



ACI NSW Agency
for Clinical
Innovation

Model of Care for the NSW Paediatric Rheumatology Network

Musculoskeletal Network
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FORWARD

The Agency for Clinical Innovation (ACI) is the primary agency in NSW for promoting innovation, engaging clinicians and designing and implementing new models of care. The ACI's clinical networks provide a forum that brings together clinicians, managers and consumers across the NSW health system to design, deliver and support implementation of effective sustainable models of care.

All ACI models of care focus on the needs of patients, and are underpinned by extensive consultation and research conducted in collaboration with leading researchers, universities and research institutions.

The ACI Musculoskeletal Network has developed this model of care to support access to appropriate and effective care of children, and their families, who live with a variety of rheumatic conditions. The model has benefited from the experience of expert multidisciplinary clinicians, parents, young people who live with one of the conditions, and Arthritis NSW who represent the needs of these people across NSW.

International, national and local evidence has been reviewed to inform the best practice included in the model. The Musculoskeletal Network has conducted qualitative research with the proposed users of the model, families who have a child with a rheumatic disease, and has hosted an expert international and local reference group to formally review the model. International clinicians who have coordinated models of care for children with these conditions were involved in the expert panel.

I am pleased to introduce the *Model of Care for the NSW Rheumatology Network*. The next step is to conduct economic, financial and service utilisation impact analyses of the model of care to determine its viability and develop a business case, business proposal and resourcing strategy to support implementation.

On behalf of the ACI I would like to thank the Working Group and the Musculoskeletal Network for lending their expertise, time and commitment to develop this model and guiding principles for implementation across NSW.



Dr Nigel Lyons
ACI Chief Executive

ACKNOWLEDGEMENTS

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* *Barbara Holborow passed away in May 2012. The ACI Musculoskeletal Network would like to acknowledge the significant contribution Barbara made as a consumer member of the network.*

Expert Advice

The Agency for Clinical Innovation (ACI) is indebted to the families and young people who live with paediatric rheumatological diseases who gave their time to share their experiences and advice to help inform this model of care.

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EXECUTIVE SUMMARY

In 2010, the Agency for Clinical Innovation (ACI) Musculoskeletal Network established the Paediatric Rheumatology Working Group to consider the needs of paediatric rheumatology services in NSW. The Working Group was given the task of determining a model of care (MOC) that would provide international best standards of practice and meet the needs of families and children affected by paediatric rheumatic disease.

The Working Group was composed of paediatric rheumatology health professionals, peer support groups, transition experts, and consumers. The Working Group was part of a wider ACI Musculoskeletal Network which has overseen and contributed to the development of the model and supported extensive consumer input and evaluation.

The MOC has been externally reviewed by an expert panel, and incorporates its input. This panel included two paediatric rheumatologists invited as international clinical experts, a young person living with a rheumatic disease, the mother of a child with juvenile arthritis, as well as local multidisciplinary experts not involved in the Working Group.

This Executive Summary describes the key components of the MOC; the detailed report provides an overview of paediatric rheumatic disease in NSW and outlines the roles of a multidisciplinary team that will form a NSW Paediatric Rheumatology Network. Background data has revealed:

- Paediatric rheumatology services in NSW fall well below national benchmarks and international guidelines and represent a major inequity in the NSW health system.
- Paediatric rheumatic diseases are a significant cause of acquired disability in children.
- Rheumatic diseases affect more than 6,000 children and young people in NSW. These diseases are complex and chronic in nature and include Juvenile Idiopathic Arthritis (JIA), Juvenile Systemic Lupus Erythematosus (SLE), Juvenile Dermatomyositis (JDM), Scleroderma, along with a number of other debilitating conditions.
- Rheumatic diseases in children often result in poorer outcomes than similar diseases in adults, due to disease severity and a longer duration of disease over the lifetime.
- Many children with these rheumatic conditions will suffer long term disability and functional impairment.
- Mortality of some forms of JIA and JDM are around 5% while the 10 year mortality of SLE is 10% to 20%.
- Early diagnosis and aggressive treatment to induce and maintain remission often involves powerful immunosuppressive agents. These have been shown to improve long term outcomes, but may also have serious adverse side effects.
- The significance of these diseases is well recognised and in developed medical economies such as North America, the United Kingdom, Western Europe and New Zealand, the response has been to develop specialist multidisciplinary teams consisting of medical, allied health and nursing staff to treat and support these children and families.

Paediatric Rheumatology Services in NSW

- Service availability falls well behind national benchmarks and international guidelines.
- Children and young people are at risk of suboptimal care.
- Children and young people with delayed diagnosis and inadequate treatment are at risk of long term disability and complications.
- These deficiencies represent a significant inequity in health care provision.

Current Situation in NSW

- Access to expert paediatric rheumatology services in urban, regional and rural NSW falls well behind national benchmarks and international guidelines.
- In NSW there are only 16 hours per week of publicly funded consultant paediatric rheumatologist time (which equates to less than 15 minutes per patient per year).
- There is no specific funding allocated for allied health and nursing essential in the care of children and young people with rheumatic disease.
- The lack of easily available expert rheumatology services results in many children being managed by clinicians without specific expertise – they are managed by either physicians trained in adult rheumatology care or physicians without specific rheumatology training.
- Inadequate access results in many children undergoing unnecessary, costly and sometimes painful investigations before diagnosis is confirmed.
- The shortfall in services and expertise leads to delays in diagnosis and treatment which have been shown to predispose to long term disability and poor health outcomes.
- 70-80% of care is provided in private practice settings which can be costly for families and does not provide the internationally accepted best practice of multidisciplinary team care.
- Currently there is no standardisation or quality assurance in the care of children and young people with rheumatic diseases.
- Children and young people from regional and rural areas are particularly disadvantaged due to the long distances required to travel to access expert care.

- There are no established transition services to facilitate a seamless shift to adult care settings.
- There is a lack of opportunity and support of formal education for health care providers caring for children and young people with rheumatic diseases.

The NSW Paediatric Rheumatology Network

In line with international best practice and to meet the needs of families and children affected by paediatric rheumatic disease, the ACI Musculoskeletal Network recommends the establishment of the NSW Paediatric Rheumatology Network (NSWPRN) and a Foundation Centre for Paediatric Rheumatology.

The Working Group recommends the immediate establishment of the Foundation Centre and implementation of the full NSWPRN after an initial two year period, and a five year time frame for the NSWPRN to achieve all of its stated aims. Table 1 outlines staffing requirements for these stages.

Step 1 – The Foundation Centre of the NSWPRN

The Foundation Centre will be a tertiary Centre of Excellence with clinical and education roles and strategic planning responsibilities. It will develop a single point of access for coordinated care from a multidisciplinary team to avoid delays in diagnosis and direct patients to appropriate services. It will allow for high quality training of medical, nursing and allied health staff, building capacity and specialist skills to train other clinicians in a

Table 1. Staffing levels for NSWPRN at Full Implementation and Foundation Centre*

| | Rheumatologist | Specialist Nurse | Physiotherapist | Occupational Therapist | Dietitian | Social Worker | Psychologist | Clinical Support Officer | Program Development Officer |
|---------------------|----------------|------------------|-----------------|------------------------|-----------|---------------|--------------|--------------------------|-----------------------------|
| Current | 0.375 | 0 | 0.3 | 0 | 0 | 0 | 0 | 0 | 0 |
| Foundation Centre | 1.2 | 1.2 | 1.0 | 0.5 | 0 | 0 | 0 | 1.2 | 1.0 |
| Full Implementation | 2.5 | 2.5 | 2.5 | 1.0 | 0.3 | 0.3 | 0.5 | 1.5 | 1.0 |

*All numbers are expressed as full time equivalents (FTE)

flow on manner. The Foundation Centre will also work to develop collaborative partnerships with other tertiary paediatric services, Local Health Districts (LHD), general practitioners and Medicare Locals, peer advocacy groups, universities and other key stakeholders to provide a statewide and coordinated approach to the care of children and young people with rheumatic diseases.

The key tasks to be achieved in the first two years are to:

- establish the operational structure of the multi-disciplinary team
- establish the roles of the essential members of the multidisciplinary team
- develop links with network partners to improve health professional education
- develop effective mechanisms for evaluation and demonstration of impact.

Step 2 – The NSWPRN at Full Implementation

Achieving the Foundation Centre objectives will facilitate the implementation of the full NSWPRN structure in a sustainable and cost effective manner. The Working Group envisages that the initial three years of full operation of the NSWPRN will see expansion of the tasks undertaken by the Foundation Centre along with implementation of the strategic directions already developed in the Foundation period through extensive consultation. These strategies will include expanded clinical services including outreach services, a virtual ward and satellite services. Expansions of the service will be based on a hub and spoke pattern spreading from the tertiary service with a strong emphasis on engaging local services. Other important features will include enhanced education roles, a commitment to safety and quality improvement, research and advocacy within the field.

These aims parallel those of the recently legislated statutory health corporation known as NSW Kids and Families, established on July 1, 2012.

Key objectives of the NSW Paediatric Rheumatology Network

- Improved physical health and well-being of children and young people with rheumatic disease
- Improved health education and support services for children and young people with paediatric rheumatic disease and their families
- Establish a culture of quality improvement in paediatric rheumatology
- Improved education for health professionals in the recognition and management of paediatric rheumatic disease
- Establish a culture of research
- Develop and maintain a sustainable paediatric rheumatology service.

Benefits of the NSWPRN

The implementation of the NSWPRN will result in multiple benefits to children with rheumatic disease and their families. It will address the inequity in access and service that currently exists when paediatric rheumatology is compared to other chronic childhood diseases. Children and young people with rheumatic diseases will benefit from an adequately resourced service providing care beyond the physical boundaries of tertiary hospitals into primary and secondary care settings, regional and rural areas. Transition services will be enhanced to meet the ongoing health needs of young people throughout their lifespan.

NSW health budgets will benefit from a reduction in health costs through the avoidance of inappropriate treatments, unnecessary procedures and investigations, and a reduction in complications that result from inadequately or inappropriately treated disease.

Finally, the community as a whole will benefit through a reduction in the long-term financial and societal costs of disability that are carried through life as a consequence of childhood rheumatic disease and through the provision of a sustainable high quality service into the future.

AIMS, CONTEXT AND SCOPE

This document describes an optimal model of care (MOC) for the provision of service delivery to support the management of children and young people with rheumatic diseases in NSW. It details children's and families' experiences of care, and provides a comparison to national benchmarks and international guidelines.

It presents evidence of the poor long term outcomes of rheumatic disease in the young and demonstrates the benefits of early, appropriate and well coordinated care during childhood, through adolescence and into adulthood. Finally, this document provides a plan for addressing these deficiencies through a coordinated multidisciplinary approach, in line with the international standards of best practice.

The guiding data and clinical documents used in the development of the model are:

- Davies, K., Cleary, G., Foster, H., Hutchinson, E. and Baildam, E. on behalf of the British Society of Paediatric and Adolescent Rheumatology (BSPAR) Standards of Care for Children and Young People with Juvenile Idiopathic Arthritis 2010. Available at <http://rheumatology.oxfordjournals.org/content/49/7/1406.full.pdf+html>
- National Health and Medical Research Council and Royal Australian College of General Practitioners Clinical Guideline for the Diagnosis and Management of Juvenile Idiopathic Arthritis 2009. Available at: http://www.nhmrc.gov.au/_files_nhmrc/file/publications/synopses/cp119-juvenile-arthritis.pdf
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- Australian Institute of Health and Welfare. A snapshot of juvenile arthritis. 2013 Available at: <http://www.aihw.gov.au/publication-detail/?id=60129542583>
- American College of Rheumatology and American Academy of Paediatrics Position Statement Guidelines for the Referral of Children and Adolescents to Paediatric Rheumatologists 2005. <http://rheumatology.org/publications/position/pediatricreferrals.asp>
- Tong, A., Jones, J., Speerin, R., Filocamo, K., Chaitow, J., & Singh-Grewal, D. Consumer perspectives on paediatric rheumatology care and service delivery: a qualitative study. *Journal of Clinical Rheumatology*. In press. 2013. Key themes derived from this research are described on page 29.

The target population group of this model of care is children, young people with rheumatic disease and their families.

Services, although based in one location, will require strong network links. The MOC provides significant improvements in clinical service, and allows an efficient use of resources through improved coordination of patient care and avoidance of duplication. The MOC will provide a solution for the NSW health system through:

- providing education of health professionals to encourage early recognition of disease
- facilitating appropriate and timely referral
- developing local expertise to establish collaborative networks that allow disease management close to home where appropriate, and
- providing support and education to encourage self management skills in children, young people and their families and reduce long term reliance on medical services.

THE NEED FOR CHANGE

Matilda

Five year old Matilda had her first symptoms of a swollen and sore right knee in November 2006. Matilda had been playing in the park one sunny Sunday afternoon, when she became upset because her knee really hurt. Her mum noticed her knee was swollen but she didn't remember Matilda falling or having banged her knee. Matilda's mum and dad, Josie and Dougal, took her to the local Emergency Department, but the doctor found nothing wrong and advised Josie and Dougal that Matilda must have knocked her knee. Matilda was given paracetamol and sent home without any arrangements for follow-up.

A week later, Josie took Matilda to see their local doctor as Matilda wasn't sleeping because of the pain in her knee. The doctor was unsure what was causing the pain and referred Matilda for an X-ray. He assured Josie that Matilda's knee would probably heal over the next few weeks.

The results of the X-ray were normal. However, after another week, Matilda's knee was no better so they returned to their doctor. Again he advised them to wait another month to see if the pain and swelling settled down. By Christmas things were still no better and, for the third time, Josie took Matilda back to see their local doctor. Once again, he reassured them that there were no broken bones so everything would be all right and they should wait another month.

By the end of the January, three months after the pain and swelling began, Matilda's knee had not improved. She was avoiding playing with her friends, avoiding walking, wanting to be carried and was crying at night. Josie was exhausted trying to care for Matilda and her younger children, but once again her doctor suggested they wait. Then in February, Josie and Dougal again visited the doctor and this time they insisted some action be taken. Subsequently, Matilda was referred to an orthopaedic surgeon who requested a bone scan, MRI and made an appointment for Matilda at the orthopaedic clinic. They waited until May to get an appointment. In June 2007, the orthopaedic surgeons registrar performed an aspiration of the knee but there was no sign of injury or infection in the aspiration.



Matilda was then referred to an adult rheumatologist at a hospital outpatient clinic. She was prescribed high doses of anti-inflammatory medication and had further X-rays of her knees, which showed fluid on both knees. She started to see a physiotherapist to try and settle the pain and swelling and get her knees moving better.

Finally, in April 2008, almost 18 months after Matilda's initial symptoms, the family saw a paediatric rheumatologist. The diagnosis of juvenile idiopathic arthritis was confirmed and cortisone injections were administered into Matilda's knee. She was commenced on appropriate regular medication and remission of symptoms was achieved.

Although Matilda's parents were dismayed at the length of time it took to gain definitive diagnosis and care for Matilda's arthritis, they were relieved to finally have their happy little girl back to her old self. They now know that when Matilda's joints look swollen, if she complains of pain or she begins to limp, they can contact their paediatric rheumatologist for advice and support.

INTRODUCTION AND BACKGROUND

The Scope of Paediatric Rheumatic Disease

Paediatric Rheumatology is the specialty that cares for children and young people with diseases of the musculoskeletal system, or any inflammatory diseases local or systemic. Systemic inflammation may involve multiple organ systems such as the heart, lungs, kidneys, skin and eyes. The management of musculoskeletal or systemic inflammatory disease requires a comprehensive understanding of the effects of inflammation on the body and requires specific training. This knowledge transcends the traditional organ specific treatment of disease provided by many other specialty areas.

Juvenile Idiopathic Arthritis

The most prevalent paediatric rheumatic disease is Juvenile Idiopathic Arthritis (JIA). It affects 3 per 1000 children below the age of 16 years [1, 2]. This equates to as many as 6000 children and young people in NSW currently diagnosed with JIA. It is estimated that there are 22,000 people (children and adults) in Australia who suffer from the effects of juvenile onset arthritis [1].

Children with JIA may suffer disabling pain, stiffness and difficulty performing normal activities of daily living such as caring for themselves, attending school or participating in sporting and social activities. Twenty percent of children with oligoarticular JIA will develop sight threatening eye inflammation (uveitis) and a smaller but significant number will suffer potentially life threatening complications such as pericarditis (inflammation around the heart), severe infection or macrophage activation syndrome (overwhelming systemic inflammation).

There are a number of subgroups of JIA, which include:

- Oligoarticular JIA involves up to four joints. This form classically affects children in the preschool ages. Children often present with a limp and morning stiffness with swelling of the joints. The diagnosis of JIA is often delayed as symptoms may be dismissed as “growing pains” or the diagnosis unrecognised by

primary practitioners or non-rheumatology specialists. Oligoarticular JIA is associated with inflammation in the eyes (uveitis) in 20% to 30% of children and may cause blindness. Forty percent of children with oligoarticular JIA will continue to have arthritis in adulthood and left untreated this will cause skeletal abnormalities and joint destruction necessitating early joint replacement.

- Polyarticular JIA involves five or more joints and includes the very aggressive rheumatoid factor positive form of JIA. This causes rapid and irreversible joint destruction if not treated promptly and aggressively. Children with a positive rheumatoid factor continue to have disease throughout their lives and frequently experience long term disability.
- Systemic JIA is a form of the disease that is associated with high fevers, rash, weight loss and serositis, including pericarditis that may cause life threatening pericardial tamponade. Historically, five to ten percent of children with this form of JIA died of infection or macrophage activation syndrome while many others continued to have destructive joint disease throughout their life. Up to 70% will continue to have disease into adulthood.
- Enthesitis Related Arthritis is the juvenile form of adult spondyloarthropathy. It includes ankylosing spondylitis and is characterised by the presence of enthesitis (inflammation of tendons and ligaments where they insert into bone) and arthritis in childhood and progresses to involve the spine in adolescence and adulthood. Remission rates are low and long term disability is high.
- Psoriatic Arthritis is associated with psoriasis, which is an inflammatory skin condition and it may cause a destructive arthritis that most often continues into adulthood.

Other paediatric rheumatic conditions

Other less prevalent, but potentially life threatening conditions, also fall under the care of paediatric rheumatology services. These conditions are often severe and require expert and aggressive management to limit long term mortality and morbidity.

A non-exhaustive list of other conditions treated by paediatric rheumatology services includes:

- **Juvenile Systemic Lupus Erythematosus (SLE)** is a systemic auto-immune disease which may affect multiple organ systems including the skin (rash), joints (arthritis), kidneys (nephritis), central nervous system (psychiatric symptoms, stroke and vasculitis), and haematological systems (anaemia, low white cell counts and low platelet counts). SLE has a prevalence of around 1:5,000 in childhood. It predominantly affects females and 20% of all people with lupus present with symptoms prior to adulthood. Childhood onset SLE has a poor prognosis with high rates of brain and kidney involvement, and a ten year survival as low as 80-90% even in modern times [3] which is comparable to childhood leukaemia [4]. Expert aggressive management can improve outcomes in this life-long disease.
- **Juvenile Dermatomyositis (JDM)** has a prevalence of around 1:10-15,000 children and causes inflammation of the skin and muscles resulting in disfiguring rashes and profound weakness. In severe cases, children with JDM are unable to walk and experience respiratory and swallowing difficulties which are life threatening. Early diagnosis and treatment has been shown to prevent long term complications such as soft tissue calcification, contracture and disability. If untreated JDM has a high mortality. Even in the modern age of aggressive therapy, mortality rates up to 5% have been reported [5].
- **Vasculitic conditions.** Vasculitis is inflammation of blood vessels and this group of conditions includes Kawasaki disease, which is the commonest paediatric cause of acquired heart disease in the developed world. Other rare vasculitic conditions, such as Granulomatosis with Polyangiitis, Polyarteritis Nodosa, Churg-Strauss Syndrome and Takayasu Arteritis, also have serious implications for mortality and morbidity. As these conditions are rare in childhood, diagnosis and treatment are a challenge to those inexperienced in the area.
- **Scleroderma** is a disease causing thickening and hardening of the tissues that can affect the skin, lungs, heart or kidneys. In the paediatric population it is usually of the limited cutaneous form, sparing deeper organ involvement, but may still result in significant disability if it affects areas surrounding joints. This results in contracture of the joints and when it affects the face it causes severe deformity.
- **Periodic Fever Syndromes** include Familial Mediterranean Fever, TNF Receptor Associated

Periodic fever syndrome and the Cryopyrin associated periodic fevers. Without appropriate treatment, these diseases may result in chronic renal failure and other complications.

- **Non-inflammatory connective tissue diseases** include hyper-mobility syndromes and collagen diseases such as Ehlers Danlos Syndrome.
- **Chronic pain syndromes** include Complex Regional Pain Syndrome and Fibromyalgia which have been shown to be as debilitating as inflammatory musculoskeletal disease in many cases.
- Other non-inflammatory musculoskeletal conditions such as mechanical and sports related injuries are managed by paediatric rheumatologists.

Each of these conditions, whether relatively common in the case of JIA or rare in the case of childhood vasculitides, requires a coordinated multidisciplinary approach to management. The high risk of long term joint damage and disability in JIA, and organ damage in SLE, JDM and the vasculitides, has become apparent in the past decade [3, 6-10]. Consequently, there has been a move internationally towards earlier aggressive and coordinated therapy to improve outcomes.

The Burden of Paediatric Rheumatic Disease

Rheumatic diseases have a major impact on children, their families and society. Rheumatic disease of childhood can cause long term disability with the personal and societal costs of joint or organ damage a lifelong issue. Thus paediatric rheumatic disease represents a significant burden not only to sufferers and their families but to the community as a whole.

The physical and emotional impact of JIA on children and their families is undeniable and the Australian Institute of Health and Welfare (AIHW) review of JIA in the Australian context [1] found that:

- 50% of children with the disease continue to have arthritis into adulthood
- >80% have pain from their arthritis on a daily basis
- 85% have limitation of activity and reduced ability to participate in school and sports
- school absence and poor academic achievement are common
- uveitis affects 20% of children with oligoarticular disease and blindness may occur

- deformities of skeletal growth are common in inadequately treated disease
- growth failure and delayed puberty is common in some forms of JIA
- early onset degenerative joint disease necessitating joint replacement is seen in inadequately treated disease
- 20% of these children enter adulthood with significant disability
- 25,000 adults in Australia suffer long term disability as a result of JIA and this impairs their ability to perform activities of daily living
- unemployment exceeds 40% of adults living with the after effects of childhood arthritis
- 86% report social isolation and poor social adjustment
- psychological stress affects 25% of those living with the after effects of childhood arthritis
- these children have far higher rates of health care utilisation when compared to their peers.

The AIHW report also highlighted the large burden of disability from JIA as it affects not only the individual and their family, but also the community. Disabilities established in childhood and adolescence will be carried throughout life. Children and young people with other rheumatic diseases including JDM and SLE have been shown to have a poor quality of life, poor self-esteem, poor school achievement and increased school absence when compared with their peers [11-14].

The complexity of treating rheumatic disease in childhood places a significant burden on families and the health system. The diseases themselves along with the treatments used are associated with numerous complications involving multiple systems of the body.

Changes as fundamental as the widespread use of intra-articular steroid injections for JIA, and the introduction of a number of new disease modifying agents (often called 'biologics'), have revolutionised treatment of many of the rheumatic diseases. Biologic disease modifying agents are genetically engineered to block the immune system's signaling molecules that perpetuate inflammation and result in organ injury. While effective, these agents are expensive and are associated with significant potential side effects. They require expert supervision to ensure effective use and to avoid complications, thus highlighting the need for specialist rheumatology care in these children and young people. Paediatric rheumatology services are required for the initiation of Pharmaceutical Benefits Scheme (PBS) supported biologic therapy.

The Economic Costs of Paediatric Rheumatic Disease

Paediatric rheumatic diseases are associated with significant direct costs related to the treatment of the disease. This includes the cost of medical care such as medications and hospital admissions. In addition to the direct costs, are the indirect costs of illness including the lost productivity of parents caring for ill children and long term disability in children themselves. These indirect financial costs may be more than twice the direct medical cost of illness in paediatric rheumatic disease [15, 16].

The direct and indirect cost of JIA to sufferers and their families, along with the indirect societal cost of chronic disease, was calculated as €17,000 (approximately \$A28,800 at the time) per year per patient in 2004 [17] and represents an ongoing cost for the duration of the person's life. In 1992, some 20 years ago, the direct and indirect cost to families of children with JIA, excluding any societal costs, was estimated at \$US11,000 (approximately \$A14,700 at the time) per annum per child [18]. Both are likely to be a significant underestimate in today's terms with the effect of inflation and relative increases in healthcare costs including medication costs.

The direct costs of paediatric SLE have been shown to be as high as \$US15,000 (approximately \$A19,500 at the time) per annum per patient [19, 20]. The studies of adult onset SLE show that the indirect cost of the disease beyond medical care is at least twice the direct cost with a significant proportion of these individuals unable to successfully undertake work, or participate in normal family functions [15]. This situation is likely to be even worse for children with SLE who enter adulthood with established organ damage and disability [21].

What are the Accepted Standards of Best Practice?

The consensus standards for the care of children and young people in Australian health services state that "Staff involved in the care of children and young people should have special training to recognise and meet the special health, psychological, developmental, communication and cultural needs of children and young people" (p. 80) [22]. These standards emphasise there are significant differences between adult and paediatric healthcare including the important issues of growth, development and family function [22].

It is accepted that paediatric health services need to be provided in a coordinated fashion which is “patient and family-centred, assessment-driven, team-based environment, designed to meet the needs of children and youth while enhancing the care giving capabilities of families” (p. 8) [23]. According to Antonelli and colleagues such a comprehensive approach to paediatric care “addresses interrelated medical, social, developmental, behavioural, educational, and financial needs in order to achieve optimal health and wellness outcomes” (p.8) [23].

Recent North American data suggested that at least 30% of paediatric rheumatology services were provided by non-paediatric rheumatology specialists (usually adult trained physician rheumatologists or immunologists) often without any support from an expert. A majority of these practitioners conceded that they had no specific training or ongoing professional education in the area [24]. This non-expert care was deemed to be inappropriate and as a result, in 2007 dedicated funds were made available within the United States to improve training programs and rheumatology unit staffing to establish appropriate services [25].

The internationally accepted best practice in chronic illness care, including children and young people with rheumatic disease, is through the care provided by a coordinated, multidisciplinary team (MDT) [26-30]. In paediatric rheumatology, the team is composed of expert physicians, allied health professionals including physiotherapists, occupational therapists, dietitians, podiatrists, social workers, school liaison personnel, and specialist nurses working in partnership with children, families, general paediatricians, and in some instances adult rheumatologists. Inter-disciplinary services for rheumatic conditions such as uveitis in conjunction with ophthalmology, systemic lupus erythematosus with nephrology, scleroderma with dermatology, haemophilic arthropathy with haematology, are the standard of care in most developed health systems.

The need for expert MDT care in paediatric rheumatology is formally recognised internationally by numerous professional groups including the National Health and Medical Research Council and the Royal Australian College of General Practitioners [31], the Alliance for the Canadian Arthritis Program [32], the British Society of Paediatric and Adolescent Rheumatology [33], and the American Academy of Pediatrics [34], along with many other respected authorities [35-37].

In Victoria, the establishment of a coordinated multidisciplinary paediatric rheumatology service has resulted in a demonstrable shift from adult oriented rheumatology services and non-specialist providers, to dedicated paediatric rheumatology services [38]. Additional resources have seen Victorian paediatric rheumatology services undergo a significant improvement over the past five years evolving from a poorly supported private practice based model to a coordinated multidisciplinary service. This has resulted in proven improvements in clinical care, junior staff training, research and advocacy [39].

The structure of the Victorian model is shown in Figure 1 and it contains elements of well established models of chronic care designed to move from an acute, inpatient reactive system to one which is anticipatory and largely community based [40, 41]. The main aspects of effective models of chronic care are:

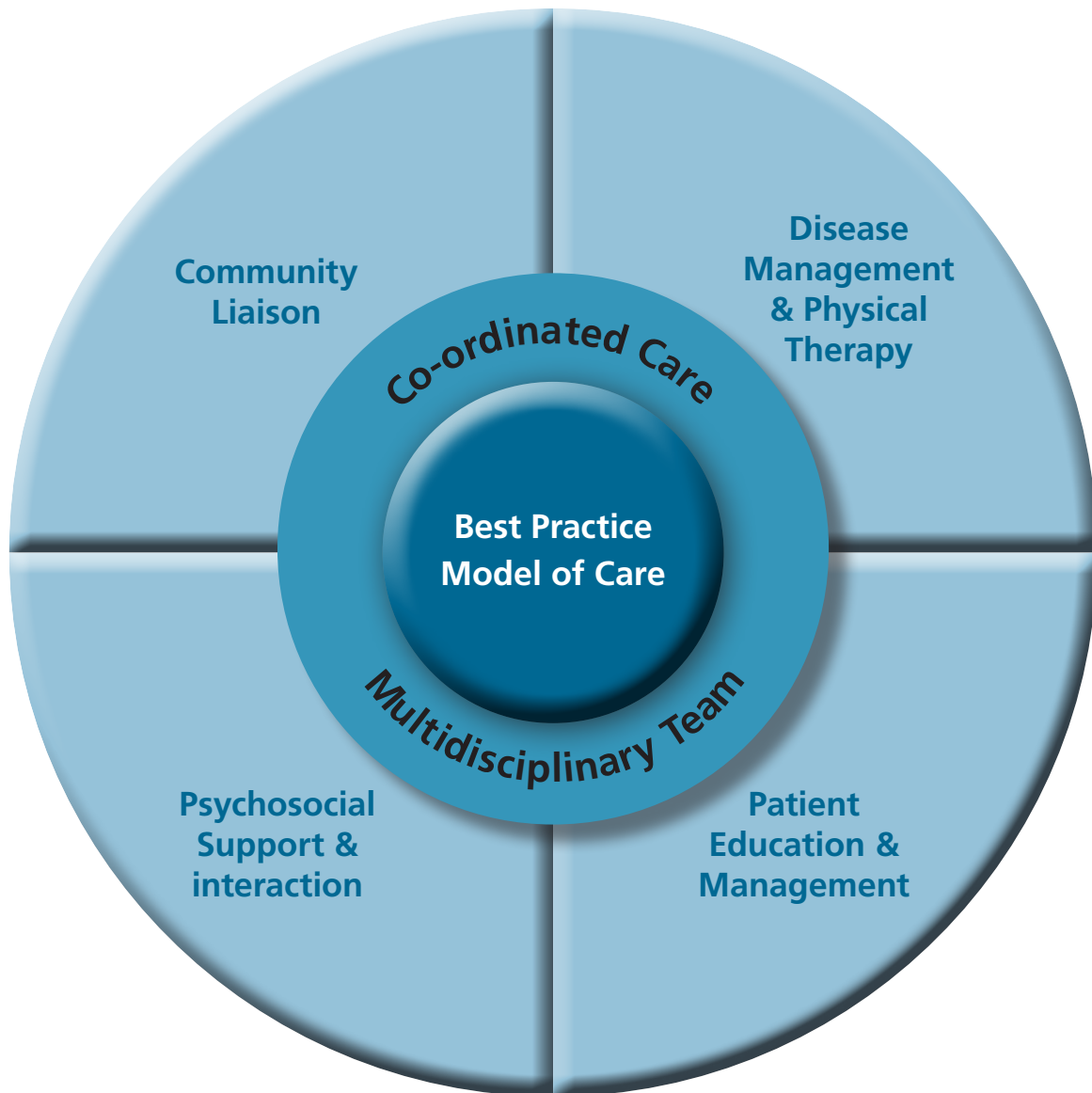
- team care with regular planned interactions
- support of self-management
- strengthening community supports
- integrated decision support for health care providers
- patient registries to allow for quality improvement
- supportive information technology.

Formal assessment of the Victorian Model has shown:

- improved consumer satisfaction
- improved child and parent knowledge of the disease and its management
- improved coordination of care
- reduced delays to definitive treatment
- reduced duplication of services.

Ongoing quality improvement activities of the Victorian model implementation continue to assess the long term benefits of this model of care [38, 39].

Figure 1: Paediatric Rheumatology Best Practice Model of Care - Courtesy of the Royal Children's Hospital Melbourne Department of Rheumatology [42]



PAEDIATRIC RHEUMATOLOGY SERVICES IN NSW

In 2013, NSW does not meet accepted international guidelines and also falls well behind the very modest benchmarks seen in comparable states of Australia including Victoria, Western Australia and South Australia. Table 2 presents service comparisons between NSW, other states of Australia and New Zealand. The source of this information is the Australian Paediatric Rheumatology Group in 2011.

International guidelines have recommended that one paediatric rheumatologist with MDT support is required

for each 300,000 to 500,000 children <16 years of age purely for the provision of quality clinical care [43]. Using this recommendation, NSW will require around four full time equivalent (FTE) paediatric rheumatologists to provide adequate clinical paediatric rheumatology services to its population. Essential elements of the service such as education, research, administration and quality improvement require additional resources suggesting that the true figure stands between 6 and 8 FTE.

Table 2: Specifically funded tertiary hospital resources for paediatric rheumatology in Australia and New Zealand at November 2011*

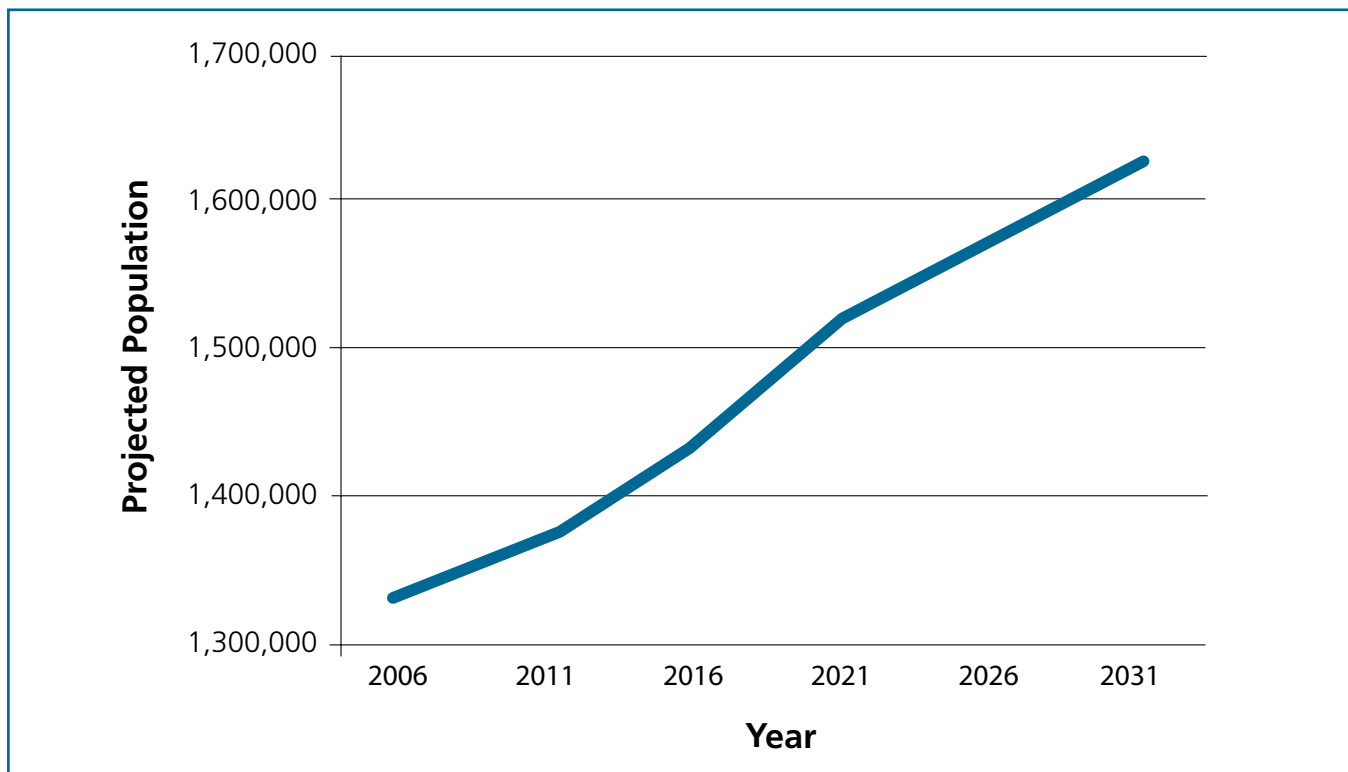
| | NSW (+ACT) | | | | QLD | SA (+NT) | WA | VIC (+TAS) | NZ |
|-------------------------------------|------------|-------|------|-------|--------|----------|-----|------------|------|
| Population 2006 (x10 ⁶) | 6.8 | | | | 3.9 | 1.7 | 2.0 | 5.4 | 4.4 |
| Hospital | SCH | CHW | JHCH | TOTAL | | | | | |
| Rheumatologist | 0.2 | 0.075 | 0.1 | 0.375 | 0.0375 | 0.4 | 1.0 | 1.58 | 1.35 |
| Nursing | 0 | 0 | 0 | 0 | 0 | 0.2 | 1.0 | 1.5 | 1.0 |
| Physiotherapy | 0.2 | 0.1 | 0 | 0.3 | 0.2 | 0.2 | 0.6 | 0.3 | 1.2 |
| Occupational Therapy | 0 | 0 | 0 | 0 | 0.2 | 0.2 | 0.2 | 0.25 | 0.7 |
| Social Work | 0 | 0 | 0 | 0 | 0.1 | 0 | 0 | 0 | 0 |
| Psychology | 0 | 0 | 0 | 0 | 0 | 0 | 0.5 | 0 | 0 |
| Educational Advisor | 0 | 0 | 0 | 0 | 0 | 0 | 0.2 | 0 | 0 |

*All figures are in FTE unless otherwise stated (0.1 FTE = 4 hrs/wk).

Source: Australian Paediatric Rheumatology Group (2011).

With a projected growth in the NSW paediatric population (those aged 0 - 14 years) from 1,333,199 in 2006 up to 1,620,212 by 2031, NSW will fall further behind in accepted benchmarks.

Figure 2: Population projections in NSW for children 0 -14 years, 2006-2031 [44]



Paediatric rheumatology services

Problems arising from paediatric rheumatology service shortfalls in NSW include:

- Delays in diagnosis and treatment are common
- Inadequate access to appropriate services
- Inadequate transition services for young people
- Lack of services for children, young people and families in regional and rural areas
- No inter-disciplinary specialist services
- Inadequate undergraduate and postgraduate education for health professionals
- Excessive reliance on services provided in private practice
- Quality and safety is not addressed
- Paediatric rheumatology services do not meet standards set by NSW Ministry of Health

Diagnosis and treatment

Early diagnosis of rheumatic disease is critical to good long term outcomes. In NSW, paediatric rheumatic diseases are currently treated by a group of health professionals with variable skills and experience. As a result, rheumatic conditions in children frequently remain undiagnosed for some time with children and young people being seen on multiple occasions in primary care or by specialty services including paediatrics, orthopaedic surgery, adult rheumatology, immunology and allied health services, before the correct diagnosis is considered [35, 45].

Many families are told the child simply has “growing pains” which they will grow out of [36]. Disturbingly, a significant number of children undergo painful, costly procedures and investigations including joint aspiration, MRI scans, arthroscopy or synovial biopsy before the diagnosis is made and definitive therapy is started by a paediatric rheumatologist [45, 46]. These interventions serve to increase child and family anxiety and undermine their faith in the health system. Furthermore, this is an inefficient use of health resources [21, 45].

International comparisons show that Australian children

and young people who have JIA had the longest documented delay in diagnosis. Data from Western Australian (WA) has shown a median time of 10 months between JIA symptom onset and assessment by a paediatric rheumatology professional [46, 47]. This was confirmed by patient journeys provided to Arthritis NSW by the parents of children with JIA, as well as through independent research conducted by the ACI Musculoskeletal Network [48]. One of these typical patient journeys is described through 'Matilda's' story on page seven of this document. While names have been changed the story is a true account of a family's experience. The reported delays in WA are likely to be even more significant in NSW due to a ten-fold lower level of public health sector expenditure on paediatric rheumatology services per capita within NSW.

It has been clearly demonstrated that much of the pain, distress and long term disadvantage experienced by children and young people with rheumatic disease is preventable through early diagnosis and appropriate therapy [31, 49]. Delayed therapy in other rheumatic diseases, such as JDM, has also been clearly demonstrated to result in poorer long term outcomes [50].

Access to appropriate services

When paediatric rheumatic disease is identified or suspected, there are few appropriate services in NSW for families to access. These services are located either in public tertiary care centres or private practice settings. This results in children being referred to adult physicians or other peripherally related specialties with limited expertise in rheumatic diseases. This places children and young people with rheumatic disease at risk of inadequate treatment and poor outcomes from their disease.

Transition services for young people

Currently there are no formalised transition processes for young people in NSW who have rheumatic disease. Adolescence is often associated with periods of poor adherence to therapy, disease relapse and a very high risk of joint and other organ damage resulting in long term disability [51-53].

Services for young people and young adults need to be sensitive to the issues of self determination, independence, academic and vocational success, along with physical, psychological and sexual development. Furthermore, the management of young people requires consideration of the added complexities that may impact at this time of life such as substance use, family dynamics and mental health issues. The "cradle to the grave" approach used by adult physicians in the past has failed to recognise issues of growth and development, while paediatric physicians continuing to care for children into adulthood have been criticised for not recognising the changing needs of the adolescent and young adult [53].

Failure to provide a coordinated transition from paediatric to adult services results in poor adherence to therapy, reduced attendance at follow-up appointments and long-term outcomes that could be improved if transition to adult services were implemented [52-56]. Processes allowing smooth transition are essential [54, 56]. Properly managed transition of care, commencing in early adolescence, will ensure the highest level of care for those who continue to have active disease into adolescence and adulthood. This includes those who have a chronic disability resulting from their childhood onset condition. Quality care is maintained in well established transition services [51].

Services for children, young people and families in regional and rural areas

Children and young people in regional areas represent a group at particular disadvantage. Over 25% of the NSW population live in regional and rural areas, and more than one million live outside Sydney and Newcastle. Sydney and Newcastle are the only sites with local access to paediatric rheumatologists but no other funded multidisciplinary services. Thus children and young people from regional and rural areas are obliged to travel long distances to obtain specialist care.

Successful outreach services have been established in areas such as juvenile diabetes, cystic fibrosis, asthma, nephrology and cardiac disease [57]. Outreach has great advantages including the provision of care close to home and the engagement of local clinicians. Working with medical, nursing and allied health

professionals locally allows for up-skilling and ongoing education of this group of health professionals and has been shown internationally to be a valuable outcome [58]. The resulting establishment of strong local links and regional networks of care are particularly important in rheumatic diseases that are relapsing and remitting in course.

Inter-disciplinary specialist services

As rheumatic diseases are frequently multi-organ in nature there is also a move towards inter-disciplinary care for some patient groups. Combined ophthalmology and rheumatology clinics for the treatment of the 20-30% of children and young people with JIA who have potentially vision threatening uveitis are the standard of care throughout the developed world. Without such clinics in NSW, children and young people attend multiple appointments with ophthalmologists to monitor disease activity, and rheumatologists to manage immunosuppression. The disconnect between specialist care results in communication delays that may compromise care with the logistic issues even more significant for families from regional and rural areas.

Other areas known to benefit from interdisciplinary care include systemic lupus erythematosus with nephrology, scleroderma with dermatology and haemophilic arthropathy with haematology.

Inter-specialty clinics have been shown to improve the quality and efficiency of treatment for children with rheumatic disease [59, 60]. Inter-specialist services are the standard of care in many developed health systems and provide the advantages of shared knowledge and experience in these disorders [31, 33].

poor [64]. In NSW, doctors, nurses and allied health professionals often receive no formal exposure to paediatric rheumatology in their tertiary training. General practitioners and subspecialty groups such as orthopaedic surgeons, paediatricians and emergency physicians are often the first point of contact for children with rheumatic disease and educational deficiencies result in perpetuation of the problems of delayed diagnosis [61].

The Royal Australasian College of Physicians (RACP) does not accredit any site in NSW for training of paediatric rheumatologists due to the lack of adequately supervised and clinically appropriate experience. Thus doctors wishing to practice as paediatric rheumatologists must obtain training outside of NSW in order to develop adequate skills in the management of patients with complicated rheumatic diseases. A similar lack of training opportunities and exposure to paediatric rheumatology exists for allied health and nurses wishing to gain advanced skills in the area. Without adequate training of health professionals patients will be left at risk of suboptimal care.

The National Health and Medical Research Council (NHMRC) and Royal Australian College of General Practitioners (RACGP) in combination with the Australian Paediatric Rheumatology Group (APRG) have developed clinical guidelines for the diagnosis and treatment of JIA which have been widely distributed amongst primary care practitioners [31]. The APRG is also developing Management Standards for JIA which will be in line with international standards [61]. Within these guidelines the primary care physician or general practitioner is a key member of the MDT with responsibilities for initial assessment and ongoing treatment of children with rheumatic disease in concert with the other members of the team. In order to fulfil this role, primary care practitioners will require education and training.

Undergraduate and postgraduate education for health professionals

Deficiencies in the education of health professionals regarding childhood rheumatic diseases has been recognised and addressed in other parts of the world [61-63]. Studies have shown that in primary care settings doctors rate their expertise in the musculoskeletal paediatric examination as being very

Services provided in private practice

Half of the Australian population have private health insurance [65]. This rate is lower in children and those from rural and regional areas [66]. Health insurance covers only in-hospital costs and most paediatric rheumatology services are outpatient based. Thus the cost of services provided in private practice settings is met partially by the Medicare rebate while

the remainder is met by the family, representing an additional burden on families. Specialist nursing and allied health interventions are not readily available for children with rheumatic conditions managed in private practice settings and if available there is little Medicare support for these services.

In NSW, the reliance on private sector care is far heavier than other states of Australia with 70-80% of care being provided in private settings compared to around 50% in Victoria [67]. Furthermore, in NSW many children and young people managed by private physician's access allied health and other multidisciplinary services from public hospitals. This is partly due to cost issues and partly due to a lack of appropriate skills in the private sector. Utilisation of publicly funded services for allied health in this group is under-recognised and places an added burden on the public sector service.

Quality and safety

At present children and young people with paediatric rheumatic disease in NSW are cared for by a group of health professionals not connected through any formal structure. As a result of this fragmented care there is little available data to assess the performance of the current system of care. Thus there are no means of quality assurance within the current system of care and no data to inform service planning.

Paediatric rheumatology services

One of the 32 explicit goals of the NSW state plan 2021: A Plan to Make NSW Number One is to "Provide world class clinical services with timely access and effective infrastructure" [68]. In contrast to these aims the situation encountered by children, young people and families requiring paediatric rheumatology care represents a significant inequity in the NSW health system.

The development of this MOC for paediatric rheumatology services in NSW coincides with the establishment of NSW Kids and Families, the statutory health corporation formed to implement the intent of the recommendations on paediatric services from the Garling Inquiry. It aims to "represent and champion the health interests of all children and young people,

whether they are at home, in the community or in or out of hospital" and has a number of guiding principles including the following:

- equitable universal access to children's health services across the spectrum of care
- children achieving their optimal health and developmental outcomes
- adherence to the principles of patient centred care
- the ability of a child to enter the health system at any place and be given the right level of care in the most appropriate environment
- the system will respond to the child's needs by:
 - providing safe services as close to home as possible, and
 - respecting parent's responsibility as primary carers for their children's health and thus their need to be actively engaged in building the child and family's health and wellbeing.

Ref: http://www.health.nsw.gov.au/resources/nswkids/pdf/nsw_kids_expert_group_rep.pdf

The coordinated, statewide services proposed by this MOC are precisely aligned with the aims and principles of NSW Kids and Families and provide sustainable high quality provision of care for these patients and their families.

DELIVERING IMPROVED PAEDIATRIC RHEUMATOLOGY SERVICES IN NSW

The primary objective of the NSWPRN is to ensure children and their families receive the right care, at the right time, by the right person and in the right place [69, 70]. The MOC aims for equity of access for all those affected by paediatric rheumatic disease. The MOC will foster appropriate transition to adult services, allow for ongoing education of children, young people and their families, carers, health professionals and the community. It will aid in developing a sustainable service for the future. The NSWPRN provides a holistic model of care.

The MOC for the effective management of children with rheumatic diseases in NSW will be known as the New South Wales Paediatric Rheumatology Network (NSWPRN) and services delivered through a Centre of Excellence for Paediatric Rheumatology. Research undertaken by the ACI and Arthritis NSW has revealed many problems families encounter when expert care and information is not provided. Parents and young people confirm the need for such a centre of excellence.

International experts who reviewed this MOC identified that experience with the American and Canadian models indicate that any perceived disadvantage of having to travel to a central multidisciplinary centre is outweighed by the advantage of being able to access expert multidisciplinary care in one location i.e. in a “one-stop shop”. Furthermore, this significantly reduces the burden on families by eliminating the need for frequent travel to access different types of care and ensures messages concerning their child’s healthcare are consistent and embedded in evidence based care.

The MDT forms the core of the NSWPRN and has a child and family centred approach to the management of rheumatic disease. It is based on the principles of the Paediatric Rheumatology Best Practice Model of Care implemented in Victoria [39, 42].

Services within the NSWPRN are structured and resourced to be available for all children and young people with paediatric rheumatic disease in NSW. While it is expected that many families will chose comprehensive multidisciplinary team care when it becomes readily available [48, 67], the MOC recognises

that a proportion of paediatric rheumatology services will continue to be provided in the private sector. Providers and patients within the private sector will be considered an integral part of the MOC and all measures will be taken to engage these groups to ensure quality of service and support in the private sector for paediatric rheumatic diseases through education and access to support from experts within the NSWPRN when required.

Achieving the key objectives of the NSWPRN

Key objectives of the NSW Paediatric Rheumatology Network

- Improved physical health and well-being of children and young people with rheumatic disease
- Improved health education and support services for children and young people with paediatric rheumatic disease and their families
- Establish a culture of quality improvement in paediatric rheumatology
- Improved education for health professionals in the recognition and management of paediatric rheumatic disease
- Establish a culture of research
- Develop and maintain a sustainable paediatric rheumatology service.

The key objectives of the NSWPRN are listed above and in detail within Appendix 1.

1. Improved physical health and well-being of children and young people with rheumatic disease

This objective will be achieved through a number of actions of the MOC as seen below.

Elevate and maintain care at a level that conforms to best practice standards

Implementation of the recommendations of this MOC in its entirety with a fully staffed MDT service will raise resources to an acceptable standard. However, this in itself is not adequate to ensure the provision of care at a standard equivalent to international best practice. Incorporation of improvements in clinical care from international research and experience are integral to maintain the quality of care and the drive for ongoing improvement in services locally. These aims are achieved by:

- all MDT members having the training and expertise to implement best practice clinical care
- all MDT members committing to undertake ongoing professional development
- ongoing incorporation of evidence based innovations in care
- a team commitment to continuing audit and quality improvement.

Prevent delays in the diagnosis and referral

Early recognition of rheumatic disease allowing appropriate referral is a key aspect of the NSWPRN. The MOC addresses this issue by:

- targeting professional education at primary care, allied health, specialty medicine and specialty surgical levels where children with rheumatic diseases may present
- education programs at undergraduate, postgraduate and continuing professional education levels
- improving awareness of rheumatic diseases in childhood among all health care professionals including doctors, nurses and allied health professionals
- fostering access to paediatric rheumatology services through the defined referral pathways provided by the network.

Prevent long term disability and improve health outcomes

Disability and illness adversely affects schooling, social interactions, self-esteem, resilience and coping mechanisms in children and young people. Delays in diagnosis and inadequate definitive treatment place patients at risk of poor outcomes. The MOC addresses this through:

- coordinated, best practice care by experts in partnership with other health services
- attention to the psychosocial aspects of chronic disease and their impact on quality of life
- an ongoing commitment to quality and service improvement
- commitment to improving transitional care.

Improve access in regional and rural areas

The provision of dedicated outreach services to regional and rural areas of NSW on a regular basis will provide children and young people in these areas with improved services by the concept of a 'hub and spoke' model and specifically:

- foster a local service model for rural and regional children, young people and their families supported by the NSWPRN
- engage local health professionals as part of the MDT
- up skill local practitioners and services allowing improved interval care
- opportunistic educational opportunities for non-rheumatology health professionals including primary care to improve the recognition and understanding of childhood rheumatic disease
- improve communication between rheumatology specialists and regional practitioners
- explore novel means of providing service such as tele-health consultation where appropriate.

Improve transition processes

Transition planning is necessary to encourage young people with chronic illness to take an active role in their ongoing health care, as well as negotiate the educational, vocational, social and other challenges of adolescence complicated by chronic disease. The MOC achieves this through:

- commencing the process in early adolescence so the concepts of self-management are well accepted at the time of transition to adult services
- recognising the importance of inclusion of the adolescent person in the management of their chronic illness
- adequate provision of health education for young people about their disease and enabling them to take an active role in the management of their disease in a developmentally appropriate manner
- engaging and partnering with adult rheumatology services in LHDs to provide seamless transition to adult services.

2. Improved health education and support services for patients and their families

Children and young people with rheumatic disease and their families often feel isolated and unsupported. This MOC will address this as described below.

Provide psychological and social support

Parents of children with rheumatic disease are often shocked at the diagnosis as they generally perceive that arthritis and inflammatory disease affects only older people. It is important to recognise that parents need support structures and appropriate information at this time. Likewise, children and young people often struggle psychologically in living with their rheumatic disease and need support through their illness. The MOC addresses these issues by:

- providing access to a paediatric rheumatology specialty nurse who is available to coordinate care from the initial investigations through to diagnosis and ongoing management of the condition
- developing and providing health education on diseases and their management not only for children and young people but also their families and siblings in a manner appropriate to their age, developmental level and background
- supporting children and their families to develop skills and knowledge to enable them to have an active role in the management of their disease, and implement self-management strategies that will reduce the burden on health care services.

Strengthen partnership with advocacy and peer support groups

Arthritis NSW provides support to families affected by JIA through peer support groups, resource material, seminars and children's camps. Lupus NSW, and the newly established JDM parents group, contain similar networks and are developing resources, educational materials and support services for children, young people and families affected by other rheumatic diseases. Strengthened partnerships with these groups will:

- provide children, young people and families with the benefits of healthcare and community supports working together
- avoid duplication of resources and services
- establish a strong united voice on peer advocacy issues.

3. Establish a Culture of Quality Improvement in Paediatric Rheumatology

Quality and safety monitoring are integral to health care provision. Absence of such controls places patients and organisations at risk.

Develop comprehensive data collection systems to support quality improvement

At present there are no accurate means of data collection on the management of children and young people with rheumatic conditions in NSW. The current care systems are diverse, do not collaborate and do not possess the ability to monitor the outcomes and performance of the system. Thus there are no mechanisms for accountability or improvement in the system. The MOC addresses these through:

- establishing a dedicated and interconnected team
- providing a structure for data collection on patient presentations, progress and outcomes
- mandating mortality and morbidity processes, critical incident reporting, internal review and quality improvement within the network.
- monitoring by the ACI Musculoskeletal Network data system designed to monitor the outcomes of all projects implemented by the Network.

4. Improved education for health professionals in the recognition and treatment of paediatric rheumatic disease

There has been little emphasis on paediatric rheumatology in medicine, allied health and nursing education. A lack of familiarity with paediatric rheumatologic diseases results in poor recognition which may result in late diagnosis. Poor knowledge also makes the aim of shared care between specialists and primary care, community allied health and paediatricians problematic. Inability to provide comprehensive paediatric rheumatology training for subspecialists also limits NSW ability to service its population's needs into the future. The MOC will address this through:

- establishing partnerships with universities and other training organisations
- providing the opportunity for supervised clinical training.

(Please also see the actions listed in *Prevent delays in the diagnosis and referral* above).

5. Establish a culture of research

One hallmark of well functioning tertiary/quaternary services is their contributions to areas outside of clinical care. These areas include research aimed at improving diagnosis, treatment, patient experiences and outcomes. It is expected that all core members, non-core members and network partners will actively contribute to research. The MOC will contribute in this area by:

- concentrating and combining team members' expertise to drive research
- providing a setting that will attract clinicians with advanced skills in research to the multidisciplinary team
- establishing patient cohorts to provide the clinical base for answering important research questions
- implementing the findings of clinical research within the network to improve healthcare experiences and outcomes for those accessing the care.

6. Develop a sustainable service for the future

At present the need for paediatric rheumatology professionals exceeds supply due to the inadequate quality of training in NSW. This is compounded by the majority of clinical care being provided in private settings resulting in limited clinical training opportunities in NSW. When current clinicians retire expert care will become even scarcer and ongoing care for children will be jeopardised. The MOC will address the issue of sustainability of health professionals to meet the needs of these children and young people by:

- providing comprehensive training for future paediatric rheumatologists and expert allied health and nursing staff
- establishing a team approach to patient care that will ensure that clinical care extends beyond the availability of any individual health care professional
- establishing a structure and service which will attract trainees to paediatric rheumatology
- building capacity through networks that acknowledge and build upon the skills of primary and secondary level practitioners thus engaging them in the care of people with rheumatic disease.

Structure of the NSWPRN

Implementation of the state-wide Children and Young People's Health Authority known as NSW Kids and Families [71], established July 2012, will assist NSW-wide coordination and streamlining of paediatric services. The Expert Group's recommendations on the governance, strategy and service provision of NSW Kids and Families provides guidelines for specific aspects of the arrangement of paediatric services such as the NSWPRN [72]. This MOC provides a blue print to allow paediatric rheumatology services to be aligned with the statewide remit of NSW Kids and Families.

The NSWPRN will be a centre of excellence for Paediatric Rheumatology care. It will function as an integrated MDT providing coordinated care for patients throughout NSW. Outreach services will be developed in a hub and spoke fashion in collaboration with LHDs.

The Multidisciplinary Team

To achieve the NSWPRN’s objectives the model of care will require an appropriately skilled and resourced MDT comprising a multitude of professionals and organisations some of which are directly involved in patient care, others in service improvement, while some will be involved in both of these functions. While the terms ‘Core’ and ‘Non-core’ are used particularly in the description of these groups the terms do not denote the

importance of the inputs but more the funding source i.e. whether it is envisaged from within or outside the NSWPRN budget. As can be seen from Figure 3 all groups involved in care, education, research, quality and advocacy will have strong links.

Not all patients will require input from each of the listed services but it is felt by the Working Group that all patients affected by paediatric rheumatic disease should have equitable access to these services.

Figure 3: Team members and partners of the NSWPRN



Core team members

All core team members will be specifically trained in the care of children with rheumatic diseases and funded by the NSWPRN. Core team members and their roles are listed below.

- Paediatric Rheumatologists to provide medical leadership, clinical interventions, and participation in research, service development and promotion of the NSWPRN.
- Clinical Nurse Consultants (CNC) will provide the 'care coordination' of the services, targeted and specific child and family education, and ongoing support and nursing care as required by the families.
- Physiotherapists with advanced skills in the management of musculoskeletal disease to overcome physical limitations and to optimise mobility, independence and participation in physical activities.
- Occupational therapists with expertise in the assessment and management of children with musculoskeletal difficulties, especially involving the upper limb, affecting children's capacity to participate in self-care, preschool/school and play/leisure domains in varying environments including home and school/preschool.
- Psychologists to assist children and their families with issues including depression, anxiety, stress and social isolation related to the diagnosis of chronic disease. Consideration will include painful procedures and management of specific issues in children with central nervous system disease including cerebral lupus.
- Dietitians to provide education and intervention for nutritional deficiencies, weight (low and high) management and dietary supplementation. They will provide information about supplements and alternative treatments and information on diets for children on long term steroid medications. Steroids are the mainstay of management in many rheumatic diseases and have significant side effects such as obesity, hyperlipidaemia, osteoporosis, and diabetes.
- Social Workers to address social and financial issues.
- Administrative support to ensure seamless operation of the MDT.
- Program development officer to co-ordinate achievement of the aims of the NSWPRN in the initial five years after establishment. The role will include coordination, monitoring and evaluation of the MOC. These tasks will be achieved through the development of resources such as clinical practice guidelines designed to standardise care state wide, databases designed to allow monitoring of the service and the

development of educational and other resources.

The role will also support the establishment of links with key Network Partners.

Further details of the roles of each core team member are provided in Appendix 2.

Non-core team members

Non-core team members are integral to the success of the NSWPRN but are not funded specifically by the Network. Non-core members and their roles are listed below.

- General paediatricians are integral in the recognition and appropriate referral of children and young people with rheumatic disease. Also skilled in the management of complex medical conditions including assessment of patients, drug monitoring, interval care and management of co-morbidities and inter-current illness.
- General practitioners are integral in the recognition and appropriate referral of children and young people with rheumatic disease. Important in the management of a young person's illness within the family context. Also play a role in interval care and management of co-morbidity and inter-current illness.
- Adult rheumatologists are particularly important in the field of transition but will also have a role in assessment, diagnosis, initial and/or ongoing management in partnership with the support of NSWPRN, especially in regional and rural areas.
- Community based nurses, physiotherapists and occupational therapists will provide care for patients managed in private or rural and remote settings with education and support from the NSWPRN as required.
- Orthotists and podiatrists for children and young people requiring mechanical gait correction.
- Pharmacists in all settings who provide medication advice and support.
- Speech pathologists for children and young people with connective tissue diseases including JDM and scleroderma associated with dysphagia.
- Play/diversion therapists to assist with procedural pain management related to injected medications and intra-articular steroid injections.
- Educational Advisors accessed through the Department of Education to assist with school integration and provide education to teachers and other school staff allowing children with rheumatic diseases to obtain the best possible access to educational services. This role will compliment that of team members including specialist nurses,

occupational therapists and physiotherapists who have essential roles in school staff education and physical school integration.

- Transition care coordinator: the ACI Transition Care Network employs coordinators to provide information and guidance for young people to access adult services, and to facilitate the development of clinical pathways and networks.
- Dentist to address orthodontic problems rising from temporomandibular joint involvement in JIA and oral health issues which have been shown to be related to JIA and other autoimmune diseases [73-75].

NSWPRN partners

These groups and individuals include:

- The Sydney Children's Hospitals Network and John Hunter Children's Hospital as the tertiary paediatric services in NSW, have an important role in the provision of care for patients with paediatric rheumatic diseases.
- LHDs where outreach services will be based and interim care provided for a proportion of the children. This connection is particularly important for regional and rural outreach services. In intra-urban areas the support of LHDs with established adult rheumatology services will be important in developing young adult transition services.
- A number of other medical specialties where collaboration with the Network in providing specific combined interdisciplinary clinics will benefit the coordination of care of these children and young people. These include ophthalmology, dermatology, haematology, nephrology and immunology.
- Arthritis NSW (ANSW) supports access to community based health education for families and those living with JIA, as well as for the general community. ANSW will be a conduit for support groups and specific activities that will encourage friendships and peer support between those living with these conditions. Lupus NSW functions in a similar way for young people suffering from SLE.
- Educational institutions including universities, primary care organisations (Divisions of General Practice and Medicare Locals), specialty colleges and societies to partner in educational and research activities.

Other features of the NSWPRN

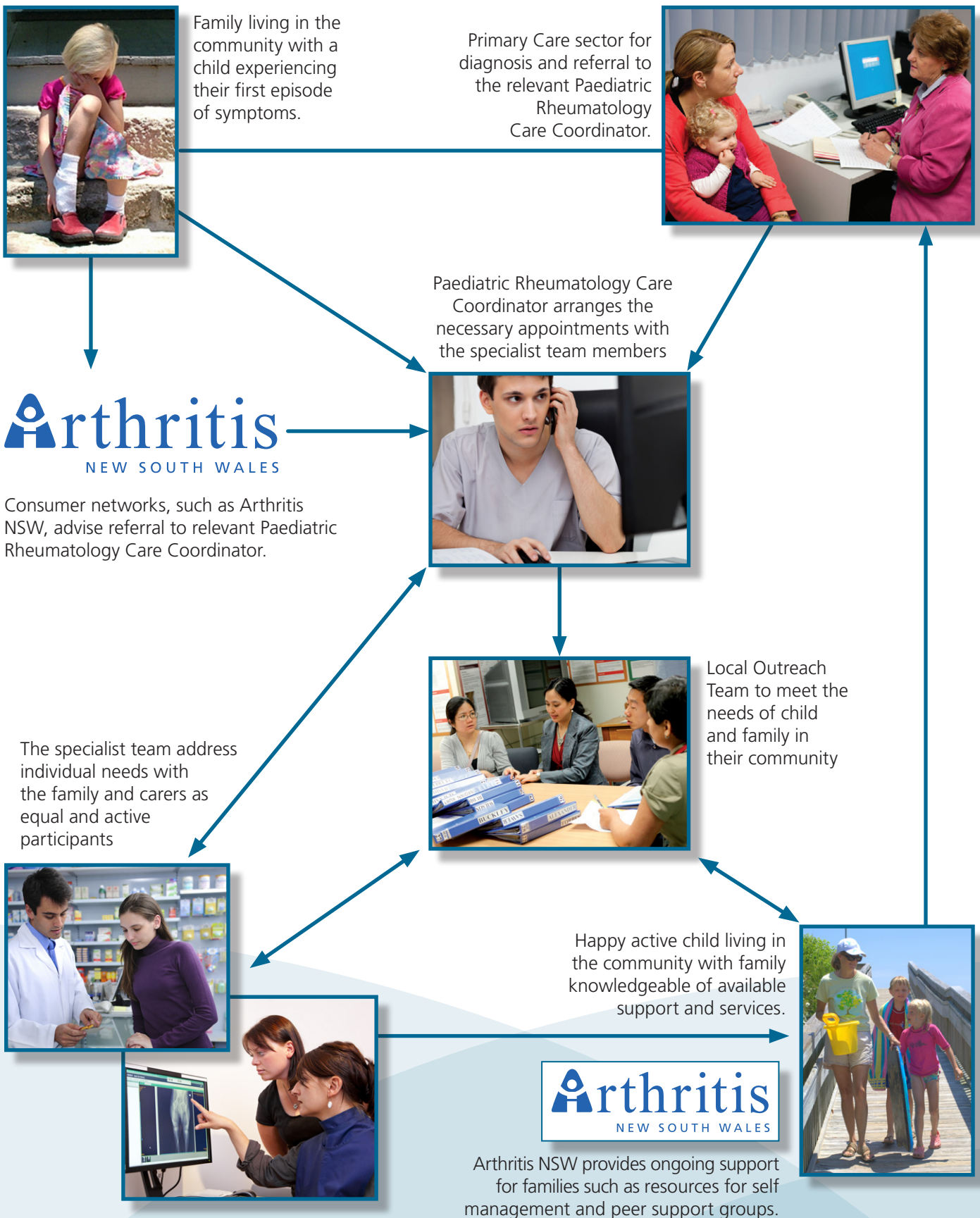
Adolescent services are important to bridge the gap between adult and paediatric services. LHDs, particularly those with existing adult rheumatology services, have intimate knowledge of the local determinants of services and together with the ACI Musculoskeletal and Transition Networks will provide valuable input to services necessary to care for young people transitioning from paediatric to adult services.

Outreach services will be established in collaboration with LHDs. Preliminary discussions have identified a number of regional centres with an interest in supporting this service for the benefit of their local populations. The Australian Government's Medical Specialist Outreach Assistance Program (MSOAP) may be utilised to support implementation of outreach services. Other innovative means such as tele-health will be explored to achieve this aim.

Procedures such as intra-articular steroid injection for children and young people suffering acute painful arthritis need to be performed with appropriate sedation or anaesthetic cover. These will be provided in a regular coordinated manner by the NSWPRN. Although this will require travel for some families from regional and rural areas at least initially, the intention will be to provide regional outreach to develop local services or engage other specialists such as orthopaedic surgeons to perform these procedures locally where appropriate.

Figure 4 is a pictorial representation of the successful operation of the NSWPRN in delivering coordinated, timely expert care for young people suffering rheumatic disease.

Figure 4: Pictorial model of the operation of the NSW Paediatric Rheumatology Network



IMPLEMENTATION OF THE MODEL OF CARE FOR THE NSWPRN

The Working Group recommends the implementation of the NSWPRN as a staged process with immediate establishment of the Foundation Centre and implementation of the full NSWPRN after an initial two year period lead by the Foundation Team. It is envisaged that the NSWPRN will achieve all of its stated aims within a five year time frame.

The Foundation Centre of the NSWPRN

Staffing requirements of the Foundation Team are shown in Table 3.

The Foundation Centre will be a Centre of Excellence with some clinical and education roles but also important strategic planning responsibilities. It will develop a single point of access for coordinated care from a multidisciplinary team to avoid delays in diagnosis and in directing patients to appropriate services. It will allow for high quality training for medical, nursing and allied health staff building capacity and specialist skills to train other clinicians in a flow on manner. The Foundation Team will also develop collaborative partnerships with other tertiary paediatric services, LHDs, general practitioners and Medicare Locals, peer advocacy groups, universities and other key stakeholders to provide a state wide and coordinated approach to the care of children and young people with rheumatic diseases.

The tasks of the Foundation Team of the NSWPRN are to:

- establish the operational structure of the MDT
- establish the roles of the essential members of the MDT
- develop links with network partners particularly to improve health professional education
- consult with regional LHDs and formalise plans to establish regional and rural (and intra-urban) outreach services
- consult with adolescent services and LHDs and formalise plans for transition services

Table 3: Foundation Team of the NSW Paediatric Rheumatology Network

| Health Professional | FTE |
|--|-----|
| Rheumatologist | 1.2 |
| Clinical Nurse Consultant – Care Coordinator | 1.2 |
| Physiotherapist | 1.0 |
| Occupational therapist | 0.5 |
| Clinical Support Officer | 1.2 |
| Program Development Officer | 1.0 |

- develop policies and procedures to guide referral, clinical interventions and medication monitoring.
- develop patient education and self-management programs
- establish standardised data collection systems to allow audit and quality improvement within the network
- work with other specialty areas to facilitate the development of interdisciplinary clinics – initially ophthalmology for the management of uveitis and nephrology for management of SLE
- establish a budget to ensure the sustained operation of the network
- be advocates for children and young people with rheumatic disease
- establish local, national and international research collaborations
- conduct ongoing assessment of the implementation process to ensure it is achieved effectively and remains relevant to the child, adolescent and family needs.
- provide feedback on progress to the administrative structures of the SCHN, ACI and the NSW Ministry of Health.

The Foundation stage of implementation will be heavily strategic and require the input of individuals who have extensive experience in their field and in the operation of a rheumatology MDT. These initial tasks are expected to take two years to complete.

Table 4: Staffing required for a best practice model of care for children with paediatric rheumatic disease in the NSW Paediatric Rheumatology Network compared to currently allocated services.*

| Health Professional | Proposed Total | Current |
|--|----------------|---------|
| Rheumatologist | 2.5 | 0.375 |
| Clinical Nurse Consultant – Care Coordinator | 2.5 | 0 |
| Physiotherapist | 2.5 | 0.3 |
| Occupational therapist | 1.0 | 0 |
| Dietitian | 0.3 | 0 |
| Social Worker | 0.3 | 0 |
| Clinical Psychologist | 0.5 | 0 |
| Clinical Support Officer | 1.5 | 0 |
| Program Development Officer | 1.0 | 0 |

All figures are in FTE unless otherwise stated (0.1 FTE = 4 hrs/wk)

Full implementation of the NSWPRN

Achieving the Foundation Centre objectives will facilitate the implementation of the full NSWPRN structure in a sustainable and cost effective manner. The Working Group envisages that the initial three years of full operation of the NSWPRN will see further implementation of the strategic directions already developed in the Foundation period through extensive consultation. These strategies will include expanded clinical services including outreach services, a virtual ward and satellite services. Expansions in the service will be based on a hub and spoke pattern spreading from the tertiary service with a strong emphasis on engaging local services. Other important features will include enhanced educational roles, a commitment to safety and quality improvement, research and advocacy within the field.

As the structure of the NSWPRN is rolled out between years three and five, an increasing clinical load to the MDT is expected as a result of the recognition of an expert service for the care of paediatric rheumatic diseases in NSW. The remaining staff will be integrated into an already functioning structure and the existing roles in the Foundation Team expanded and augmented to meet the ideal staffing for the model as shown in Table 4.

These aims parallel those of the recently legislated statutory health corporation known as NSW Kids and Families, established on July 1, 2012. NSW Kids and Families will implement the Garling Inquiry recommendations with regard to paediatric services in NSW [76].

At the completion of this phased process, children and young people with paediatric rheumatic disease and their families will be able to access a best practice model of care. Furthermore, the health professionals and organisations involved will be able to establish an efficient and effective service that is well integrated into existing and new services at tertiary, secondary and primary care levels.

Ideal Child and Family Experience – post-implementation of the NSWPRN

Xavier's Story

Seven year old Xavier was diagnosed with juvenile arthritis when he was just past his first birthday. Xavier's Mum, Janine, identified that at 13 months he had stopped walking, had become needier of her time and wanted her to carry him. The family had been overjoyed that he had started walking at 11 months so this was of concern to Janine and Xavier's dad Michael.

Janine took Xavier to see their general practitioner (GP) who couldn't find anything wrong so suggested they 'wait and see' how he progressed. After one week, Xavier's right knee became swollen so Janine took him back to the GP where he saw the GP registrar. The registrar immediately considered arthritis so he contacted the local paediatrician while Janine was in the rooms. Tests were ordered including X-rays, and an appointment was made to see the paediatrician the next day. At this time the paediatrician started Xavier on antibiotics and arranged for him to see the paediatric rheumatologist at the nearest children's hospital. By now Xavier's knees and an ankle were swollen.

Xavier was admitted to hospital and spent a week having his diagnosis confirmed and a multidisciplinary care plan agreed to by Xavier's Mum and Dad, as well as the Paediatric Rheumatology team. The family was introduced to the specialist nurse on the team who they were told could act as their 'navigator' of Xavier's care in the future if needed. Considerations concerning access to care in the local area where the family lived were a high priority. Included in the careplan was a link to a local physiotherapist who could teach the family about warm water exercises. Janine and Michael were also linked with the Arthritis NSW JIA Support Group as well as a family who have a child with arthritis.

After discharge, Janine took the hospital discharge letter to their GP and local paediatrician with the plan that the two local doctors would work with the family to implement. The aim was to have his local doctors manage Xavier's ongoing medical needs and consult the paediatric rheumatologist on a needs basis only. He would only require visits to the children's hospital on rare occasions where specialist treatments were required to settle any exacerbations that proved difficult under the agreed care plan.

The GP linked the family with the local Child and Adolescent Unit which was about a 20 minute drive from



their home. Here they had access to the physiotherapist, social worker and an occupational therapist. These team members have attended inservices provided by the Paediatric Rheumatology team at the children's hospital. The physiotherapist came to Xavier's play group to monitor his gross motor skills and also came to the family home on a monthly basis in the early days after diagnosis.

By the time Xavier turned three years of age it was obvious he would require aggressive treatment of his arthritis and so the paediatric rheumatologist was once again consulted. He started a new drug and this seemed to settle his condition. At age five he started school brimming with confidence and no noticeable difference in physical skills compared with his peers. At age seven, he hasn't needed to use the services of the Child and Adolescent Unit for two years. The school has had education provided by the occupational therapist at the Child and Adolescent Unit concerning childhood arthritis and so are very supportive of any specific needs Xavier has had in his two years at school.

As Xavier grows into adolescence the family feels confident that he will be supported by the team at the Child and Adolescent Unit as he gradually moves into adult care services. Xavier's family feels confident for his future.

VALIDATION OF THE NSWPRN

Parents and young people

The NSWPRN model of care was developed following reports by clinical teams of the long journey for families to gain the diagnosis for their child and the subsequent best practice treatment. These reports were independently validated by parents across NSW who provided Arthritis NSW with written accounts of their own experiences.

Following the first draft of the model of care the ACI Musculoskeletal Network undertook qualitative research with another group of parents and young people from across NSW. The first aim was to determine what the participants believed was currently lacking in health care services in NSW for parents to gain early diagnosis and treatment for their child with a rheumatic condition [48]. Secondly, the research sought to gain their feedback on how they believed the proposed model of care would meet their needs and whether it included all the required actions and interventions. Focus groups and individual interviews were conducted until saturation of themes was achieved. The data was collected and analysed by an independent professional qualitative researcher.

Five high level themes were deduced from the data concerning the needs of the informants in their life journey with rheumatic conditions in childhood. These were:

Optimised service efficiency by:

- Promoting awareness about JIA among health care professionals
- Minimising delays in diagnosis and subsequent treatment through easy access to health care professionals with specific expertise
- Provision of holistic and integrated care through coordination of MDT input
- Establishing outreach programs to rural and regional areas
- Providing pharmacy support for immunosuppressive medication and provision of needles, sharps bins for example.

Need of transitional services aimed at:

- Establishing trust and rapport with the adult rheumatology services
- Providing comprehensive information transfer of health history.

Need for psychosocial support including:

- Social and financial aid
- Access to mental health services for anxiety and other chronic illness issues
- Specific vocational guidance
- Peer support.

Need for better information concerning:

- Medication side effects and administration including injections
- Nutritional guidance
- Pain management
- Access to medical equipment.

School-based support and advocacy to:

- Promote acceptance of students and their needs
- Provide academic assistance where required
- Facilitate environmental modifications if necessary
- Offer alternative curricula particularly in terms of physical activity where necessary.

The NSWPRN model of care was endorsed by the participants of the qualitative research and all of the identified themes from the research have been incorporated into the model of care. To further validate the model consumer input will be sought at least annually in a formal manner and through opportunistic situations during the delivery of the model to its users.

Post-implementation Evaluation

Ongoing evaluation will be conducted after the implementation of the model of care to ensure that the model of care is feasible, relevant and meets the needs of the families, children and young people using the model of care. Care to ensure that the MOC meets the strategic aims and goals of the NSW public health system on an ongoing basis will also be necessary. Local quality projects will be encouraged to help inform these requirements.

In addition, data elements related to paediatric rheumatic disease care will be added to the ACI Musculoskeletal Network state wide quality database. This will assist the collection of key performance indicators to assess whether the model of care is effective in achieving measurable outcomes as well as monitor clinical outcomes of those people accessing the model of care.

The following KPI's will be built into the Evaluation Plan to demonstrate the impact of the NSWPRN:

- referrals received
- waiting time for care
- waiting time for access to joint injections
- waiting time for ophthalmology assessment
- days missed from school
- days missed at work by parent/carer
- reduction in Intensive Care Unit (ICU) admissions.

Cost savings have been shown through the use of multidisciplinary team care in paediatric rheumatology in prospective cohorts and retrospective studies [77-79] largely due to the prevention of long term disability [16, 79]. Randomised controlled trials have not been conducted as it would be unethical to undertake considering the body of evidence of an accepted beneficial intervention such as multidisciplinary team care compared with more limited models of care [80].

Cost-Effectiveness

The cost-effectiveness of multidisciplinary services for children with rheumatic conditions has been reported predominantly from the perspective of improved quality of life and social costs. These include:

- reduction in pain
- improved attendance at school
- more likely to gain professional training
- more likely to maintain employment in positions that are chosen by the individuals, and
- less social and financial strain on families.

INFORMING THE COMMUNITY

Following launch of this model of care the ACI Musculoskeletal Network will undertake a process of informing key stakeholders of the model. Included in the process of community information will be communication with the associated professional bodies, consumer organisations, educational institutions, Medicare Locals and general practice groups, along with LHDs across NSW. Arthritis NSW and other advocacy groups will assist in alerting the general community of NSW of this MOC.

APPENDIX 1: KEY OBJECTIVES OF NSWPRN

| DOMAIN | OBJECTIVE | |
|--|--|---|
| Objective 1 - Improved physical health and well-being of children and young people with rheumatic disease | | |
| Clinical care | Actions of the Model of Care (MOC) | Outcomes of the MOC |
| | <ul style="list-style-type: none"> • Establish multidisciplinary paediatric rheumatology services • Provide care based on evidence and best practice • Establish transition services for adolescent patients • Establish regional and rural outreach services • Establish primary care and paediatric links to facilitate care • Increase awareness of paediatric rheumatic disease among health professionals | <ul style="list-style-type: none"> • Appropriate and prompt access to expert care in all areas of NSW • Prevention of delays in diagnosis and treatment • Improved patient outcomes and prevent complications and disability • Coordinated care in childhood, through transition into adult services |
| Objective 2 - Improved education and support services for children and young people with paediatric rheumatic disease and their families | | |
| Patient Support | Actions of the MOC | Outcomes of the MOC |
| | <ul style="list-style-type: none"> • Develop age and disease appropriate educational materials • Develop family and community educational resources • Establish strong partnerships with advocacy groups • Guarantee access to social work and psychology services if needed | <ul style="list-style-type: none"> • Improved disease understanding • Empowerment of children, young people and their families • Enhanced self management skills • Alleviate feelings of isolation and the psychosocial affects of disease • Improved consumer advocacy • Enhance school and social integration |
| Objective 3 - Establish a culture of quality improvement in paediatric rheumatic disease care | | |
| Quality | Actions of the MOC | Outcomes of the MOC |
| | <ul style="list-style-type: none"> • Develop comprehensive data collection systems • Establish outcome monitoring and formalised audit processes | <ul style="list-style-type: none"> • Information to guide continuing improvement efforts • Accountability • Long term maintenance of best practice |

| DOMAIN | OBJECTIVE | |
|--|---|--|
| Objective 4 - Improved education for health professionals in the recognition and management of paediatric rheumatic disease | | |
| Health Professional Education | Actions of the MOC | Outcomes of the MOC |
| | <ul style="list-style-type: none"> • Establish educational partnerships with tertiary and postgraduate bodies • Provide opportunities for supervised clinical training | <ul style="list-style-type: none"> • Early recognition and prompt referral to specialist services • Increased capacity for shared care in non specialist settings • Capacity to train paediatric rheumatologists to ensure sustainability of services |
| Objective 5 - Establish a culture of research | | |
| Research | Actions of the MOC | Outcomes of the MOC |
| | <ul style="list-style-type: none"> • Foster local expertise in clinical, epidemiological and science research • Establish collaborative networks locally, nationally and internationally • Establish patient cohorts to support research | <ul style="list-style-type: none"> • Contribution to improvements in diagnosis, treatment and outcome |
| Objective 6 - Develop and maintain a sustainable paediatric rheumatology service for the future | | |
| Sustainability | Actions of the MOC | Outcomes of the MOC |
| | <ul style="list-style-type: none"> • Establish multidisciplinary paediatric rheumatology services • Provide education for health care professionals | <ul style="list-style-type: none"> • An evolving and responsive patient-centred service for patients and families |

APPENDIX 2: TEAM MEMBER ROLES

Paediatric Rheumatologist

- Provide clinical leadership in medical management as part of a multidisciplinary team
- Support the team members and partners in their interventions as required
- Be supportive and actively participate in quality and research projects
- Lead the review of data collection concerning the implementation of the model of care
- Lead collaboration with the team members on model of care adjustments as the data and other information indicates
- Support educational opportunities including development and delivery
- Promote the model of care in appropriate forums, along with other team members.

Clinical Nurse Consultant

- Team and care coordination
- Point of contact for families for advice, especially regarding access to medical assessment and treatment
- Provide self-management support to families and young people on disease processes and management
- Provide education for nurses regarding the care of children and young people with rheumatic disease.
- Collaborate with others regarding procedures involving children with rheumatic conditions
- Participate in research activities
- Coordinate transition planning with adult clinical service providers to ensure continuity of care and timely transfer of information.

Physiotherapist

- Assessment and management of children referred to the rheumatology service which is timely, effective and evidence based
- Assessment and management of pain, range of motion, strength and functional abilities with task and context specific interventions including hydrotherapy, stretching and strengthening, splinting and casting
- Assessment and intervention which aims to optimise participation in physical activity including sports within the home, school and community environments. This may include specific advice regarding modification and choice of suitable activities
- Liaison with local services to coordinate ongoing physiotherapy management where possible
- Act as a state-wide consultant and clinical resource for health and other professionals in the physiotherapy management of children with rheumatic conditions
- Assist in the development of educational resources for health and education professionals, children with rheumatic conditions and their carers
- Provide education and support for physiotherapists across the state
- Develop, participate in and encourage research
- Develop and utilise outcome measures appropriate for physiotherapy
- Develop, implement and review evidence-based clinical guidelines for physiotherapy
- Establish and maintain effective communication networks and provide up to date information as appropriate.

Occupational Therapist

- Assessment and management of children participating in self-care, preschool, school or leisure activity and level of difficulty. Intervention may include task or environmental modification, education, functional training, and compensatory techniques
- Assessment and management of upper limb function, joint range of motion, joint protection and muscle strength of the upper limb. Intervention may include stretching, splinting, casting, strengthening programs, functional training, adaptation of tasks and activities
- Home assessment where the home environment imposes limitation on participation for children or risk for the child and family and/or carer. Intervention may include equipment provision and prescription, recommendation of home modifications and liaison with relevant organisations such as Housing NSW and home modification schemes
- School assessment where the environment imposes limitation on participation for children or risk for staff/carers. Intervention may involve prescription of equipment or modifications (e.g. ramps, lift installation, taps, appropriate furniture and modification to tasks and activities)
- School liaison and education regarding individual children to maximise their access to the curriculum. Interventions may include prescription of equipment (e.g. pen grips, slope boards or special scissors) modification to access to the curriculum, modification to means of recording written work (e.g. accessing others notes, using technology or writers)
- Assessment and intervention for handwriting difficulties including alternative means of accessing written work, use of technology (prescription and integration of laptops and other technology into school), supporting applications for Disability Provisions for the School Certificate and Higher School Certificate
- Non-pharmacological means of pain and/or sleep management such as relaxation therapy and energy conservation with children and young people with rheumatic conditions
- Model of intervention may involve regular therapy, regular contact and/or review, referral to local services with support and monitoring from tertiary services, intermittent review, and/or consultancy or liaison with other involved agencies such as schools, preschools, sport or leisure providers, as the particular child's needs indicate

- Development of outcome measurement integral to occupational therapy practice with children and young people with rheumatic conditions
- Development and maintenance of evidence-based clinical guidelines for occupational therapy management of children with rheumatic conditions
- Conduct of research and best practice related to occupational therapy assessment and management of children with rheumatic conditions
- Participation in rheumatology service research projects
- Education of occupational therapists and other health professionals about the needs of children and young people with rheumatic conditions.

Dietitian

- Parents will require much dietary advice and support as some of the aspects of rheumatic disease in children are exacerbated by dietary habits
- Education and intervention for nutritional deficiencies, weight (low and high) management, dietary supplementation
- Provide diet and nutritional advice for children on long term steroid medications, the mainstay of management in many rheumatic diseases that have significant side effects such as obesity, hyperlipidaemia, osteoporosis and diabetes
- Required to address the issues concerning supplements and complementary therapies.

Social Worker

- Provision of social, psychological support and counselling for children and families living with rheumatic conditions
- Ensure access to financial and social support for these families
- Encourage self-management skills and support parents to foster independence and health literacy.

Clinical Psychologist

- Provision of assessment and intervention for children with rheumatic conditions and their families where the disease is an influence on social, psychological or mental health or adjustment to disability and/or ill health.

Educational Advisor

- Development of educational resource material (presentations, written and/or web based) for families, schools and the community for general education about rheumatic conditions in children, in collaboration with the MDT and Arthritis NSW.

Clinical Support Officer

- Management of database
- Administration of clinics
- Organisation of transport and accommodation arrangements for outreach service
- Coordination of staff in terms of infrastructure and administrative support.

Program Development Officer

- Assist with the implementation of a collaborative, coordinated approach to the planning and delivery of the NSWPRN including the initial set up of the Foundation Centre
- Assist with the development of pathways of care across care settings in NSW
- Assist with liaison and collaboration with service providers, government and non-government bodies such as Arthritis NSW and Lupus NSW
- Develop a plan to facilitate ongoing monitoring of the NSWPRN
- Develop an ongoing evaluation strategy for the NSWPRN
- Co-ordinate the ongoing monitoring and evaluation of the NSWPRN
- Assist with strategies to achieve and maintain sustainability of the NSWPRN.

APPENDIX 3: GLOSSARY OF TERMS

| | |
|--|--|
| ACI – Agency for Clinical Innovation | RACP – Royal Australian College of Physicians |
| ACT – Australian Capital Territory | SA – South Australia |
| AIHW – Australian Institute of Health and Welfare | SCH – Sydney Children’s Hospital |
| ANSW – Arthritis New South Wales | SCHN- Sydney Children’s Hospitals Network (Randwick and Westmead Hospitals) |
| APRG – Australian Paediatric Rheumatology Group | SS – Staff Specialist |
| BSPAR – British Society of Paediatric and Adolescent Rheumatology | TAS - Tasmania |
| CHW – Children’s Hospital, Westmead | TNF – Tumour Necrosis Factor |
| CNC – Clinical Nurse Consultant | USA – United States of America |
| FTE – Full-time Equivalent | VIC - Victoria |
| GP – General Practitioner | WA – Western Australia |
| JDM – Juvenile Dermatomyositis | Young people – refers to people aged 13 – 25 years as utilised by the AIHW |
| JHCH – John Hunter Children’s Hospital | |
| JIA – Juvenile Idiopathic Arthritis | |
| JSLE – Juvenile Systemic Lupus Erythematosus | |
| LHD – Local Health District | |
| MDT – Multidisciplinary Team | |
| MOC – Model of Care | |
| MRI – Magnetic Resonance Imaging | |
| MSOAP – Medical Specialist’s Outreach Assistance Program | |
| NHMRC – National Health and Medical Research Council | |
| NSW – New South Wales | |
| NSW KIDS - refers to NSW Kids & Families, a statutory health corporation in NSW | |
| NSWPRN – New South Wales Paediatric Rheumatology Network | |
| NZ – New Zealand | |
| PBS – Pharmaceutical Benefits Scheme | |
| QLD - Queensland | |
| RACGP – Royal Australian College of General Practitioners | |

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