant impact on their ability to participate in social activities was around the time of the initial diagnosis.

When patients are children

Those who care for children with rheumatology conditions (including carers, rheumatology nurses, rheumatologists, allied health workers) identified the unique issues faced when patients are children.

A rheumatology nurse spoke of the specific issues faced by carers of children and where timely access to a rheumatology nurse was so useful: *'getting the child to take the medication', 'managing medications around school with weekly dosing and when adverse effects might peak' 'education around children missing school because of pain and the need to involve the psychology team', 'the timing of infusions around school exams', and eventually 'transitioning patients into the adult system.'*

A social worker spoke of the value they saw that rheumatology nurses brought to the care of children, in particular *'having a 'go to' person, someone who knows them, knows the child's journey.'* *'The follow-through by nurses inspired confidence.'* They noted that it was a shame that a lack of resourcing prevented everyone from getting such a service, but children *'who were really unwell, needed significant intervention or were psychosocially more complex tended to be prioritised.'* *'Family dynamics' may also influence the care needed: 'conflict, separated parents, parents unable to understand what is required of them, the impact on siblings and parents.'*

When nursing support is of greatest value

Rheumatology nurse survey results

The stage in a patient's condition progress where nursing support was considered to be of greatest value was for patients who have recently been diagnosed, identified as when the greatest value was achieved by 77% of respondents. It was rated in the top 3 areas of greatest value by 91% of respondents.

Nursing support was also considered by respondents to be of higher value when patients:

- are having a flare-up of their condition. This was rated in the top 3 areas of greatest value by 82% of respondents.
- are not coping emotionally (e.g. are experiencing depression). This was rated in the top 3 areas of greatest value by 48% of respondents.

These were followed by those who have limitations in performing activities of daily living or who are changing medication.

Nursing support was considered to be of least value by respondents when patients are in remission. Lesser value was also placed on nursing support for patients for whom inflammatory arthritis is suspected but not yet diagnosed.

Respondents perceived the benefits of rheumatology nurses and improved patient satisfaction to be related to:

- Education (by 64%) – nurses had more time to provide education about the condition and the treatments
- Emotional support (by 60%)
- Navigation, coordination and patient advocacy (by 12%)
- Timely access (by 8%) – patients benefited 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 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
- Clinical administration (by 8%) – nurses undertake preparations for rheumatologist appointments, ensuring test results are available and PBS application requirements for biologics are met, to streamline consultations with the rheumatologist.

Respondents also considered their role to achieve health system cost savings, e.g. optimising care can reduce ED presentations, waiting times and efficiency of services through triage and nurse consultation systems can be improved, the burden on rural patients by supporting telehealth clinics when they may otherwise need to travel to metropolitan locations for care can be reduced, the time of rheumatologists can be freed up.

Rheumatologist survey results

The stage in a patient’s condition progress where nursing support was considered to be of greatest value was for patients who have recently been diagnosed, identified as when the greatest value was achieved by 55% of respondents. It was rated in the top 3 areas of greatest value by 73% of respondents.

Nursing support was also considered by respondents to be of higher value when patients:

- are having a flare-up of their condition. This was rated in the top 3 areas of greatest value by 78% of respondents.
- are not coping emotionally (e.g. are experiencing depression). This was rated in the top 3 areas of greatest value by 55% of respondents.
- are changing medication. This was rated in the top 3 areas of greatest value by 55% of respondents.

These were followed by those who have limitations in performing activities of daily living.

Nursing support was considered to be of least value by respondents for patients for whom inflammatory arthritis is suspected but not yet diagnosed. Lesser value was also placed on nursing support for patients who are in remission.

Respondents perceived rheumatology nurses improved the quality of care and efficiency of processes, with the benefits drawn from their:

- Education and support to 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.’*

Benefits to the health system that were identified by respondents included:

- Connecting care
- Improving patient safety and quality of care
- Reduced waiting times for new patients
- Reduced admissions
- Improved health outcomes and patient satisfaction.

One respondent noted it brought a *‘cost-effective management option for lower complexity patients.’*

Concern relating to costs was only expressed if nurses were ordering tests and imaging, noting that there may be a *‘lack of comprehension that an investigation should only be performed if the outcome will make a difference to management.’*

Education at the point of initial diagnosis is critical

A rheumatologist working in a public hospital environment spoke of the criticality of education to newly diagnosed patients. *‘A rheumatologist has no time for education so critical to newly diagnosed patients. It takes 15-20 minutes. Just no time. Give written information. A nurse could do this better.’*

Another rheumatologist working in both public hospital and private practice emphasised the need for patients to understand *‘the urgent components in the disease process, crises and how they can be managed appropriately’* and that rheumatology nurses could do this.

Clinical workforce survey results

The stage in a patient’s condition’s progression where nursing support was considered to be of greatest value was for patients who have recently been diagnosed, identified as when the greatest value was achieved by 58% of respondents. It was rated in the top 3 areas of greatest value by 74% of respondents.

Nursing support was also considered by respondents to be of higher value when patients:

- are having a flare-up of their condition. This was rated in the top 3 areas of greatest value by 88% of respondents.
- are changing medication. This was rated in the top 3 areas of greatest value by 63% of respondents.

These were followed by those who are not coping emotionally (e.g. are experiencing depression).

Nursing support was considered to be of least value by respondents for patients who are in remission and for whom inflammatory arthritis is suspected but not yet diagnosed. Lesser value was also placed on nursing support for patients who have limitations in performing activities of daily living.

Respondents perceived rheumatology nurses most improved the quality of care and efficiency of processes, with the benefits drawn from their:

- Education and support to patients – they have *'better listening skills and holistic attitude.'* *'A nurse with knowledge of joint disease is likely to have a greater understanding of the issues the patient may face and what needs they may have.'* They *'bring the human side into the equation. Patient advocate.'*
- Care coordination – they are *'a consistent contact point'* and *'provide a stable base and continuity for families to contact with questions, educated about medications, help with procedures and deliverance of medications and keep an eye on the wellbeing of vulnerable patients.'* They *'help with co-ordinating all the allied health care someone with RA needs.'*
- Access – Rheumatology nurses are *'often the first port of call for questions from families and patients which is essential to providing high quality care by educating and supporting the families and allowing the clinicians to manage more acute issues or be uninterrupted in clinics.'*

Respondents believed rheumatology nurses increased efficiency, effectiveness and timeliness of care. Workload could be distributed to allow more complex cases to be seen by the specialists.

A rheumatology trainee (training to be a rheumatologist) stated: *'They are an integral part of the rheumatology unit running smoothly. They allow education to be provided to families and patients in a timely manner with enough detail and provide continuity to patient care within a busy unit. They assist with procedures so other nursing staff are not required to undertake extra work. They answer many phone calls and are often the first port of call for questions from families and patients which is essential to providing high quality care by educating and supporting the families and allowing the clinicians to manage more acute issues or be uninterrupted in clinics. They prompt doctors if early reviews are required with disease flares and facilitate this process occurring. They liaise with other specialty units as required and play a crucial role in care coordination.'*

Consumer and carer survey results

The stage in their condition's progression where nursing support was considered to be of greatest value was for patients who have recently been diagnosed, identified as when the greatest value was achieved by 48% of respondents. It was rated in the top 3 areas of greatest value by 72% of respondents.

Nursing support was also considered by respondents to be of higher value when they:

- are having a flare-up of their condition. This was rated in the top 3 areas of greatest value by 71% of respondents.
- are not coping emotionally (e.g. are experiencing depression). This was rated in the top 3 areas of greatest value by 49% of respondents.

These were followed by those who are changing medication (rated in top 3 by 45%) and having limitations in performing activities of daily living (rated in top 3 by 44%).

Nursing support was considered to be of least value by respondents for patients who are in remission and for whom inflammatory arthritis is suspected but not yet diagnosed.

The benefits reported by patients and carers to having access to a rheumatology nurse were influenced by the types of activities/services they had experienced from their nurse. Greatest benefits were perceived by those receiving the full range of support, who reported benefits of:

- Time available for education and support (by 66%) – *‘it’s overwhelming when diagnosed and then trying the various medications and dealing with the reactions’, ‘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.’*
- Timeliness of access (by 23%) – they are *‘someone to call when need advice on how to manage my condition’, can answer questions ‘when rheumatologist away/busy’, they provide ‘access to quick advice when required.’*
- Care coordination specific to rheumatology needs (by 18%) – *‘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 (by 16%) – *‘Can keep down trips to specialists and doctors.’*
- Person-to-person care factor (by 6%) – *‘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.’*

One respondent stated: *‘Having a go to for support is very empowering.’*

These benefits reported were consistent with those perceived to be the benefits by patients who had not had access to a rheumatology nurse. 94% of respondents identified benefits to having access to a rheumatology nurse, overall perceiving a nurse would bring specialised knowledge about their condition and offer timely access to education and support, particularly during flares. Many reported it was a role that their GP did not offer: *‘I feel like my GP doesn’t know or care about my condition, thinks that’s the specialist’s job.’, ‘GP doesn’t have the knowledge to assist’, ‘Quick access when required’ and ‘GP has no experience in rheumatology.’*

Of those who reported having seen a rheumatology nurse, 41% believed having access to a rheumatology nurse reduced the number of times they have seen specialists and or their GP about their condition.

Where activities/services received by the patient were limited, some patients reported less or no benefit: *‘None – only of benefit to the doctor i.e. Administered injection for the doctor.’* An experience with a nurse who did not have sufficient knowledge led one patient to report no benefit: *‘They did provide education but it was incredibly poor and was not specific to young children (e.g. she talked about not getting tattoos, taking drugs or drinking too much alcohol). When I asked questions about current research or effects of her medications, she was unable to provide answers.... I don’t feel they have offered any benefits.’* One respondent reported having a great relationship with their rheumatologist and allied health support team, and so also perceived there to be less benefit in having a rheumatology nurse.

The involvement of a rheumatology nurse makes a visible difference

A rheumatology nurse in an adult public hospital outpatient clinic spoke of the anxiety a patient faces when they are first diagnosed with rheumatoid arthritis: *'They think of the joint deformities, the disablement',* after seeing the registrar/consultant, *'they are a bit like a deer in headlights.'* *'A rheumatology nurse provides the time to explain and education about the condition, about the process of contact with the health system, the tests that are done and why they are needed.'*

A social worker working in a paediatric public hospital observed the differences across many aspects of care when patients came from a private specialist practice that does not have a rheumatology nurse entered care: *'Paperwork was not as complete', 'families don't have an understanding of why they are there', 'the transition is not as smooth', 'the handover is not the same.'*

Rheumatology nurses contributing to their full potential

Rheumatology nurse survey results

The most frequently cited barrier to rheumatology nurses contributing to their full potential was funding. Reliance on clinical trial funding meant more time was spent on data entry than supporting patients. Positions in hospitals were often not permanently funded, unlike other specialist nursing roles, contributing to job insecurity and uncertainty.

Other barriers that were identified as needing to be addressed included:

- Standardisation and recognition of the role and expectations. One respondent expressed: *'Roles and expectations are not standardised, so not all rheumatology nurses do the same job roles or have the same responsibilities. Nurses are sometimes unsure of what their role involves and what they are allowed to do. Management are not familiar with rheumatology and what nurses can offer.'*
- A lack of understanding of the complexity of arthritis and connective tissue disease patients. One respondent expressed: *'Despite the statistical data regarding effects of musculoskeletal conditions on significant cost on economy and overall cost of health and social care systems in Australia as well as United States and Europe, public awareness about those effects still remains extremely low. Therefore there is a real need for health awareness campaigns and more government funding supporting those activities.'*
- Training and mentoring; support from colleagues.

Rheumatologist survey results

The most frequently cited barrier to rheumatology nurses contributing to their full potential was funding.

Role recognition, both in primary and secondary care, was identified as being needed: *'being aware of what the breadth of their skills are and what they can or cannot do administratively.'* However this may be complicated by each nurse and position being so different: *'each nurse and position are so different - there might be a nurse who does clinical trial only to another who fills in bDMARD forms to another who fields all the phone calls to another who educates - the same as some rheumatologists see SLE patients, other do lab based research, other teach in Med Schools, other work in industry.'*

Attitudes and low levels of acceptance by the rheumatology medical community was also identified as a key barrier. One respondent noted there needed to be *'development of trust between nurse and clinician and endorsement then of nurse to patient that better overall care can be provided by a team rather than a single clinician.'* It was identified that the Australian Rheumatology Association needs to embrace nurse

practitioners. Another recommended *'keep things simple, provide examples and testimonials of practice improvement.'*

A relevant training pathway and training opportunities were also reported to be needed.

A focus on the outcomes is needed not just the expenditure

A rheumatologist in a public hospital recommended that ***'hospitals consider their role in providing high level care for complicated patients. It is the expectation of their service. [Having rheumatology nurses] is the internationally accepted model of care.'***

Administrators need to be looking at patient experience and whether patients are satisfied with their service. *'They should be asking their patients (not just consumer representatives): Did you feel supported? Did you wait too long? Did you receive the education you needed?'*

'The value in the role should not just be measured by a reduction in emergency department admissions' (as is currently occurring in some trials).

Clinical workforce survey results

Barriers identified by the clinical workforce included:

- Funding
- Role recognition: *'The multidisciplinary team including doctors do not understand/value these nurses skills and therefore do not take advantages of the skill sets.'* *'Their acceptance by rheumatologists.'*
- Sufficient number of nurses to substantiate a governance framework and training program.

For rheumatology nurses to contribute to their full potential, respondents identified:

- Rheumatology and arthritis would need to be recognised by government as an area of need, with funding for the role so that public patients have access to full care
- There would need to be a greater understanding amongst rheumatologists of the need for the role. There needs to be a *'clear understanding of their role'*, and rheumatology nurses need to *'advertise their role/services they can provide.'*
- Training opportunities need to be available.

It's about what patients want

Rheumatologists interviewed spoke of needing to...

'move away from what doctors want, to what the patients want.'

'share stories of work with rheumatology nurses'

Some spoke of the need for the professional body for rheumatologists actively participating in and supporting the implementation of rheumatology nursing roles.