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NSW Paediatric Rheumatology Services

Advisory Group Findings and Recommendations

October 2023

Musculoskeletal Network



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Not for further circulation



Executive summary

Paediatric rheumatology is the speciality that manages rheumatic diseases affecting joints, tendons, ligaments, bones, and muscles in children, diagnosed before their 16th birthday and with symptoms lasting over 6 weeks¹⁻³. Approximately 80% of the condition burden is juvenile idiopathic arthritis (JIA) also known as juvenile arthritis. Dramatic advances in treatment for juvenile idiopathic arthritis (JIA) over the past decade have resulted in major improvements to outcomes. Much of the joint damage, deformity, disability, and joint surgery associated with the condition may now be prevented.

In February 2023, at the request of the Deputy Secretary, Health System Strategy and Patient Experience, the ACI Musculoskeletal Network convened a Paediatric Rheumatology Advisory Group (Advisory Group) with the purpose of providing expert advice to identify issues related to current and future paediatric rheumatology care within NSW and proposing options to manage and mitigate these issues.

The Advisory Group included clinical subject matter experts, Ministry of Health representatives from Workforce, Health and Social Policy Branch, the Chief Allied Health Officer and ACI representatives from the Musculoskeletal, Paediatric, and Transition networks and virtual care and evidence teams. The Advisory Group met four times and developed findings and recommendations informed by a clinical guidance comparison matrix, rapid evidence review, data analysis and experiential evidence case studies.

NSW requires a sustainable model of care, with the lack of paediatric rheumatology workforce being the major barrier to providing timely and accessible care for the children and young people of NSW. If these recommendations are not addressed, further delays in diagnosis and treatment will contribute to preventable disability and significant impact to quality of life for children and their families, as well as costs to the system.

Key findings

The Advisory Group found:

- there is documented unmet need and this is expected to increase in the future
- access to expert paediatric rheumatology services in urban, regional and rural NSW falls well behind national benchmarks and international guidelines
- NSW Health provides services across three sites: Sydney Children's Hospital Network (SCHN, approximately 150 clinics/year and inpatient care) Liverpool Hospital (12 clinics/year) and John Hunter Hospital (12 clinics per/ year, Belmont (6 clinics per/year)
- outreach services are limited with provision to Wagga and Orange by an NSW based paediatric rheumatologist (fully funded by the Commonwealth medical specialty outreach program)
- the paediatric workforce is a small, but critical workforce and there is significant shortage of paediatric rheumatologists in NSW



- shortfalls in specialist multidisciplinary services lead to delays in diagnosis and access to multidisciplinary team (MDT) care contributing to unnecessary long term disability and poor health outcomes
- children and young people from regional and rural areas are particularly disadvantaged due to the long distances required to travel to access limited expert care
- NSW has the greatest deficiency compared to other states
- clinical staff are experiencing burnout and there is a risk of significant knowledge loss; members of the small core team are approaching retirement age
- NSW is not able to run an accredited training program for paediatric rheumatologist within NSW due to workforce shortages
- there may be a time limited opportunity to secure available paediatric rheumatologists interested in working for NSW from 2024
- the partially implemented [2013 ACI Model of Care](#)¹ remains valid
- The existing model has embedded an advanced nursing position, a multidisciplinary approach, the use of virtual care and features two HealthPathways.

Recommendations

The Advisory Group made 13 recommendations: seven immediate term (12 months), five medium term (3-5 years) and one long term (5+ years). These recommendations address the current and future needs of the children and young people of NSW with juvenile arthritis and other paediatric rheumatic diseases.

Seven immediate recommendations (within 12 months);

1. NSW Health consolidates services into a state-wide networked with a centralised state-wide triage system and rural and regional outreach to improve equity of access. SCHN would be the initial led site
2. NSW Health enhances paediatric rheumatology services workforce to meet current need for state-wide networked model; with total immediate funding (Stage 1) for:

Clinical services

 - 4 FTE paediatric rheumatologists
 - 1 FTE paediatric advanced trainee positions
 - 1 FTE state-wide service coordinator role (including transition and coordinator function within roles, AHP or Nursing role)
 - 3 FTE advanced practice nursing
 - 2.5 FTE physiotherapist
 - 1.5 FTE occupational Therapist
 - 0.5 FTE ophthalmology
 - 2.0 FTE administration officers
 - outreach to support rural and regional people

Implementation

 - 1.0 FTE State-wide Implementation Lead (2 years, ACI)



3. NSW Health builds prioritised referral, within the paediatric rheumatology clinics, to facilitate timely needs-based access to psychological, dietetics, social work in the networked services with local pathways to access ophthalmological screening services to enhance the foundational paediatric rheumatology MDT services
4. SCHN to regain paediatric rheumatology advanced trainee accreditation with dedicated training positions. Limitation currently is minimum requirement of 2.0 FTE per advanced trainee
5. ACI publish an update to the 2013 model of care to align to recent literature and to embed virtual care, a formal networked approach and consider alternative care approaches for advanced and extended practitioner workforce models and ways to facilitate stronger multidisciplinary workforce access
6. NSW Health commits to agreeing on a minimum dataset for monitoring, evaluation, and quality improvement as part of this work NSW assesses the applicability of participating in the Australian Juvenile Arthritis Registry (AJAR)
7. The ACI Musculoskeletal and Transition Networks partner to develop a formal paediatric rheumatology transition program to support people as they move to adult services.

Five medium term recommendations (3-5 Years);

8. NSW Health commit to provide a world class care standard for the assessment and treatment of childhood arthritis
9. NSW takes a Value Based Health Care approach to evaluating the enhancement of services for children living with juvenile arthritis. Evaluation of the model (if funded) to be undertaken including clinical outcomes, hub and spoke model review and workforce requirements
10. Further enhancement of paediatric rheumatology services workforce to allow NSW Health to deliver a world class standard of care for patients with Juvenile Idiopathic arthritis. Based on current evidence and consensus, this enhancement would require total funding (Stage 2) for:

Clinical services

- 5.0 FTE (+ 1.0) paediatric rheumatologists
- 2.0 FTE (+ 1.0) additional paediatric advanced trainee positions
- 4.0 FTE (+1.0) advanced practice Nursing. Service to have specialist Nurse practitioner role and/or advanced nursing roles within the paediatric rheumatology service
- 1.5 FTE (+1.0) ophthalmology
- 4.0 FTE (+1.5) physiotherapist. Service to including a clinical specialist physiotherapy role within the paediatric rheumatology service
- 3.0 FTE (+1.5) occupational Therapist. Service to include a clinical specialist occupational therapy role
- 1.0 FTE psychologist
- 1.0 FTE social worker
- 0.5 FTE dietitian
- 2.0 FTE administration officers
- 1.0 State-wide coordinator
- Dedicated transition services
- Outreach to support rural and regional people including MDT team



11. NSW Health continues to build the multidisciplinary workforce that is responsive to innovations in care by:
- developing a strategy to sustain the specialist paediatric rheumatology workforce, including positions for newly qualified advance trainees
 - initiating advanced allied health practitioner (clinical specialist level 6) and nurse practitioner (Nurse practitioner) models
 - assessing viability of a GP outreach model as developed in QLD

12. NSW considers aligning to Henry Report recommendations relating to paediatric rheumatology cohort, promoting the tenant of right care, right time, right place. Explore options for including subspecialty appointments, cross credentialing of paediatric rheumatology staff, and potential reverse IPTAAS funding to facilitate.

One long term recommendation (5+ Years);

13. NSW Health explores extended scope health practitioner models used overseas to support ongoing sustainability.



Background

Paediatric rheumatology overview

Paediatric rheumatology is the speciality that manages rheumatic diseases affecting joints, tendons, ligaments, bones, and muscles in children, diagnosed before their 16th birthday and with symptoms lasting over 6 weeks¹⁻³. Approximately 80% of the condition burden is juvenile idiopathic arthritis (JIA) also known as juvenile arthritis. This cohort also includes other inflammatory conditions including systemic lupus erythematosus (SLE), juvenile dermatomyositis (JDM), scleroderma, vasculitis, uveitis, periodic fever and auto-inflammatory syndromes. Other non-inflammatory rheumatic diseases such as chronic widespread musculoskeletal pain, joint hypermobility, genetic collagenopathies and growth-related musculoskeletal conditions are also managed by this speciality.

The focus of this report is on the inflammatory arthritis conditions and predominately juvenile arthritis¹⁻³. The management of these musculoskeletal and/or systemic inflammatory diseases (often involving multiple organ systems such as the heart, lungs, kidneys and eyes) requires a comprehensive understanding of the effects of inflammation on the body and requires specific training^{1, 4-6}. These conditions have significant variation in presentation, prognosis, and complications with knowledge of management transcending the traditional organ specific treatment of disease provided by many other specialty areas^{1, 2, 5}. Clinical guidance recommend early referral to a paediatric rheumatologist for children diagnosed or suspected of having rheumatic diseases^{1, 4-6}.

Juvenile arthritis is one of childhood's most common, serious and persistent medical conditions. It affects 1-3 children per thousand under 16 years of age and is as common in children as type 1 diabetes^{2, 7}. More than 80% of children and young people living with these conditions experience daily joint and muscle pain^{1, 7}. They can also experience skin diseases, high fevers, and vision problems, including blindness⁷. Advances in medical management through immunosuppressive agents have been shown to drastically improve outcomes but these drugs can have serious side effects and the regular injections can cause significant disruptions and distress to the children⁷. While outcomes vary for each individual child, remission rates have been estimated to range from 7% at 18 months to approximately 40% after 10 years old². Eighty five per cent of children have limitations to their participation in school activities, sport and play. This social isolation combined with the need for regular medical treatment means many of these children experience mental health problems^{1, 2, 7}. Early diagnosis and intervention has been demonstrated to prevent significant disability, suffering and future health costs^{1, 7}. Half of children will continue to have arthritis into adulthood and 20% of children enter adulthood with significant disability^{1, 7}.

Previous relevant and affiliated activities

NSW health activities

In 2013, the ACI partnered with SCHN to release a [Model of Care](#)¹ for the NSW Paediatric Rheumatology Network. The model was structured around getting children the best access to available services at that time, and to bridge the gap between primary care and the limited availability of paediatric rheumatologists in NSW. The specialist component has been partially implemented by the SCHN in partnership with ACI including the following activities;

- Between 2013 and 2015 ACI supported the implementation of the Model.



- In 2015, SCHN launched a paediatric rheumatology website for patients, families and the community
- Two Health Pathways have been established. This is an online health information portal for general practitioners and provides information on how to assess, manage and refer patients. These are undergoing minor updates currently through John Hunter Hospital due to changes in available medications
- As part of the 2020-21 NSW budget process, SCHN received limited growth funding. The Network, balanced against other clinical needs, allocated from total growth funding a staff specialist (0.5 FTE) and administrative support (0.8 FTE). This enhancement did not increase the number of juvenile idiopathic arthritis (JIA) clinics but provided the current clinical nurse consultant the ability to provide more clinical management for existing patients.

Other government activities

In December 2021 a Commonwealth parliamentary inquiry⁷ into childhood rheumatic diseases was launched and its interim report⁷ was released in March 2022 ahead of the Federal election. The inquiry highlighted the significant impact these diseases have on children and recommended 4 key areas of need for immediate attention:

1. the shortage of staff across the rheumatology workforce
2. the need for better education and awareness of childhood rheumatic diseases such as juvenile idiopathic arthritis
3. improved access to medication and treatments
4. the need for a well-established transition service or process for paediatric patients moving into adult care (Parliament of Australia 2022).

A full list of the 15 recommendations can be found at the [Inquiry into childhood rheumatic disease: interim report⁷](#)

In June 2023 the Australian Institute of Health and Welfare updated its Juvenile Arthritis report². It estimated 18,500-30,100 Australians aged 0-24 years are living with juvenile arthritis, highlighted the workforce shortages across Australia. increase in acute health service utilisation and the impact on the people living with juvenile arthritis².

Stakeholder affiliated activities

There has been significant advocacy for improvements in paediatric rheumatology services in NSW and Australia. Numerous stakeholders including Juvenile Arthritis Foundation of Australia (JAFA), Australia Rheumatology Association (ARA), Arthritis NSW and numerous NSW parliamentary members have been advocating to improve access. NSW has been identified as having the greatest need and as such is a high priority for advocacy groups. Minister Park met with JAFA and made a public commitment to improving the care for these children. Since the Parliamentary inquiry in 2022, there has been affiliated activities including two JAFA proposals, ARA workforce report⁸, Australian Juvenile Arthritis Registry (AJAR) launched, and Draft Standards of Care for JIA in Australia⁴. Before the end of 2023 Australian Paediatric Rheumatology Group (sub group of the Australian Rheumatology Association) plans to publish the Australian Standards of Care.

Methodology

In February 2023, at the request of the Deputy Secretary, Health System Strategy and Patient Experience, the ACI convened the Advisory Group with the purpose of providing



expert advice to identify issues related to current and future paediatric rheumatology care within NSW and propose options to manage and mitigate these issues.

The Advisory Group included clinical subject matter experts, Ministry of Health representatives from Workforce, Health and Social Policy Branch, the Chief Allied Health Officer and ACI representatives from the Musculoskeletal, Paediatric, and Transition networks and virtual care and evidence teams. Given the small workforce there were acknowledged conflicts of interest with some of the subject matter experts on the working group having formal relationships with Juvenile Arthritis Foundation Australia.

The Advisory Group met four times formally and provided review and endorsement of the documents outside of the meetings Findings and recommendations were agreed through expert clinical consensus and informed by a clinical guidance comparison matrix, rapid evidence review, data analysis and experiential evidence case studies. Findings and recommendations of the group are non-binding and presented to the Deputy Secretary, Health System Strategy and Patient Experience.

A detailed methodology can be found in the Appendix– 1



Current State

NSW service provision

A total of three paediatric rheumatology services are provided by NSW Health servicing both NSW and ACT residents: with SCHN providing the vast majority (approximately 150 clinics per year and inpatient care across two sites) with approximately monthly service provision at Liverpool Hospital (12 clinics per year) and John Hunter Hospital (12 clinics per year and 6 clinics per year at Belmont). Outreach services are provided to Wagga and Orange by an NSW based paediatric rheumatologist but are fully funded by the Commonwealth medical specialty outreach program. There are no paediatric rheumatology services available in the Australian Capital Territory (ACT); NSW supports these children and young people.

Approximately 50% of care is provided in private practice settings which can be very costly for families, does not provide the internationally accepted best practice of MDT care and further contributes to inequity of access for lower socioeconomic groups.

NSW services operate a model that

- Assesses and diagnoses new patients
- Review care to existing patients including planned and acute management
- Provide education, self-management support and psychosocial support to patients
- Care coordination including referrals to MDT or specialists (within team or hospital where available) and administrative duties/paperwork associated with routine care
- Medication treatment plans, intra-articular joint injections and infusions
- Education of medical, nursing and allied health staff and students
- Contribution to research which improves patient care including drug trials
- Advocacy for patients and their families within the health service.

Details of the current paediatric rheumatology service provision in NSW can be found in Appendix 2.

There is only 1.25 FTE publicly funded paediatric rheumatologist consultant time across NSW with 0.8 FTE of covered by a staff specialist and the remainder as visiting medical officer (VMO) hours (Appendix 3). Outside of the paediatric rheumatologist consultants the the only dedicated positions to support this cohort is a paediatric rheumatology Clinical Nurse Consultant (CNC) and administrator at SCHN. There is limited access to other recommended core MDT members including physiotherapists, occupational therapists and ophthalmology.

Clinician experience

The clinicians within the paediatric rheumatology services in NSW have gone to considerable efforts to meet the needs for the children of NSW and in aligning their care to best practice evidence despite limited resources. Clinical staff are experiencing burnout and there is a risk of significant knowledge loss with several within the small core team members approaching or at retirement age. The consultants have taken a moral stand to ensure children are seen in timely fashion, with clinics commonly overbooked (up to 3 times) further



contributing to clinician burnout. Current waitlists for category 1 patients are between 4 – 9 months, with international guidelines recommending patients be seen within 30 days. The paediatric rheumatology service at SCHN is unable to see new referrals for mechanical and hypermobility issues and cannot support appropriate on call ratios.

From interviews with clinicians the most common barriers to improved and sustainable services were workforce infrastructure and funding. Other common barriers cited were lack of physical infrastructure and space, partnerships and connections (with primary care and schools) with local conditions relating to lack of centralised transition services (SCHN) and fractional rheumatology service (Liverpool). Clinicians have made requests over the last 10 years to seek funding enhancements to meet the needs of their patients. As part of the 2020-21 NSW budget process, SCHN received limited growth funding. The Network, balanced against other clinical needs, allocated from total growth funding a staff specialist (0.5 FTE) and administrative support (0.8 FTE). These allocations are represented within the current totals referenced.

“The current system is precariously dependant on the existing specialists. We need to have a safety net and build capability for sustainability with more people. The role of the clinical nurse consultant is pivotal to making the whole thing work”,

“Parents cannot afford to go to a private physician in South West Sydney, and even if they could, there are very few general paediatricians available in this area, so there are real barriers here. Equity issues. So having a service like this at Liverpool is gold for the community”

NSW Health should commit to fund the service they want and stop expecting it without adequate funding or publicly announce that they don't intend to service this patient group”

Case for Change

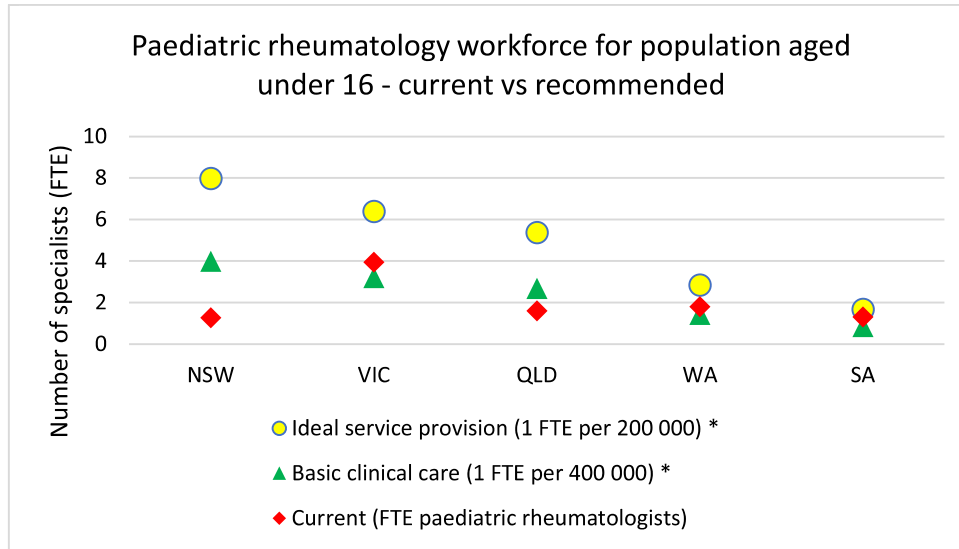
There is a considerable unmet need for paediatric rheumatology services in NSW and this is expected to increase in the future. Children and young people are at risk of suboptimal care with delayed diagnosis and inadequate treatment putting them at risk of long term disability and complications, continuing into adulthood. There is a lack of access to specialty paediatric rheumatology services especially for those in rural and regional areas. Compared to other states, NSW has the greatest shortfall for current provision and falls well behind national benchmarks and international guidelines (see figure 1). The shortfalls in paediatric rheumatology workforce is the major barrier to providing timely and accessible care for the children of NSW. The current workforce model is unsustainable with no training pathway, high levels of clinical burnout, waitlists and overbooking of clinics to provide necessary clinical care, limited dedicated MDT access and with the current workforce around or approaching retirement age. Advanced nursing positions, virtual care and Health Pathways are already embedded within current service provision and used where clinically appropriate. Dramatic advances in treatment for JIA over the past decade have resulted in major improvements to outcomes. Much of the joint damage, deformity, disability, and unnecessary surgery associated with the condition can now be prevented. There may be a time limited opportunity



to secure available paediatric rheumatologists interested in working for NSW from those on temporary contracts and wishing to returning to NSW from other states or overseas (see Appendix 3). The [2013 ACI Model of Care of Paediatric Rheumatology¹](#) that was only partially implemented remains a valid. The model requires an update to meet best practice as a multidisciplinary model using emerging innovations. The Advisory Group findings and recommendations align to those within the Parliamentary Inquiry⁷, AIHW report² and to currently unpublished Australian Standards of Care for Juvenile Idiopathic Arthritis⁴.

Paediatric rheumatologists are a small and critical workforce, with a shortage of paediatric rheumatologists across Australia ^{2, 9}; the greatest shortage is seen in NSW (see Appendix 4⁷). The shortfall is projected to grow over the years based on estimates of population forecast, historical workforce growth, specialists' average qualification age and retirement age ^{2, 9}. NSW does not currently hold accreditation as a training centre for paediatric rheumatology. There is currently an insufficient number of paediatric rheumatologists in NSW to enable SCHN to be an accredited centre and undertake advanced traineeships in paediatric rheumatology.

Figure 1 Paediatric rheumatology workforce shortages across Australian States



* Australia Standards of Care ⁴ and Cox, Piper, Singh- Grewal ⁹(3) recommend public services to 1 FTE: 200000 population with minimum 1:400000 for basic clinical care ⁹)

Table 1 Reported paediatric rheumatology workforce shortages in NSW

NSW	Paediatric rheumatologists	Nursing	Physiotherapy	Occupational therapy
Children population (age <16) ^e	1,670,402	1,670,402	1,670,402	1,670,402
Current (FTE)	1.275	1.0	0.2	0.2
For Provision of basic clinical care 1 FTE per 400, 000 ^g	4.176	4.176	4.176	4.176
Best practice Expectation (1 FTE per 200, 000 children population) ^{f, g}	8.352	8.352	8.352	8.352
Shortfall	7.08	7.35	8.25	8.25

^e Based on NSW population data for those aged 0- 15 years

^f Recommendation from the Australian Paediatric Rheumatology Group (APRG) Standards of Care for JIA in Australia for specialist

^g Cox A, Piper S, Singh-Grewal 2017 ⁹ MDT unspecified by assumption that MDT to include the top three professions (see table 3)



The Advisory Group documented the following problems arising from the current paediatric rheumatology service shortfalls in NSW include:

- Access to expert paediatric rheumatology services in urban, regional and rural NSW falls well behind national benchmarks and international guidelines
- Shortfalls in evidence based specialist multidisciplinary service access leads to delays in diagnosis and treatment shown to predispose to long term disability and poor health outcomes
- Delays in timely assessment, diagnosis and treatment initiation from 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
- It is not uncommon for 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
- Inadequate access results in many children undergoing unnecessary, costly and sometimes painful investigations before diagnosis is confirmed
- Difficulty monitoring responses to or adverse reactions from treatments, especially in rural areas
- Inadequate access to appropriate allied health multidisciplinary services considered to be best practice in the specialty
- Clinical staff have a high risk of burnout and risk of significant knowledge loss with a number of small core team members approaching or at retirement age
- Due to the lack of paediatric rheumatologists in NSW there is no accreditation for training new pedestrians in this area. There is little incentive for specialists to work in NSW and a lack of feasible succession planning, in light on the age of the current workforce
- Inability to cover a 7 day a week on call service
- Lack of sustainable services for children, young people and families in regional and rural areas
- Inadequate transition services for young people
- Limited access to inter-disciplinary paediatric subspecialist services (outside of SCHN)
- Limited ability to support formal education and capability development for other health care providers and schools (especially out of the Sydney metropolitan area)
- Inadequate undergraduate and postgraduate education for health professionals
- Excessive reliance on services provided in private practice (provided by the same paediatric rheumatologist as public hospitals).

Future state

There is current unmet need for paediatric rheumatic conditions in NSW and this is expected to increase in the future.



Estimates of the number and hospitalisations of people with juvenile arthritis vary depending on the definition used, age thresholds, methods of data collection and level of awareness of juvenile arthritis and the workforce shortage which may delay diagnosis. In March 2023 the Australian Juvenile Arthritis Registry was launched with the aims to collect key information on juvenile arthritis and other childhood rheumatic conditions for Australian children and young adults for the purpose of better estimating the burden of these conditions and their impact.

The Advisory Group agreed to the conservative estimate of 100 per 100,000 children, informed by

- AIHW² estimates the rate of juvenile arthritis as between 241 and 383 per 100,000 population aged 0-24 years for the 2021 Census and 2017-18 National Health Survey (NHS) data respectively
- AIHW² estimates of arthritis in children aged 0-14 are between 86 and 100 per 100,000 population (Census and NHS respectively) but are noted to be interpreted with caution
- international estimates between 100-400 children per 100,000 population aged 0 – 15 years¹⁰.

These numbers are comparable to Type 1 diabetes in children affecting 310 per 100,000 population (0-24 years) based on National Diabetes Service Scheme and Australasian Paediatric Endocrine Group state-based registers².

The number of children in Australia has increased over the last 5 decades and from 2022 is expected to increase by 6.4 million children by 2048¹¹. This will further impact the number of children living with JIA. The shortfalls in current service may additionally have a future impact on young people and adults who have greater disability from delayed access to best practice care as children historically within NSW.

In the past five years, NSW hospitalisation rates for JIA were between 30 to 40 per 100,000 population, which is comparable to the current AIHW report². AIHW also showed the number of hospitalisations due to juvenile arthritis increased by 5.6% per year on average (between 2001-02- 2020-21), which is almost double the average increase for other musculoskeletal and connective tissue hospitalisations².

In Ireland, a country with a population of 5 million (NSW population approximately 8 million) service demand for paediatric rheumatology services grew 400% from 2006 to 2018. The speciality of rheumatology was one of the most rapidly growing services within the country's largest tertiary hospital and accounted for the highest number of medical day care patients per year¹².

There is a lack of access to specialty paediatric rheumatology services especially for those in rural and regional areas. To promote equity of access and prevent unnecessary disability, NSW to move to an enhanced statewide networked model of paediatric rheumatology.

Access to expert paediatric rheumatology services in urban, regional and rural NSW falls drastically behind national benchmarks (Appendix 4) and international guidelines^{1, 6, 12}. This was evident through the research^{1, 6, 12}, data, experiential evidence from current services and through the expert Advisory Group. Paediatric rheumatologist are a small and critical workforce, with a critical shortage of paediatric rheumatologist across Australia^{2, 9} and the greatest shortage in NSW (see Appendix 4⁷). Children and young people from regional and



rural areas are particularly disadvantaged due to the long distances required to travel to access expert care ⁷.

There is likely unwarranted clinical variation and under-servicing of children based on regional or rural location and those who cannot afford private care. For NSW the only local provision of services outside of Sydney or Newcastle is an outreach service provided to Wagga Wagga and Orange which is temporarily funded by the commonwealth medical specialty outreach program.

The available literature on paediatric rheumatology models of care is largely descriptive, with a mix of qualitative studies, service design descriptions and expert statements. Limited but moderate quality evidence exists for the effectiveness of virtual modes of care delivery. In the peer reviewed evidence models of care focused on virtual care, outreach models, allied health (physiotherapy models) and transition to adult services.

Strategies in the literature to tackle workforce shortages include:

- Increasing training positions for paediatric rheumatologists ¹³
- Increasing the interest in paediatric rheumatology training among medical students and junior doctors by increasing their exposure to the field ¹³
- Increasing the use of telemedicine ^{13, 14}
- Increasing nurse practitioner, physician assistant and pharmacist utilisation¹⁴
- Reducing burnout to increase retention^{14, 15}.

A range of networked models have been adopted in NSW to support and build the capability of the health system to meet the health care needs of people living in NSW.

Recommendations have suggested that SCHN is the initial led site and that service provision be consolidated within a statewide service with dedicated outreach activities to regional and rural locations.

Models that would be considered include;

- **The Statewide Intellectual Disability Health Service:** with a network of six teams and nine clinical positions across the state
- **Menopause services:** with four hubs and 13 referral sites networked across the state
- **NSW Telestroke Service** with a host site in one district and a range of referring sites. This model includes credentialing of medical staff across multiple districts
- **The Tiered Perinatal Network:** a formalised arrangement between maternity and neonatal services within and across LHDs in NSW and the ACT that are linked with a tertiary (Level 6) hospital to provide support where higher level care is required.

The state-wide service would be responsible to support and coordinate any virtual care service provision and for a formal paediatric rheumatology transition program to support these children as they move to adult services.

NSW Health commit to provide a world class care standard for the assessment and treatment of childhood arthritis through enhancing workforce

A multi-disciplinary approach to treatment of childhood rheumatic disease is internationally regarded as best practice ^{1, 4-7, 12} with strong consensus on a core MDT to include those referenced by the Australia standards of care ⁴. The Australian Standards of Care ⁴ due for



publication by the end of 2023, lists the expectation that public workforce is provided at a minimum as:

- 1 Full Time Equivalent (FTE) paediatric rheumatologist per 200,000 children
- 1 FTE paediatric rheumatology advanced practice nurse per 200,000 children
- 1 FTE paediatric rheumatology physiotherapist per 200,000 children
- 1 FTE paediatric rheumatology occupational therapist per 200,000 children.

With pro-rata for small populations, which may be achieved through links with larger urban services as appropriate

This aligns with Cox, Piper and Singh-Grewal⁹ recommending at least one paediatric rheumatologist and MDT(undefined) for every 200,000 children to provide a comprehensive services or per 400,000 children for the provision of clinical care only.

There is strong consensus for the core or extended members to including the following roles;

- advance practice nursing^{1, 3-6, 12}
- physiotherapist^{1, 3-6, 12}
- occupational therapist^{1, 3-6, 12}
- psychology services^{1, 3-6, 12}
- social worker^{1, 3-5, 12}
- dietitians^{1, 3-6, 12}
- ophthalmology/eye care services^{4-7, 12}
- orthotist/podiatrist^{1, 4, 6, 7, 12}
- pharmacist^{1, 4, 7, 12}
- play therapy (now known as child life therapy)
- administration officer^{1, 4, 7}.

See Appendix 5 Multidisciplinary team roles across clinical guidance for more detail.

There are risks to the retention of current staff with burn out and no current training pathways in NSW to attract future workforce across medical, nursing or allied health.

NSW does not currently hold accreditation as a training centre for paediatric rheumatology. NSW lost its accreditation as a training site in 2009. There is currently an insufficient number of paediatric rheumatologists in NSW to enable SCHN to be an accredited centre and undertake advanced traineeships in paediatric rheumatology. NSW is therefore reliant on the recruitment of any future paediatric rheumatology from those trained in other states of Australia or from overseas.

There is minimum requirement of 2 FTE per trainee for a centre to gain accreditation. To gain accreditation the trainee must be able to assess and treat children in conjunction with onsite subspeciality paediatricians (ophthalmology, endocrinology, nephrology, neurology, dermatology, orthopaedic surgery) and to an allied health paediatric rheumatology multidisciplinary team. Clinicians estimate 6 months would be required for training program development and accreditation.

There is a workforce shortage for paediatric rheumatologists across Australia^{2,9} and New Zealand. Paediatric rheumatologist shortage and geographic imbalance in distribution (more concentrated in big cities) are also reported across Canada, United States and other countries in North and South America¹⁵⁻¹⁷.



Paediatric rheumatologists are a small and critical workforce, with a shortage of paediatric rheumatologists across Australia ^{2,9} and the greatest shortage in NSW (see Appendix 3 ⁷). The shortfall is projected to grow over the years based on estimates of population forecast, historical workforce growth, specialists' average qualification age and retirement age ⁹. NSW does not currently hold accreditation as a training centre for paediatric rheumatology. There is currently an insufficient number of paediatric rheumatologists in NSW to enable SCHN to be an accredited centre and undertake advanced traineeships in paediatric rheumatology.

There may be a time limited opportunity to secure available trained paediatric rheumatologists interested in working for NSW (Appendix 3). There are no formal training opportunities available in Australia relating to paediatric rheumatology outside of the specialist consultant training program.

AIHW estimates as of 2017, the shortfall in Australia was 68% (8.6 versus 14) for minimum required workforce based on accepted figures (1: 400,000 population < 16 years of age) and 225% (8.6 versus 27) for ideal workforce (1: 200,000 population <16 years of age). The shortfall was projected to grow over the years based on estimates of population forecast, historical workforce growth, specialists' average qualification age and retirement age ^{2,9}. AIHW ² data using the Australian Government's National Health Workforce Data Set (NHWDS) shows in 2021 there were 17 paediatric rheumatologists (14 FTE) compared to a requirement of 32 FTE (1:200,000 <16 years) across Australia. This aligns to the 2021 Australia Rheumatology Association (ARA) report ⁸ estimating 20 paediatric rheumatologists (13 FTE) and in accommodating for current work patterns (part time work) this represents a shortfall of 41 paediatric rheumatologist across Australia. NSW has the greatest shortfall with less FTE overall than QLD, VIC, SA and WA despite being the most populous state ⁷. Currently in NSW, there is 0.4 FTE paediatric rheumatologist per 200,000 children.

Within NSW outside of the paediatric rheumatologists, the only dedicated positions to support paediatric rheumatology are the paediatric rheumatology CNC and administration at SCHN. The experiential interviews indicated significant burn out for clinicians working in these services.

All other Allied health, nursing and medical resourcing is allocated from general paediatric and adult rheumatology. There are risks that at any point these allocated positions could be reduced or removed without dedicated funding. A survey of paediatric rheumatologist (¹⁸ in Australia and New Zealand (14 responses) highlighted the greatest challenge was access to speciality care particularly in the public hospital with funding the biggest barrier to establishing and maintaining MDT care. The survey showed that MDT access was better in public settings and suggested that publicly funded services are best able to provide MDT compared with private practice, this was supported by the Advisory Group. Without a concentration of expertise in a group of clinicians to disseminate best practice and support capability development for others managing children with rheumatic disease outside the hub site, there are added risks to the sustainability of the model.

The inclusion of ophthalmology into the core multidisciplinary care hub team is to reflect the specific need for timely screening and treatment of Uveitis by specialist eye services which occurs in approximately 30% ² of children with JIA. Without adequate treatment Uveitis can lead of vision loss or blindness. The Parliamentary inquiry⁷ suggests that all JIA patients should be screened as frequently as every 3 months and those that develop uveitis receiving treatment. The Advisory Group noted the consideration of how orthoptists could support the ophthalmology service access. They could provide hub assessment and monitoring and escalation of care and coordination with other eye services to get local access. The inquiry



also noted that administration staff are vital, allowing health professionals, particularly nurses, to focus on their clinical work ⁷.

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 ^{1, 4, 6}.

The 2013 ACI Model of Care of Paediatric rheumatology remains clinically valid. It will be updated in with specific reference to embedding virtual care, alternative models of care and formalising a paediatric rheumatology transition program

The Advisory Group agree that the ACI 2013 model of care ¹ remains valid. Updates would align to recent literature and embed virtual care, a formal networked approach and consideration of alternative care approaches for advanced and extended practitioner workforce models and ways to facilitate stronger multidisciplinary workforce access including general practitioners.

The available literature on paediatric rheumatology models of care is largely descriptive, with a mix of qualitative studies, service design descriptions and expert statements. Limited but moderate quality evidence exists for the effectiveness of virtual modes of care delivery. In the peer reviewed evidence models of care focused on virtual care, outreach models, allied health (physiotherapy models) and transition to adult services.

The role of transition programs within paediatric rheumatology is well documented ^{1, 4, 7, 19-22} in the literature with 50% ^{1, 4, 7} of children with paediatric rheumatology conditions persisting in adulthood. The current rheumatology transition model at John Hunter Hospital is recognised by the subject matter experts as an ideal model for transition services.

AIHW data ² increased the age of cohort from 18 to 24 to reflect that many paediatric rheumatology patients will continue to have active disease into adulthood. They may have their diagnosis reclassified into other forms of adult arthritis but are assumed to continue to broadly reflect a juvenile arthritis cohort. Prevalence rates increased with age with a rate of 291 per 100,000 for 15-19 year olds and 651 per 100,000 for 20-24 year olds.

Recommendations

The Advisory Group made 13 recommendations: seven immediate term (12 months), five medium term (3-5 years) and one long term (5+ years). These recommendations address the current and future needs of the children and young people of NSW with juvenile arthritis and other paediatric rheumatic diseases.

Seven immediate recommendations (within 12 months);

1. NSW Health consolidates services into a state-wide networked with a centralised state-wide triage system and rural and regional outreach to improve equity of access. SCHN would be the initial led site
2. NSW Health enhances paediatric rheumatology services workforce to meet current need for state-wide networked model; with total immediate funding (Stage 1) for: Clinical services



- 4 FTE paediatric rheumatologists
- 1 FTE paediatric advanced trainee positions
- 1 FTE state-wide service coordinator role (including transition and coordinator function within roles, AHP or Nursing role)
- 3 FTE advanced practice nursing
- 2.5 FTE physiotherapist
- 1.5 FTE occupational Therapist
- 0.5 FTE ophthalmology
- 2.0 FTE administration officers
- outreach to support rural and regional people

Implementation

- 1.0 FTE State-wide Implementation Lead (2 years, ACI)
3. NSW Health builds prioritised referral, within the paediatric rheumatology clinics, to facilitate timely needs based access to psychological, dietetics, social work in the networked services with local pathways to access ophthalmological screening services to enhance the foundational paediatric rheumatology MDT services
 4. SCHN to regain Paediatric rheumatology advanced trainee accreditation and have dedicated training positions. Limitation currently is minimum requirement of 2.0 FTE per advanced trainee
 5. ACI publish an update to the 2013 model of care to align to recent literature and to embed virtual care, a formal networked approach and consider alternative care approaches for advanced and extended practitioner workforce models and ways to facilitate stronger multidisciplinary workforce access
 6. NSW Health commits to agreeing on a minimum dataset for monitoring, evaluation and quality improvement as part of this work NSW assesses the applicability of participating in the Australian Juvenile Arthritis Registry (AJAR)
 7. The ACI Musculoskeletal and Transition Networks partner to develop a formal paediatric rheumatology transition program to support people as they move to adult services.

Five medium term recommendations (3-5 Years);

8. NSW Health commit to provide a world class care standard for the assessment and treatment of childhood arthritis
9. NSW takes a Value Based Health Care approach to evaluating the enhancement of services for children living with juvenile arthritis. Evaluation of the model (if funded) to be undertaken including clinical outcomes, hub and spoke model review and workforce requirements
10. Further enhancement of paediatric rheumatology services workforce to allow NSW Health to deliver a world class standard of care for patients with Juvenile Idiopathic arthritis. Based on current evidence and consensus, this enhancement would require total funding (Stage 2) for:

Clinical services

 - 5.0 FTE (+ 1.0) paediatric rheumatologists
 - 2.0 FTE (+ 1.0) additional paediatric advanced trainee positions
 - 4.0 FTE (+1.0) advanced practice Nursing. Service to have specialist Nurse practitioner role and/or advanced nursing roles within the paediatric rheumatology service
 - 1.5 FTE (+1.0) ophthalmology



- 4.0 FTE (+1.5) physiotherapist. Service to including a clinical specialist physiotherapy role within the paediatric rheumatology service
 - 3.0 FTE (+1.5) occupational Therapist. Service to include a clinical specialist occupational therapy role
 - 1.0 FTE psychologist
 - 1.0 FTE social worker
 - 0.5 FTE dietitian
 - 2.0 FTE administration officers
 - 1.0 State-wide coordinator
 - dedicated transition services
 - outreach to support rural and regional people including MDT team
11. NSW Health continues to build the multidisciplinary workforce that is responsive to innovations in care by:
- developing a strategy to sustain the specialist paediatric rheumatology workforce, including positions for newly qualified advance trainees
 - initiating advanced allied health (clinical specialist level 6) and nurse (Nurse practitioner) models
 - assessing viability of a GP outreach model as developed in QLD
12. NSW considers aligning to Henry Report recommendations relating to paediatric rheumatology cohort, promoting the tenant of right care, right time, right place. Explore options for including subspecialty appointments, cross credentialing of paediatric rheumatology staff, and potential reverse IPTAAS funding to facilitate alignment.

One long term recommendation (5+ Years);

13. NSW Health explores extended scope health practitioner models used overseas to support ongoing sustainability.

The Advisory Group findings and recommendations align to those within the Commonwealth Parliamentary Inquiry³, AIHW report² and to currently unpublished Australian Standards of Care for Juvenile Idiopathic Arthritis⁴.

An investment by NSW will enhance the paediatric rheumatology workforce to address the current unmet need and clinician burnout. This preventative investment would be a move towards NSW providing a world class standard of care that prevents unnecessary long-term disability and poor health outcomes for these children. It would also minimise future health costs for the system through early intervention. This investment would ensure the clinical staff are engaged and supported to drive better outcomes and experiences.

Appendix 1- Methodology

Advisory Group

In February 2023, at the request of the Deputy Secretary, Health System Strategy and Patient Experience, the ACI convened a Paediatric Rheumatology Advisory Group with membership drawn from clinical and health system management areas from within NSW Health. The Advisory Group had representation from the knowledge domains;

- Clinical subject matter experts in paediatric rheumatology
- Workforce and training
- Evidence and analytics
- System leadership.

The Advisory Group met virtually four times between March and August. The evidence findings were presented to the Advisory Group for clinical consensus and expertise to inform the recommendations. The proposed recommendations had four versions developed between the second and fourth meetings with out of session feedback and endorsement of the final document. The final recommendations were presented to the ACI CE for feedback and approval, prior to distribution to the Deputy Secretary, Health System Strategy and Patient Experience.

Table 2 NSW Paediatric Rheumatology Advisory Group members

Name	Job title	Advisory Group Role
Richard Cheney	Clinical Executive Director, CATALYST, ACI	Co chair Systems leadership
Chris Needs	Senior Staff Specialists -Rheumatology, SLHD, Royal Prince Alfred Hospital and MSK Network Co chair	Co chair Clinical subject matter expert and systems leadership
Jeff Chaitow	Paediatric rheumatologist, SCHN, Westmead Children's' Hospital	Clinical Subject matter expert
Davinder Singh-Grewal	Paediatric rheumatologist, SCHN, Westmead Children's' Hospital	Clinical Subject matter expert
Gabor Major	Rheumatologist, HNE, John Hunter Hospital	Clinical Subject matter expert for HNE/SCHN outreach paediatric rheumatology service, regional representative
Anne Senner	Paediatric rheumatology CNC, SCHN, Westmead Children's' Hospital	Clinical Subject matter expert
Debra Grech	Paediatric physiotherapist, SCHN Westmead Children's' Hospital	Allied Health Clinical Subject matter expert
Sarah Morton	Ministry, Health and Social Policy Branch	Systems leadership
Andrew Davidson	Chief Allied Health Officer, MOH	Workforce and training - Allied Health
Tamara Lee	Ministry, Workforce	Workforce and training



Nicola Clemens	Ministry, Workforce	Workforce and training
Kate Lloyd	Steam Manager, Chronic and Long Term Care, ACI	Systems leadership
Julia Thompson	Network Manger, Musculoskeletal, ACI	Secretariat and project lead
Mary Crum	Network Manger, Paediatric, ACI	SME advice relating to paediatric care
Rachael Havrlant	Network Manger, Transition, ACI	SME advice relating to transition care
Donna Parkes	Stream lead, Virtual Care, ACI	SME advice relating to virtual care
Kim Sutherland Proxy: Florent Gomez	Director, Evidence, ACI (Associate Director, Evidence and evaluation, ACI)	Evidence and analytics

Conflicts of interest were recorded at the start of each meeting and documented in the terms of reference, recognising the small number of clinicians within this workforce. These conflicts were able to be managed by the Co-chairs.

The following members attended the first meeting but subsequently withdrew from Advisory Group with requests for regular briefings and role vacancy respectively.

Name	Job title	Expert Role
Matthew Lutze	Principal Advisor, NaMO	Workforce and training - Nursing Practice
Justine Harris (Not replaced - Position vacant)	MOH Medical Workforce Advisor	Workforce and training - Medical Workforce

Evidence

The following sources of evidence were used to inform the development of the findings and recommendations;

- Clinical guidance comparison
- Rapid evidence check
- Data inputs
- Experiential evidence.

Clinical guidance comparison

Clinical guidance was identified by the subject matter experts and grey literature search conducted using Google by the network manager.

Clinical guidance broadly refers to models of care, clinical care standards, standards of care, clinical guidelines, standards and recommendations and a national strategy relevant to this cohort.

The clinical guidance was mapped against the principles and components of care within the ACI Model of Care for paediatric rheumatology and analysed for consensus. A separate workforce matrix analysis was undertaken against the available clinical guidance for the following:

multidisciplinary members, role in core or extended care teams, scope of practice and, where included, population based ratios.

Rapid evidence check - peer reviewed literature

The Evidence team led a rapid evidence check. It asked “What care delivery models for rheumatic diseases in children have been shown to improve outcomes?”.

Peer-reviewed articles were identified through PubMed.

PubMed search terms

PubMed: (((“rheumatic diseases”[MeSH Terms] OR “rheumatic diseases”[tiab] OR “rheumatology”[tiab])) AND (“paediatric”[Tiab] OR “pediatric”[Tiab] OR “pediatrics”[MeSH Terms] OR child*[Tiab])) AND ((Models, Organizational[MeSH] OR organizational innovation[MeSH] OR “Patient-Centered Care/organization and administration”[Mesh] OR Delivery of Health Care, Integrated[MeSH] OR “delivery of care”[Tiab] OR “model of care”[tiab] OR “models of care”[tiab] OR “care model”[tiab] OR “care delivery model” [tiab] OR “organisation of”[tiab] OR “organisational model”[tiab] OR “organisation model”[tiab] OR “organization of”[tiab] OR “organizational model”[tiab] OR “organization model”[tiab] OR “healthcare delivery model”[tiab] OR “integrated care”[tiab] OR “integrated model”[tiab] OR model*[title] OR innovat*[title] OR technolog*[title] OR tele*[title] OR workforce*[title])) Filters: from 2013 – 2023
= 99 hits on 9 May 2023

Table 3 Rapid evidence check inclusions and exclusions

Inclusion	Exclusion
<ul style="list-style-type: none"> • Population: Rheumatic diseases in children • Intervention: Care delivery models • Comparison: n/a • Outcomes: Clinical outcomes, patient/parent/carer reported outcomes, cost, system sustainability • Study types: <ul style="list-style-type: none"> • Review studies with systematic search strategy and methods • Randomised or non-randomised clinical trials • Before and after studies, time series studies with/without a comparison group • Retrospective chart review studies • Interventional/evaluative studies presenting quantitative data • Evaluative studies with quantitative or qualitative assessment of outcomes with/without a comparison group • Grey literature such as guidelines and consensus statements 	<ul style="list-style-type: none"> • Not in English • Published prior to 2013 • Studies that do not meet PICOS criteria <ul style="list-style-type: none"> • Patient / family perspectives of paediatric care broadly but not in reflecting on a specific model • Transition care from paediatric to adult care not in the context of a specific model • Workforce studies not in the context of a specific model

Grey literature

Grey literature search was conducted using Google



Google search terms

“paediatric rheumatology” and “model of care”

Data

Workforce rate in the population is calculated as the total available workforce divided by the total population (age <16 years) in NSW. Population number for the year 2011 is based on the Australian Bureau of Statistics estimated resident population in 2016 and population projections based on analysis from the NSW Department of Planning and Environment.

Experiential insights

Interviews were conducted to develop local case studies that describe how paediatric rheumatology care is organised and delivered in NSW, including perceived barriers and enablers. The invitation to participate in an interview was sent to a convenience sample of health professionals working within the paediatric rheumatology services through the ACI Musculoskeletal Network on 04/05/2023. Seven interviews ranging between 30 and 90 minutes were conducted with representation from adult and paediatric rheumatologists (n=4), a clinical nurse specialist and two clinical nurse consultants providing care at various locations across NSW between 09/05/2023 and 24/05/2023. Individual case stories were developed following the interviews – using a standard format and several rounds of iteration and feedback. The barriers and enablers were mapped to the Consolidated Framework for Implementation Research (CFIR). Using the CFIR provided a systematic and theoretical approach to understanding local barriers and enablers and identifying actionable findings for system-wide innovation or improvement. Case studies were developed for the John Hunter Hospital, Sydney Children's Hospital Network (Westmead and Randwick Hospitals), and Liverpool Hospital.

Appendix 2 - Current Paediatric Rheumatology Service Provision in NSW

This is informed by the experiential insight case studies and current state mapping as part of the Advisory Group.

Table 4 Current paediatric rheumatology service provision in NSW

	SCHN (Westmead & Randwick)	Hunter New England LHD (John Hunter & Belmont Hospitals)	Liverpool	Wagga / Orange *
Clinics	<p>Around 150 times a year</p> <p>(Westmead 2.5 times a week Randwick once a week)</p> <p>Average of five new patients and 10 follow up patients in each 4 hour clinic</p>	<p>18 times a year</p> <p>Clinic operates once a month on a Thursday (from John Hunter Children's Hospital) and every eight weeks (from Belmont Hospital).</p> <p>Average 1-2 new and 5 follow up patients per 4 hour clinic</p> <p>There were 56 new patients, and 227 reviews between March 2022 and April 2023</p>	<p>12 times a year</p> <p>Clinic operates once a month at Liverpool hospital</p> <p>Average 3 new and 8 follow up patients per clinic per 4 hour clinic</p>	<p>9 times a year</p> <p>Orange is every eight weeks or six times a year and the Wagga clinic is a hybrid clinic of three face-to-face visits a year and three telly health visits per year</p>
Multidisciplinary Team	<p>1.0 FTE paediatric rheumatologist 1.0 FTE CNC 0.8 FTE administration</p> <p>Supported by (non dedicated funding) physiotherapist, occupational therapist, paediatric registrar</p>	<p>0.15 FTE (VMO) paediatric rheumatologist Supported by (non-dedicated funding) rheumatologist, rheumatology CNC, rheumatology advanced trainee, paediatric registrar</p>	<p>0.1 FTE (VMO) paediatric rheumatologist Supported by (non-dedicated funding) rheumatologist, rheumatology CNS</p>	<p>0.025 FTE (Commonwealth Funded)</p>
Waitlists	<p>Current waitlists for acute arthritis episodes is</p>	<p>Category 1 patient is 9 months (as per waitlist on 23/5/23).</p>		



	SCHN (Westmead & Randwick)	Hunter New England LHD (John Hunter & Belmont Hospitals)	Liverpool	Wagga / Orange *
	<p>approximately 4- 5 months</p> <p>(Category 1, with international guidelines aiming to see within 30 days)</p>	<p>Between 1 January 2018 and 31 December 2022, there were 311 initial appointments for paediatric rheumatology, 9% were seen within the priority one category, and 91% were seen outside the priority category.</p>		
Eligibility	<p>Services NSW and ACT</p> <p>The service is unable to see new referrals for mechanical and hypermobility issues</p>	<p>HNELHD and JHCH catchment</p>	<p>Services SWSLHD</p> <p>Based on the patients age a clinical decision is made as to whether to refer to a paediatric rheumatologist as an outpatient or the adult service</p>	
Referrals and triage	<p>Referrals from NSW and ACT usually from primary care, paediatricians and medical subspecialists especially orthopaedic surgeons, ophthalmologists, gastroenterologists. Triage centrally by paediatric rheumatologist and then directed to most appropriate site (urgency and geographically determined) including Liverpool, Wagga Wagga, Newcastle and Orange.</p>	<p>Referrals from LHD and outreach catchment and are usually from primary practice, paediatricians and orthopaedic surgery.</p> <p>Triage by non rheumatology trained staff</p>	<p>Referrals form LHD primarily from primary practice and paediatricians.</p> <p>Triage by non-paediatric trained rheumatology nurse</p>	
Services provided	<ul style="list-style-type: none"> • Full inpatient and outpatient services 	<ul style="list-style-type: none"> • Outpatient only 	<ul style="list-style-type: none"> • Outpatient only 	.



	SCHN (Westmead & Randwick)	Hunter New England LHD (John Hunter & Belmont Hospitals)	Liverpool	Wagga / Orange *
	<ul style="list-style-type: none"> • On-call service for NSW and ACT • Outreach support for all regional and rural services across NSW is coordinated by the clinical nurse consultant • intra-articular steroid injections under GA (collaborative care agreement with private hospital due to lack of theatre space) • Infusions in day unit at Westmead and Randwick 	<ul style="list-style-type: none"> • Some intra-articular steroid injections under local anaesthetic or sedation in the paediatric ward • Infusions managed in oncology day stay clinic 	<ul style="list-style-type: none"> • Some intraarticular steroid injections under sedation in paediatric ward • No capacity for local infusions 	

Appendix 3 – NSW Paediatric Rheumatologist Workforce

Table 5 NSW paediatric rheumatologist workforce

	SCHN	JHH	Liverpool	Wagga Wagga / Orange	Context
Access	<p>Sydney Children's Hospital Randwick: one clinic per week which operates on alternate Wednesdays and Thursdays</p> <p>Children's Hospital Westmead: an average of two general rheumatology clinics a week on Thursdays and/or Fridays. Along with two additional interdisciplinary subspecialty clinics for complicated Uveitis and Systemic Lupus Erythematosus each once a month designed to streamline patient care.</p>	<p>Clinic operates once a month on a Thursday (from John Hunter Children's Hospital) and every eight weeks (from Belmont Hospital).</p>	<p>A specialist paediatric rheumatology clinic operates once a month on a Wednesday at Liverpool hospital supported by</p> <p>The staffing configuration for the clinic: two Visiting Medical Officer (VMO) paediatric rheumatologists</p>	<p>A specialist Paediatric clinic at Orange every eight weeks (six times a year) and the Wagga clinic is a hybrid clinic of three face-to-face visits a year and three tele health visits per year.</p> <p>Not funded by NSW Health. Clinical hours, travel and administration time by commonwealth medical specialty outreach program</p>	
Paediatric rheumatologists					
JC	0.2 (0.025)	0.05			
	0.2 is for 2 VMO sessions/	VMO			

	week. 0.025 is for HOD				
DSG	0.6	0.1	0.05	0.025	
	SCHN – 0.8 Staff specialist role, 0.2 is currently covered by AM	VMO	VMO	Commonwealth funded	
DM			0.05		Substantive position is at SCHN as sports medicine physician (CHISM). Dual Qualification in paediatric rheumatology and sports medicine
			VMO		
AM	0.2				Temporary contract until Dec 2023). Also working at SCHN Westmead medical school in teaching role (temporary contract)
	0.2 cover from DSG's substantive role				
Total	1.0	0.15	0.1	0.025	Grand total: 1.275

Table 6 Other known paediatric rheumatologist workforce interested to work in

Name	Level	Comments
PS	Advanced trainee – final year (WA)	Will be completed training in Jan 2024. 2 years training in Bristol (UK), final year in WA. Indicated they wish to move to Sydney in 2024.
	Advanced trainee final year (UK).	UK trained (Training being assessed by college currently). Indicated they wish to move to Sydney in 2024.
CCB	Advanced trainee – first year, non-accredited training place, SCHN	Non accredited training place at SCHN Member of the NSW Health System Advisory Council

Appendix 4 - Australian Paediatric Rheumatologist Workforce Full Time Equivalent

Table 1.1 Australia's paediatric rheumatologist workforce equivalent fulltime (EFT)

State	Population of children 0-19 years	Required paediatric rheumatologist staffing (EFT)	Actual public paediatric rheumatologist staffing (EFT)	Percentage of required public EFT
New South Wales	1,975,852	9.9	1.25	12.6 per cent
Victoria	1,589,497	7.9	3.94	49.9 per cent
Queensland	1,317,012	6.6	1.6	24.2 per cent
South Australia	411,722	2.1	1.3	61.9 per cent
Western Australia	672,432	3.4	1.8	52.9 per cent
Tasmania	125,041	0.6	0	0.0 per cent
Northern Territory	67,677	0.3	0	0.0 per cent
Australian Capital Territory	106,455	0.5	0	0.0 per cent
National	6,265,688	31.3	9.89	31.6 per cent

Source: Australian Paediatric Rheumatology Group, Submission 70, p. 15

Submission from Australia Paediatric Rheumatology Group into the 2022 Parliamentary Inquiry into Childhood rheumatic diseases. ⁷

Appendix 5 – Multidisciplinary team roles across clinical guidance

Table 7 Multidisciplinary team roles across clinical guidance

Multidisciplinary team member	Core	Extended	Total	Role details
paediatric rheumatologist	7	0	7	1 per 200,000 of a population (16)
nurse	7	0	7	Advanced practice nurse role (1, 5, 6, 8, 16,17 ²³) 1 per 200,000 of a population (16) Specialist Nurse-led OPDs – biologic assessment and pre- injections. Nurse-administered joint injections, Anticipated for every 100,000 of a population (5)
physiotherapist	7	0	7	Clinical specialist (1,5,8) 1 per 200,000 of a population (16) Specialist Physiotherapy triaged non inflammatory clinics, Physiotherapy – administered joint injections, Anticipated for every 100,000 of a population (5)
occupational therapist	7	0	7	Clinical specialist or advance practice role (1,5, 8) 1 per 200,000 of a population (16) Extended scope, Anticipated for every 100,000 of a population (5)
psychologist	5	2	7	Dedicated per 300k population (5) Patients identified as specifically important (8)
ophthalmology/ eye care services	4	2	6	
admin officer	4	0	4	
social worker	3	3	6	Senior, Dedicated per 300k population (5)
dietitian	2	4	6	Senior, Dedicated per 300k population (5)
orthotist/ podiatrist	2	4	6	Dedicated per 300k population (5)



				Dedicated per 300k population (5)
pharmacist	1	3	4	
diversional/ play therapy/ child life therapy	0	4	4	

Notes – Colour grading to reflect increasing scores across clinical guidance

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