

***House of Representatives Inquiry into
Childhood Rheumatic Diseases***

Submission from the Department of Health
to the Standing Committee on Health, Aged Care and Sport on the inquiry
into childhood rheumatic diseases

4 February 2022



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Introduction

The Department of Health welcomes the opportunity to make this submission into the *Standing Committee on Health, Aged Care and Sport inquiry into childhood rheumatic diseases*.

Context

Arthritis affects nearly four million Australians of all ages, including at least 6000 children and two million people of working age (15-64 years).ⁱ

Juvenile Idiopathic Arthritis (JIA) is the most common rheumatic condition in childrenⁱⁱ. If not treated quickly and appropriately, it can seriously affect the growth and development of a child, causing severe joint damage, growth abnormalities and permanent disabilityⁱⁱⁱ. Although JIA resolves in many children, 50 per cent of those diagnosed will continue to have active disease into adulthood^{iv}.

The Department's submission includes an overview of current Australian Government policy, programs and frameworks which support childhood rheumatic diseases, as well as outlining the Government's investments through funding of activities, programs and research to support the treatment and care of children with rheumatic diseases.

Policy and Program

There are a range of Government programs and initiatives which, at a local and national level, provide support to children with rheumatic diseases. This includes providing policy frameworks to guide action, investment in research and clinical trials and more targeted local level actions.

These initiatives are outlined below and respond to Terms of Reference 1, 2, 3 & 5 of the Committee's Inquiry.

[The National Strategic Action Plan for Arthritis](#)

The *National Strategic Action Plan for Arthritis*^v (the National Strategic Action Plan), released in 2019, is an evidence-informed blueprint to guide national efforts to improve the health-related quality of life for people living with arthritis, including children living with juvenile arthritis.

The National Strategic Action Plan identifies major evidence-practice gaps relating to the delivery of arthritis care in Australia, including delays in diagnosis and access to specialist care for children and people with inflammatory arthritis; limited access to interdisciplinary team care; and limited access to paediatric rheumatology services. The National Strategic Action Plan is guiding the Australian Government's efforts to addressing these gaps.

[The National Action Plan for the Health of Children and Young People 2020-2030](#)

The National Action Plan for the Health of Children and Young People 2020-2030^{vi} (Action Plan) builds on the *Healthy, Safe and Thriving: National Strategic Framework for Child and Youth Health* and outlines Australia's national approach to improving health outcomes for all children and young people, particularly those at greatest risk of poor health. The Action Plan is the framework for continuous improvement and innovative policy and program initiatives built to ensure the health and wellbeing of all children and youth across Australia.



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The Action Plan takes a life course approach to addressing chronic conditions and preventive health. This includes improving awareness of and screening for genetic diseases, including rheumatic diseases, and improving access to health services for children and young people with chronic conditions. The Action Plan also focusses on preventing chronic conditions by promoting programs to address nutrition, physical activity, immunisation and oral health early in life.

Additionally, the Action Plan aims to strengthen the accessibility and reach of health services, including telehealth, to children and young people seeking healthcare. The Action Plan also seeks to strengthen workforce capability to identify and address underlying conditions, including genetic and rheumatic diseases, in order to holistically support better health outcomes for children and young people.

Medical Research Future Fund

The Australian Government is committed to supporting life-saving health and medical research through the Medical Research Future Fund (MRFF). As part of the 2019–20 Budget, the Government announced a \$5 billion, 10-year investment plan for the MRFF, which provides secure funding to support lifesaving research, create jobs, strengthen industry, and reaffirm Australia's reputation as a world leader in medical research. The MRFF supports a range of research initiatives to improve the health of Australians. The two initiatives with greatest relevance to the inquiry into childhood rheumatic diseases are the Emerging Priorities and Consumer Driven Research (EPCDR) Initiative and the Clinical Trials Activity (CTA) Initiative.

Under the MRFF 10 Year Plan announced in the 2019-20 Budget, \$633 million over 10 years from 2019-20 was allocated to the EPCDR Initiative to support high quality research that improves patient care, translation of new discoveries and encourages joint collaboration between consumers and researchers in undertaking research in emerging priority areas. By doing so it will nurture the development of new treatments and cures, providing hope to many Australians with debilitating conditions, including conditions in children and adolescents.

Additionally, \$614 million was committed over 10 years under the CTA Initiative, which provides funding through the Rare Cancers, Rare Diseases and Unmet Need (RCRDUN) grant opportunities and the International Clinical Trials Collaborations (ICTC) Grant Opportunity. The MRFF RCRDUN grant opportunities support clinical trials research that investigates new drugs, devices, or treatments for rare cancers/diseases, or for areas of unmet medical need.

Further detail on specific MRFF grant funding relevant to the Inquiry is outlined in the Funding of Activities, Programs and Research section.

Key Policy Frameworks to Support Aboriginal and Torres Strait Islander children

Key policy frameworks which guide approaches to supporting the health and wellbeing of Aboriginal and Torres Strait Islander children include the *National Agreement on Closing the Gap*^{vii}, the *National Aboriginal and Torres Strait Islander Health Plan 2021–2031*^{viii} and the *National Aboriginal and Torres Strait Islander Early Childhood Strategy*^{ix}. These overarching policy frameworks continue to be considered and reflected when designing policy and



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program responses to childhood rheumatic diseases among Aboriginal and Torres Strait Islander children.

Australian Clinical Trials

The Australian Government is leading a body of work to improve the Australian clinical trials environment with a view to improving health outcomes and increasing international investment in Australia. This is being progressed in collaboration with all jurisdictions, building on international evidence that jurisdictional collaboration and congruence is critical to success in federated clinical trials systems.

Clinical trials benefit patients, advance medical knowledge and are estimated to be worth around \$1.4 billion to the Australian economy each year. The environment in which clinical trials are conducted is complex, often occurring across multiple jurisdictions and with every study needing ethics and governance approvals before it can commence.

All jurisdictions are continuing to progress the reform agenda and to identify and implement actions and system redesign that will enable a streamlined and consistent national approach to clinical trials within Australia with the intention of enhancing health outcomes and building Australia's ability to attract national and international clinical trials.

All jurisdictions have collaborated on the development of *The National Clinical Trials Governance Framework*^{*} (Governance Framework), a key element of the clinical trials reform agenda and a first step towards nationally consistent accreditation of health services undertaking trials. The Governance Framework is highly anticipated by the sector as a significant sector reform that will embed clinical trials into routine health care. It will strengthen clinical and corporate governance arrangements and aims to reduce duplication and increase efficiency, cohesion and productivity across the clinical trials sector. The Governance Framework has been successfully piloted, and implementation is anticipated from mid-2022.

Primary Health Networks

Primary Health Networks (PHNs) were established by the Australian Government Department of Health on 1 July 2015. These networks are intended to play a critical role in connecting health services across local communities so that patients, particularly those needing coordinated care, have the best access to a range of health care providers, including practitioners, community health services and hospitals. PHNs connect health services across a specific geographic area (a PHN area). PHNs commission health services to meet the identified and prioritised needs of people in their regions and address identified gaps in primary health care, including the areas of population health, chronic disease and reducing hospitalisation rates. PHNs work collaboratively within their regions to integrate health services at the local level to create a better experience for patients, encourage better use of health resources and eliminate service duplication. While the Department of Health provides support and guidance to PHNs, PHNs decide what services and activities are funded based on prioritised need in their regions and available resourcing.



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HealthPathways

Additionally, PHNs support health providers in their regions through HealthPathways. HealthPathways is a commercial platform which can be accessed by a clinician and provides region-specific advice on assessment, condition management and local referral opportunities for a large number of conditions. It also provides links to consumer-centric information and resources. HealthPathways is designed and written for use during a consultation. Each pathway provides clear and concise guidance for assessing and managing a patient with a particular symptom or condition. HealthPathways also includes information about making requests to services in the local health system.

Content is developed collaboratively by general practitioners, hospital clinicians, and a wide range of other health professionals. Each pathway is evidence-informed, but also reflects local reality, and aims to preserve clinical autonomy and patient choice. HealthPathways serves to reduce unwarranted variation and accelerate evidence into practice.

There are HealthPathways that currently exist that relate to childhood rheumatic diseases.

Medical Benefits Schedule

The Government is committed to supporting all Australians to access quality and affordable health care by providing rebates for services listed on the Medical Benefits Schedule (MBS).

There are a range of services listed on the MBS that may assist in the diagnosis of childhood rheumatic diseases and juvenile arthritis. This includes pathology tests to look for inflammatory markers and imaging tests (X-rays, CT scans, MRIs) to look for signs of joint damage that can also rule out other causes such as trauma or infection.

Telehealth

On 13 December 2021, the Government announced its commitment to retain and make permanent the telehealth items introduced in response to the COVID-19 pandemic.

Since March 2020, more than 86 million telehealth services have been provided to over 16 million patients. These services have been transformational to Australia's universal health care program, Medicare, and have played a critical role in ensuring the continuity of care for hundreds of thousands of Australian patients during the COVID-19 pandemic.

In making telehealth permanent, primary care services such as those from GPs and allied health professionals, continue largely unchanged. Eligibility for GP telehealth services continue where patients are required to have at least one face-to-face consultation with the practitioner, or practice, within the preceding 12 months of receiving a telehealth service (limited exceptions still apply).

Funding of Activities, Programs and Research

Through the policies and programs outlined above, the Government is making significant investment to support the detection, treatment and evidence base in relation to childhood rheumatic diseases.

This investment is outlined further below and responds to Terms of Reference 1, 3, 4 & 5 of the Committee's Inquiry.



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The National Strategic Action Plan for Arthritis

Under the National Strategic Action Plan^{xi}, the Government has provided implementation funding of \$4 million to date, focussed on consumer awareness-raising and education activities, and health professional education and training for arthritis. This includes:

- \$1 million to Arthritis Australia for information, education and support activities from January 2020 to December 2023. This includes activity to expand the reach and coverage of Juvenile Idiopathic Arthritis (JIA) kids' camps and programs run by arthritis organisations to cater for more children, different age groups including young adults, and children with other rheumatic conditions.
- \$1 million to support consumer awareness and education activities from April 2020 to December 2023. This grant activity includes the development and dissemination of consumer-focused care guides for people with JIA and their carers and families. It is anticipated that final versions of the guide for Juvenile Arthritis will be completed by April 2023.
- \$2 million to support activities relating to education and awareness for health practitioners from April 2020 to December 2023. This grant activity includes development of a living guideline for JIA. The guidelines are expected to be completed in 2023.

MRFF and National Health and Medical Research Council

On 14 October 2021, Minister Hunt announced the opening of a new \$20 million grant opportunity to be funded from the MRFF's EPCDR Initiative targeted at Chronic Musculoskeletal Conditions in Children and Adolescents. This grant opportunity specifically includes research on childhood rheumatic diseases such as JIA and juvenile systemic lupus erythematosus.

The objective of this grant opportunity is to provide financial assistance to support Australian medical research and medical innovation projects that develop or improve approaches for the early diagnosis of chronic musculoskeletal conditions occurring in children, and/or generate knowledge that supports the development and implementation of improved therapeutic regimes and models of care for chronic musculoskeletal diseases in children.

The grant opportunity will fund three streams of research:

- Stream 1 will target chronic autoimmune disease that effect the musculoskeletal system such as JIA, juvenile systemic lupus erythematosus and juvenile scleroderma;
- Stream 2 will target musculoskeletal pain such as knee pain, lower back pain and neck pain, including complex pain syndromes and recurrent headache (regardless of aetiology); and
- Stream 3 will target congenital musculoskeletal disease such as muscular dystrophy, scoliosis and hip dysplasia.

Applications opened on 14 October 2021 and will close 16 February 2022 (5pm AEST).

While at this stage the MRFF had not awarded funding for childhood rheumatic diseases (excluding rheumatic heart disease) or juvenile arthritis research, it has invested \$7.3 million across eight research grants for broader rheumatic disease research.



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Additionally, since 2000, the National Health and Medical Research Council (NHMRC) has expended \$12,200,868.29 towards childhood rheumatic diseases research. This includes research on: epidemiological studies understanding the causes and treatment of osteoarthritis and osteoporosis; cartilage remodelling in normal skeletal growth and development; importance of sun exposure and the links between vitamin D and autoimmune disease; and genetic information and early diagnosis for childhood arthritis, and whether genetics can be used as a diagnostic test.

Primary Health Networks

Examples of initiatives funded by PHNs to support activities in relation to childhood rheumatic diseases includes:

- Brisbane South PHN assisted in developing the 2021 Brisbane Rheumatic Disease (RHD) Workshop where a Paediatric Cardiologist presented on diagnosis and management of acute rheumatic fever; using the Acute Rheumatic Fever (ARF) diagnosis calculator app and a prepared case study to highlight how to use the calculator as a diagnostic tool that can assist clinicians.
- Northern Queensland PHN has planned to work with partners on joint approaches to chronic disease priorities in north Queensland, such as the Rheumatic Heart Disease Action Plan^{xii}. This is aimed at improving the health outcomes of individuals with chronic disease through increased access to place-based primary health services, improved integration between primary, specialist and acute health services, and access to health literacy.

Pharmaceuticals Benefits Scheme (PBS)

Government expenditure on PBS medicines for the treatment of childhood rheumatic disease was around \$5 million in 2020-21 to support the treatment of over 1,100 children under 18 years of age. This includes PBS medicines for the treatment of juvenile idiopathic arthritis, rheumatoid arthritis, psoriatic arthritis and ankylosing spondylitis.

Telehealth and Primary Health Care

In addition to the above policies and programs, the Government's broader investment in telehealth, primary health care and access to services will also provide long term benefits for children with rheumatic diseases, including those living in regional, rural and remote areas.

Under the *Long Term National Health Plan*^{xiii}, a *Primary Health Care 10 Year Plan* is driving reform of the primary health care system in Australia over the next decade, building a primary health care system that is integrated, more efficient, patient-centred and more equitable.

On 13 December 2021, the Government announced a \$308.6 million investment in strengthening Australia's primary care health system, including \$106 million to support permanent telehealth arrangements for all Australians. As noted earlier, telehealth will continue to offer greater flexibility to patients and health care providers.

The Government, through the *Stronger Rural Health Strategy*^{xiv} (Strategy), is working to address issues of unequal distribution of health workforce in rural areas. The Strategy is



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introducing comprehensive reforms through a \$550 million investment over five years from 2017–18. The aim of the Strategy is to ensure Australians have access to the right mix of qualified health professionals in the right place and at the right time to deliver high quality health care.

Rural Bulk Billing Incentives

As part of the 2021–22 Budget, the Australian Government announced that from 1 January 2022, Rural Bulk Billing Incentives^{xv} (RBBi) will increase with remoteness based on the Modified Monash Model^{xvi} (MMM) classification of the location. This measure will help improve access to quality health services for rural and remote Australians by reducing out-of-pocket costs for patients and improving the viability of primary care services in the communities. The measure will cost \$65.8 million over four years from 2020-21.

Scaling the RBBi will better recognise that doctors in rural and remote areas face higher operating costs, smaller patient populations, increased complexity in patient care and carry a greater burden of responsibility for the healthcare needs of people living in these communities.

Reports and Data

The Government funds the Australian Institute of Health Welfare for chronic conditions reporting and data collection to support the continuation of evidenced based policy.

AIHW reporting which may assist the Committee with its Inquiry, in particular Terms of Reference 1, 3 and 4, is outlined below.

Australian Institute of Health and Welfare (AIHW) reporting

The AIHW's national centre for monitoring chronic conditions is funded by the Australian Government Department of Health to monitor chronic conditions in Australia including chronic musculoskeletal conditions. The monitoring of chronic musculoskeletal conditions includes the routine monitoring of JIA.

AIHW Juvenile Arthritis Web Report

The AIHW's web report about Juvenile Arthritis^{xvii} was updated in 2020 and cites data from the *ABS 2017–18 National Health Survey* together with 2017–18 data from the AIHW National Hospital Morbidity Database. The report is expected to be updated later in 2022 when data from the *ABS 2020-21 National Health Survey* become available.

- Prevalence is estimated using the *ABS National Health Survey* (NHS) (current data is from 2017-18) and is estimated to be 1 child in every 1,000 aged 0-14 years. However, this estimate has a wide margin of error and should be interpreted with caution.
- Rate of hospitalisations is monitored. There were 1,445 hospitalisations in 2017-18 for a principal diagnoses of juvenile arthritis demonstrating the severe or acute aspects of the disease (many children would not be hospitalised but rather managed in the community setting).

Medication dispensing can also be monitored. Many medications, however, are non-specific to juvenile arthritis (such as general pain relief and anti-inflammatory use) and can be



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purchased over the counter. It is not possible to determine or identify people using these medications for juvenile arthritis management.

In 2019, the AIHW published a report on Medication use for ankylosing spondylitis, psoriatic arthritis, and juvenile arthritis 2016–17^{xviii}. This includes analysis of specific disease-modifying anti-rheumatic drugs (DMARDs) and biologic disease-modifying anti-rheumatic drugs (bDMARDs) which are specialised immunosuppressant medications.

AIHW Australian Burden of Disease Study

The AIHW Australian Burden of Disease Study: Impact and causes of illness and death in Australia 2018^{xix} measures the years of healthy life Australians lost due to living with illness and injury or dying prematurely. Estimates are available by age and sex for 17 disease groups, 219 diseases and injuries and over time (between 2003, 2011, 2015 and 2018). This includes burden of disease reporting on rheumatoid arthritis with age groups including infants and children.

The Australian Burden of Disease Study 2018^{xx} notes that for leading causes of non-fatal burden in infants and young children (aged under 5 years) “Notable differences between the sexes were that rheumatoid arthritis was ranked fifth for girls (not in the leading 10 causes for boys)”.

ⁱ National Strategic Action Plan for Arthritis. (2019). Retrieved from: <https://www.health.gov.au/resources/publications/national-strategic-action-plan-for-arthritis>

ⁱⁱ National Strategic Action Plan for Arthritis. (2019). Retrieved from: <https://www.health.gov.au/resources/publications/national-strategic-action-plan-for-arthritis>

ⁱⁱⁱ National Strategic Action Plan for Arthritis. (2019). Retrieved from: <https://www.health.gov.au/resources/publications/national-strategic-action-plan-for-arthritis>

^{iv} National Strategic Action Plan for Arthritis. (2019). Retrieved from: <https://www.health.gov.au/resources/publications/national-strategic-action-plan-for-arthritis>

^v National Strategic Action Plan for Arthritis. (2019). Retrieved from: <https://www.health.gov.au/resources/publications/national-strategic-action-plan-for-arthritis>

^{vi} National Action Plan for the Health of Children and Young People 2020–2030. (2019). Retrieved from: <https://www.health.gov.au/resources/publications/national-action-plan-for-the-health-of-children-and-young-people-2020-2030>

^{vii} National Agreement on Closing the Gap | Closing the Gap. Retrieved from: <https://www.closingthegap.gov.au/national-agreement>

^{viii} National Aboriginal and Torres Strait Islander Health Plan 2021–2031. (2021). Retrieved from: <https://www.health.gov.au/resources/publications/national-aboriginal-and-torres-strait-islander-health-plan-2021-2031>



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^{ix} National Aboriginal and Torres Strait Islander Early Childhood Strategy | National Indigenous Australians Agency. (2021). Retrieved from: <https://www.niaa.gov.au/resource-centre/indigenous-affairs/national-aboriginal-and-torres-strait-islander-early-childhood-strategy>

^x Clinical trials. (2019). Retrieved from <https://www.safetyandquality.gov.au/standards/clinical-trials#the-national-clinical-trials-governance-framework>

^{xi} National Strategic Action Plan for Arthritis. (2019). Retrieved from: <https://www.health.gov.au/resources/publications/national-strategic-action-plan-for-arthritis>

^{xii} Rheumatic Heart Disease Action Plan 2018-2021. (2018). Retrieved from https://www.health.qld.gov.au/_data/assets/pdf_file/0026/713609/RHD-Action-Plan-2018-2021.pdf

^{xiii} Australia's Long Term National Health Plan. (2019). Retrieved from: https://www.health.gov.au/sites/default/files/australia-s-long-term-national-health-plan_0.pdf

^{xiv} Stronger Rural Health Strategy. (2019). Retrieved from: <https://www.health.gov.au/health-topics/rural-health-workforce/stronger-rural-health-strategy>

^{xv} Rural Bulk Billing Incentives. (2021). Retrieved from: <https://www.health.gov.au/initiatives-and-programs/rural-bulk-billing-incentives>

^{xvi} Modified Monash Model. (2021). Retrieved from: <https://www.health.gov.au/health-topics/rural-health-workforce/classifications/mmm>

^{xvii} What is juvenile arthritis?. (2020). Retrieved from: <https://www.aihw.gov.au/reports/chronic-musculoskeletal-conditions/juvenile-arthritis/contents/what-is-juvenile-arthritis-1>

^{xviii} Medication use for ankylosing spondylitis, psoriatic arthritis, and juvenile arthritis 2016–17, Table of contents - Australian Institute of Health and Welfare. (2019). Retrieved from: <https://www.aihw.gov.au/reports/chronic-musculoskeletal-conditions/medication-use-for-ankylosing-spondylitis-psoriati/contents/table-of-contents>

^{xix} Australian Burden of Disease Study: Impact and causes of illness and death in Australia 2018, Summary - Australian Institute of Health and Welfare. (2021). Retrieved from: <https://www.aihw.gov.au/reports/burden-of-disease/abds-impact-and-causes-of-illness-and-death-in-aus/summary>

^{xx} Australian Burden of Disease Study: Impact and causes of illness and death in Australia 2018, Summary - Australian Institute of Health and Welfare. (2021). Retrieved from: <https://www.aihw.gov.au/reports/burden-of-disease/abds-impact-and-causes-of-illness-and-death-in-aus/summary>