

# Time to Move: Juvenile Idiopathic Arthritis

A national strategy to reduce a  
costly burden



Arthritis Australia  
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## TIME TO MOVE: ARTHRITIS

The Time to Move strategy provides a road map for improving care across Australia for people with arthritis.

The strategy is supported by three additional documents which respectively address the care of people with osteoarthritis, rheumatoid arthritis and juvenile idiopathic arthritis:

*Time to Move: Osteoarthritis;*

*Time to Move: Rheumatoid Arthritis;* and

*Time to Move: Juvenile Idiopathic Arthritis.*

These documents are available at [www.arthritisaustralia.com.au](http://www.arthritisaustralia.com.au)

### What is arthritis?

Arthritis is an umbrella term for a range of conditions that affects the joints.

There are over 100 different types of arthritis affecting people of all ages including children. The most common types are osteoarthritis (OA), rheumatoid arthritis (RA) and, in children, juvenile idiopathic arthritis (JIA).

### Osteoarthritis

OA is a degenerative joint disease that affects 1.9 million Australians. Although often referred to as “wear and tear” arthritis, OA is a disease and not an inevitable part of the ageing process.

### Rheumatoid arthritis

RA is a serious, chronic, inflammatory autoimmune condition that can occur at any age. Early diagnosis and appropriate treatment can prevent much of the joint damage, deformity and disability associated with RA.

### Juvenile idiopathic arthritis

JIA is an inflammatory autoimmune condition that affects around 5000 Australian children. 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 disability.

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## Executive summary

Juvenile idiopathic arthritis (JIA) is a painful, potentially disabling inflammatory arthritis that affects around 5000 Australian children under 16 years of age. Although JIA resolves in many children, there is no cure and around 50 per cent of those diagnosed will continue to have ongoing active disease into adulthood.

If not treated quickly and appropriately, JIA can seriously affect the growth and development of a child, causing severe joint damage, growth abnormalities and permanent disability.

Dramatic advances in treatment for JIA over the past decade have resulted in major improvements to short-, medium- and long-term outcomes. As a result, much of the joint damage, deformity and disability associated with the condition can now be prevented. This creates a moral imperative to ensure that children and young people receive timely and appropriate care that allows them to lead healthy, independent lives.

Evidence indicates, however, that we are failing children and young people with JIA in Australia. Many are not receiving best-practice care, severely compromising their future health and functional capacity.

Early diagnosis and treatment of JIA are critical in preventing irreversible joint damage and achieving good long-term outcomes. Yet delays in diagnosing JIA in Australia are common, with up to 41 per cent of children in some areas experiencing delays of more than six months from symptom onset to diagnosis. Inadequate public and health practitioner awareness of the condition and limited access to specialists for diagnosis and care appear to be key factors leading to these delays.

Multidisciplinary team care led by paediatric rheumatologists is consistently recommended in local and international guidelines and standards of care for JIA. However paediatric rheumatologists are in seriously short supply, with none at all in some states and territories. Similarly, there are few multidisciplinary teams trained in JIA management in Australia, particularly in rural and remote areas and in the private sector, in which around half of rheumatology practice takes place.

Limited services, inequity of access, delays in diagnosis and treatment, fragmentation of care, lack of psychosocial support and a heavy financial burden are common problems reported by families trying to cope with the devastating impact of JIA.

Improved management of the transition from paediatric to adult health care services for children with JIA is also required. Currently in Australia, little formal transition planning is taking place. As a result, young people with JIA are more likely to stop taking their medication and drop out of the health care system, increasing the risk of disease flares and complications.

If we are to address these problems and ensure that the 5000 Australian children suffering from JIA are cared for appropriately, we must drive system-level changes that help to deliver the following key elements of care in a consistent, equitable and timely manner:

- early diagnosis and referral to a paediatric rheumatologist for the initiation of appropriate treatment as soon as possible – ideally within 10 weeks of symptom onset;
- access to integrated, coordinated multidisciplinary team care by appropriately skilled practitioners led by a paediatric rheumatologist, for the development and implementation of an individualised care plan;
- age-appropriate, culturally suitable information, education and support for self-management;
- care coordination and psychosocial support for children and young people with JIA and their families;
- equitable access to appropriate, evidence-based pharmacological and non-pharmacological treatment;
- effective ongoing management, including monitoring of drug compliance, toxicity, safety and side effects, and managing complications and comorbidities; and
- planned and managed transition from paediatric to adult health services, commencing in early adolescence.

# Recommendations

- 1. Develop and implement strategies to increase awareness and understanding of JIA, and of the importance of early diagnosis and treatment, by the public, health practitioners, policymakers**
- 2. Support early diagnosis of children with JIA, and urgent referral to paediatric rheumatologists for prompt initiation of therapy**
  - 2.1 Utilise existing telephone hotlines/website booking services (e.g. HealthDirect, HealthEngine) to facilitate urgent referrals to paediatric rheumatologists for early diagnosis and treatment
  - 2.2 Support improved education of health care professionals in paediatric musculoskeletal conditions, to promote early diagnosis and treatment of children with JIA
  - 2.3 Conduct early arthritis clinics in underserved areas to provide triage and improve early access to specialist care
- 3. Provide equitable and timely access to individualised, coordinated multidisciplinary team care by appropriately skilled practitioners led by a paediatric rheumatologist**
  - 3.1 Establish comprehensive centres of excellence in paediatric rheumatology in major centres across Australia, to provide best-practice multidisciplinary care and support education and training for health professionals in the field. Core members of the multidisciplinary team should include a paediatric rheumatologist, a paediatric rheumatology nurse, a physiotherapist, an occupational therapist, a psychologist and a social worker
  - 3.2 Develop multidisciplinary clinical networks at regional/state levels to link service providers and provide training and support
  - 3.3 Establish community-based multidisciplinary clinics/teams providing public and private services, in collaboration with Medicare Locals and other stakeholders
  - 3.4 Develop system incentives/funding models to support the delivery of multidisciplinary care in the private sector, including increased access to Medicare-subsidised allied health visits under Chronic Disease Management items, in line with clinical requirements
  - 3.5 Provide services in rural and other underserved areas through outreach clinics and/or telehealth services that include clinical and educational components
- 4. Improve age-appropriate and culturally suitable information, education, coordination of care and psychosocial support to children and young people with JIA and their families**
  - 4.1 Utilise rheumatology nurses and other allied health professionals as part of multidisciplinary teams, providing patient information, education and self-management support, psychosocial support and coordination of care
  - 4.2 Develop a comprehensive information package and tools for parents and families of children and adolescents newly diagnosed with JIA, to help them understand the condition and its treatment, navigate their way around available services and supports, and coordinate their care
  - 4.3 Develop national age-appropriate resources and tools for adolescents with JIA
  - 4.4 Develop JIA resources for schools and childcare centres
  - 4.5 Refer children and young people newly diagnosed with JIA and their families to Arthritis organisations in their state or territory for access to information resources, self-management education, support groups and activities such as kids' camps
- 5. Optimise pharmacological treatment for JIA**
  - 5.1 Review existing restrictions on PBS access to biologic DMARDs to ensure they allow appropriate, timely, evidence-based access to these therapies for those who would benefit from them
  - 5.2 Streamline the application process for access to biologic DMARDs through the PBS
  - 5.3 Develop information materials to support effective medication management by other health professionals providing care for children and young people with JIA
- 6. Improve transition planning and care for young people with JIA moving to adult services, commencing in early adolescence**
  - 6.1 Identify key principles to guide the development of transition services for young people with JIA
  - 6.2 Develop resources to support young people, parents and health professionals prepare for transition, including resources for early, middle and late adolescence
  - 6.3 Provide coordinators to manage transitional care



## Recommendations

### 7. Build workforce capacity to support early diagnosis of and effective treatment for children and young people with JIA

- 7.1 Provide dedicated funding for training for paediatric rheumatologists
- 7.2 Build a cadre of rheumatology nurses/nurse practitioners to support JIA management, including in rural and remote regions and other underserved areas
- 7.3 Develop information and education materials, programs and tools for GPs, paediatricians, orthopaedic surgeons, nurses and allied health practitioners, including pharmacists, to support the early diagnosis and effective management of children and young people with JIA
- 7.4 Develop or use existing online tools (e.g. Health Pathways, Map of Medicine) to provide an information portal, enabling easy access by GPs and other health practitioners to information about JIA diagnosis and management, and clear referral pathways, as well as a guide to local services and resources

### Priorities and implementation

The following priority areas for implementation have been identified by the Steering Committee as offering the greatest scope for reducing the burden of JIA and being the most feasible in the short term:

- strategies to support early diagnosis and urgent referral to paediatric rheumatologists;
- provision of equitable access to specialist services and multidisciplinary care;
- improved transition planning and care;
- dedicated funding for paediatric rheumatology training.

Implementation of these recommendations will require collaboration between stakeholders across all sectors of the health system, as well as the education and disability sectors. Arthritis Australia will work with relevant stakeholders to encourage and support the implementation of the Time to Move strategy.

# 1. Introduction

The Time to Move strategy provides a road map for improving the care of people with osteoarthritis, rheumatoid arthritis and juvenile idiopathic arthritis across Australia.

This document outlines an optimal model of care for the management of juvenile idiopathic arthritis (JIA). The intention of the model of care is to identify key elements of best-practice treatment and support for children and adolescents with JIA and their families, recognising that local delivery models will vary across Australia depending on existing systems and resources.

Although the document focuses on JIA, children with other paediatric rheumatic conditions will also benefit from implementation of the proposed model of care.

A 'patient journey' framework was used to develop the model. Examining the patient journey across the continuum of care, from wellness through to advanced disease, provides an accepted framework for considering how clinical and support services can be reorganised and improved to achieve high-quality patient-centred care. In this paper, consideration of the patient journey has been expanded to include factors within the broader context of the Australian health care environment, in order to identify community, systemic and health workforce issues that affect the provision of care.

A number of local and international guidelines, recommendations, standards of care and models of care informed the development of the model, including the:

- Royal Australian College of General Practitioners (RACGP). Clinical Guideline for the diagnosis and management of juvenile idiopathic arthritis, 2009<sup>1</sup>
- Arthritis and Musculoskeletal Alliance UK (ARMA). Standards of Care for children and young people with juvenile idiopathic arthritis, 2010<sup>2</sup>
- American College of Rheumatology. Recommendations for the treatment of juvenile idiopathic arthritis: initiation and safety monitoring of therapeutic agents for the treatment of arthritis and systemic features<sup>3</sup>
- Royal Children's Hospital, Melbourne. Paediatric Rheumatology Best Practice Model of Care<sup>4</sup>
- NSW Agency for Clinical Innovation. Model of care for the NSW Paediatric Rheumatology Network, 2013<sup>5</sup>
- Royal Children's Hospital, Melbourne. Paediatric rheumatology nurse practitioner model of care, 2012<sup>6</sup>
- Department of Health, Western Australia. Inflammatory Arthritis Model of Care, 2009<sup>7</sup>
- Department of Health, Western Australia. Paediatric Chronic Diseases Transition Framework<sup>8</sup>

A series of stakeholder consultations was also held around the country between August and November 2013 to inform the development of the model of care.

## 2. Background

### 2.1 About juvenile idiopathic arthritis

Juvenile idiopathic arthritis (JIA) is defined as inflammatory arthritis of unknown cause that begins before the age of 16 and persists for at least six weeks. JIA is distinct from adult forms of arthritis and is one of the most common and serious chronic conditions of childhood.<sup>3</sup>

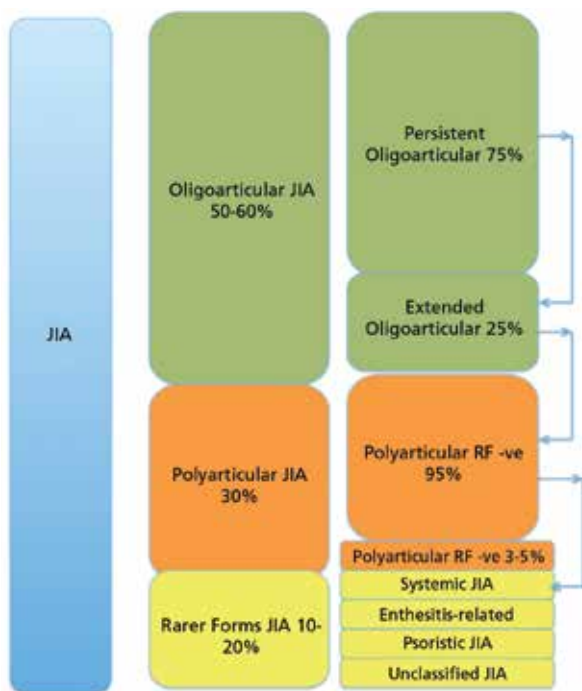
If not treated quickly and appropriately, JIA can seriously affect the growth and development of a child, causing severe joint damage, growth abnormalities and permanent disability.<sup>9</sup> In addition, complications of the disease and its treatment such as serious infections and uveitis, which can lead to blindness, require careful management.<sup>10</sup>

JIA affects around one in every 1000 children<sup>11</sup> and is classified into seven subgroups (see Figure 1) which vary in features, prognosis and severity from mild to extremely disabling. All forms cause stiff, painful and swollen joints, and some forms also affect other organs, such as the skin and eyes. The condition is diverse and unpredictable, with symptoms and severity varying significantly from child to child and even from day to day in the same child. Flare-ups, when symptoms become significantly worse, are unpredictable but common.<sup>11</sup>

Although JIA resolves in many children, there is no cure and around 50 per cent of those diagnosed will continue to have ongoing active disease into adulthood.<sup>12</sup> In these cases, the prolonged disease course and exposure to treatment increases the risk of disability, complications and other morbidities associated with the condition.

Major advances in treatment in the past decade have significantly improved short- and medium-term outcomes for JIA, provided that the condition is diagnosed early and appropriate treatment commenced as soon as possible.<sup>3</sup> Although there is no cure, complete remission is increasingly becoming a realistic treatment goal.<sup>13</sup>

**Figure 1: JIA subtypes**



Source: Based on Kahn P, 2012. Juvenile Idiopathic Arthritis: An Update for the Clinician. Bulletin of the NYU Hospital for Joint Diseases 2012; 70(3):152-66



## 2.2 Impact of JIA in Australia

At any one time, JIA is estimated to affect around 5000 Australian children, although this number may be underestimated.<sup>14,15</sup> This is similar to the number of children affected by Type 1 diabetes.<sup>16</sup>

JIA can have a devastating impact on the affected children and their families, with far-reaching physical, emotional and financial effects that may include:

- Disabling pain, fatigue, restrictions in physical activity, and the potential for growth abnormalities, irreversible joint damage and other complications
- Challenging and complex treatment regimens, with potentially severe side effects
- Psychological and social impact on both children and families, including depression, anxiety and feeling alienated from peers.<sup>10</sup>
- Absences from and difficulty participating in school (e.g. difficulties in sitting, writing, concentrating, participating in sports),<sup>11</sup> affecting educational attainment and employment prospects
- Financial pressures due to the costs of medical and allied health care, medications, and travel to access specialists. In a recent survey in Queensland, 38 per cent of parents reported that their child's condition had had a significant impact on their finances, with 25 per cent reporting that costs had stopped them from accessing services for their child.<sup>19</sup> Economic hardship for caregivers is associated with worse health-related quality of life for children with JIA.<sup>20</sup>

The parents of children with JIA report that the process of diagnosis is difficult and there is a significant emotional toll on both the child with JIA and the family, with arthritis taking the driving seat in many family situations.<sup>17</sup> In one survey of adolescents with JIA and their parents, 39 per cent of parents and 17 per cent of adolescents reported clinical-level psychological symptoms.<sup>18</sup>

The disability burden of JIA is significant. In 2008, JIA was estimated to be the main disabling condition for around 1600 children. This represents one in three prevalent cases. Of these, 83 per cent had severe activity limitations.<sup>11</sup>

The impact of JIA continues into adulthood, with the condition persisting in around half of those diagnosed, increasing the risk of joint damage, disability and other health issues.<sup>12</sup> Even if the condition resolves, many affected by JIA will continue to experience long-term impacts from the disease or its treatment into adulthood.<sup>21</sup>

In Australia, one in three adults diagnosed with juvenile-onset arthritis reports severe limitations on activity, with

more than 25,000 adults estimated to be living with JIA-related disability in 2003. In addition, the 2004–05 National Health Survey found that 40 per cent of adults with juvenile-onset arthritis were unemployed while one in four experienced high or very high levels of psychological distress.<sup>11</sup>

JIA can also have an ongoing psychosocial impact that extends into adulthood and may include increased anxiety and depression, social isolation and relationship difficulties.<sup>11,22</sup>

The advent of improved treatments for JIA in the past decade is expected to reduce future JIA-related disability significantly for those who have been recently diagnosed, provided timely access to appropriate treatment can be achieved. As yet, however, insufficient time has elapsed to enable a full understanding of the long-term outcomes under current treatment paradigms.

## 2.3 Economic burden

The costs of JIA include:

- direct medical, medication and hospital costs for treatment of the condition and its complications;
- welfare costs, such as payments for the Disability Support Pension, Carer's Payment and Carer's Allowance; and
- indirect costs, including lost productivity and wellbeing, for the child who may experience long-term disability and for parents caring for a child with JIA.

Australian data specific to the costs of JIA are limited<sup>23</sup>; however, international data suggest that the costs per patient with JIA can be substantial.<sup>24,25</sup>



## 3. The patient journey

### 3.1 Risk factors and prevention

Little is known about the risk factors or causes of JIA. Gender is a known risk factor, with girls more likely to develop the condition than boys. A complex interplay of genetic and environmental factors, including infection and viral agents, is likely to affect development of the condition but is poorly understood.<sup>11,26</sup>

More research is needed to identify risk factors and causes of JIA and ascertain whether and if so, how they can be modified.

A JIA biobank called CLARITY (ChiLdhood Arthritis Risk factor Identification sTudY) was established recently in Melbourne to collect information and biological samples from children with JIA and their families, with the broad aim of identifying and understanding genetic and environmental risk factors associated with the condition.<sup>27</sup> The biobank will provide a valuable platform for future research into the identification of potentially modifiable risk factors for JIA that could assist in developing prevention strategies in future.

#### Opportunities for improvement – Risk factors and prevention

- Support increased funding for research into JIA risk factors to support the development of prevention strategies

### 3.2 Early detection and diagnosis

Early diagnosis and treatment of JIA are critical in preventing irreversible joint damage and achieving good long-term outcomes. Evidence indicates that the sooner an accurate diagnosis is made and appropriate treatment initiated, the better outcomes are likely to be.<sup>28</sup>

Early referral to a paediatric rheumatologist is critical to confirm the initial diagnosis and initiate appropriate early treatment, and is recommended in existing local and international standards of care and clinical practice guidelines.<sup>1,2</sup> The RACGP guidelines recommend referral to a paediatric rheumatologist for children with suspected JIA whose symptoms persist beyond four weeks, while the ARMA Standards of Care recommend a target of referral to and assessment by paediatric rheumatology services within 10 weeks of symptom onset.

Despite the importance of early diagnosis, delays in diagnosis and referral for JIA are common, locally and

internationally.<sup>29,30</sup> A 2012 survey conducted by Arthritis Queensland showed that the time from symptom onset to diagnosis for 41 per cent of children was longer than six months.<sup>31</sup> An unpublished NSW survey had similar results.<sup>1</sup> A 2005 Victorian survey found that 24 per cent of children experienced delays of four months or longer from symptom onset to diagnosis (a further eight per cent did not know). Of those who participated in the Victorian survey, almost half felt that it was difficult or very difficult to get a diagnosis.<sup>18</sup>

As a result, many children and adolescents with JIA experience a potentially avoidable burden of disease and disability that is likely to affect them for their entire lives.

In Australia, GPs are usually the first port of call for children and adolescents with symptoms of JIA, so they play an important role in identifying potential cases, referring them appropriately for assessment and care, and providing initial symptomatic management. While clinical practice guidelines exist for the diagnosis and management of JIA in general practice, the extent to which GPs are aware of these guidelines or use them is unclear.

#### 3.2.1 Barriers to early detection and diagnosis

There are a number of likely reasons for delays in diagnosis and referral to paediatric rheumatology services for suspected cases of JIA.

Firstly, arthritis is generally considered by the community as a condition of old age. There is limited public awareness that children may also have arthritis, and that early diagnosis and treatment is critical to achieve good long-term outcomes. This is likely to lead to delays in seeking medical advice or in pressing for a definitive diagnosis. Existing delays in diagnosis in Australia indicate that awareness of JIA among medical practitioners is also limited.

Secondly, diagnosis of JIA in primary care can be difficult; the condition is relatively uncommon and diverse in its presentation, and diagnosis relies on excluding a large range of other conditions. There is no single test for diagnosing JIA, although clinical tests may increase diagnostic certainty and help identify subgroups and potential complications. Diagnosis of JIA is based primarily on history-taking and clinical examination.<sup>1</sup> However, children and adolescents are often difficult to evaluate, due to their development and behavioural stages,<sup>32</sup> and international evidence suggests that the skill and experience of primary-care clinicians in undertaking paediatric musculoskeletal assessment may be limited.<sup>33,34</sup>

<sup>1</sup> Personal communication from Dr Davinder Singh-Grewel



In Australia, lack of exposure to paediatric rheumatology in training programs for doctors, nurses and allied health professionals, as well as for sub-speciality groups such as paediatricians and orthopaedic surgeons, has been identified as a contributor to delayed diagnosis.<sup>5,8</sup>

Thirdly, patients may be inappropriately referred to multiple health service providers or may undergo costly, painful and unnecessary procedures and investigations before referral to a paediatric rheumatologist, delaying accurate diagnosis and initiation of appropriate therapy.<sup>29,30</sup> A 2005 audit of referrals to paediatric rheumatology services in Victoria found that only half of all new patients were referred directly from GPs, with 22 per cent referred from paediatricians, 17 per cent from orthopaedic surgeons and the remainder from a variety of other practitioners.<sup>18</sup> In a recent NSW survey (unpublished), 71% of respondents reported that they saw three or more health professionals before a diagnosis was confirmed, indicating that there has been little improvement in diagnosis and referral patterns for JIA in primary care.<sup>i</sup>

One of the most significant barriers to early diagnosis and initiation of treatment for JIA in Australia is the serious shortage of paediatric rheumatologists (See Workforce issues). This means that many children and young people face long waiting times or need to travel great distances to access paediatric rheumatologists. Alternatively, they are managed by other health practitioners who are not optimally trained to deliver best-practice care for JIA, risking inadequate or inappropriate treatment and poor outcomes.

Stakeholder consultations for this project consistently highlighted lack of awareness and delayed diagnosis of JIA as crucial issues that need to be addressed. Participants particularly identified the need to educate GPs so that they consider the possibility of JIA and make the crucial diagnosis and referral early, rather than dismissing the symptoms as 'growing pains'. Information and education programs for other health professionals such as pharmacists and physiotherapists, who may encounter children with undiagnosed JIA, could also assist in reducing delays to diagnosis.

There is substantial scope for using internet-based programs and tools to provide easily accessible information to GPs and allied health practitioners on the diagnosis and management of JIA, including information on local services and referral pathways. Existing tools being implemented by some Medicare Locals, such as Health Pathways<sup>ii</sup> and Map of Medicine,<sup>iii</sup> could be used or new resources could be developed.

Internationally, early arthritis clinics – specialist clinics for early assessment of patients with inflammatory arthritis – have been successful in reducing delays in the initiation of treatment for rheumatoid arthritis (RA), in which early treatment is also critical. These clinics offer a more structured approach to triage, assessment and referral of patients with inflammatory arthritis<sup>35,36</sup> and could be useful in supporting early diagnosis of JIA. Some hospital-based early arthritis clinics operate in Australia, but there is scope for more widespread implementation of the concept at the community level.<sup>35</sup> In paediatric rheumatology, where workforce shortages are a major barrier to access, early clinics could be led by paediatric rheumatology nurses (See Workforce issues). Alternatively, innovative triage models such as telephone hotlines or online clinics could be used.

### 3.3 Early treatment

In the past decade, significant advances in treatment for JIA have resulted in major improvements to short-, medium- and (on early evidence) long-term outcomes.<sup>37</sup> In particular, the advent of disease-modifying antirheumatic drugs (DMARDs) and especially the newer genetically engineered biologic DMARDs (bDMARDs) has revolutionised treatment and outcomes for JIA as these drugs can alter the course of the disease, preventing or delaying disability caused by joint damage and growth abnormalities (see Ongoing management).

To achieve these outcomes, early and aggressive treatment is essential. Such treatment has been shown to increase the likelihood of disease remission, which in turn reduces the risk of disease complications and long-term disability and improves quality of life.<sup>21,28,38</sup> The sooner appropriate treatment for JIA is initiated, the greater the chance of achieving disease remission. Evidence indicates that each month earlier that aggressive treatment is begun increases the chance of remission after six months by 32 per cent.<sup>28</sup>

While there is as yet no cure for JIA, complete clinical remission is an increasingly realistic treatment goal. It is not yet clear, however, whether new treatment paradigms will result in fewer people with JIA having active disease into adulthood. Nor is it clear what the long-term effects of treatments may be.

In Australia, limited access to paediatric rheumatologists and appropriately skilled multidisciplinary teams is a major barrier to initiating effective early treatment of JIA. Under the Pharmaceutical Benefits Scheme – and appropriate to

<sup>i</sup> Personal communication from Dr Davinder Singh-Grewel

<sup>ii</sup> Health Pathways provides an online health information portal for primary care clinicians to use at the point of care; it also includes a guide to local resources. <http://www.canterburyinitiative.org.nz/Home.aspx> and [http://www.hnehealth.nsw.gov.au/innovation\\_support/programs\\_for\\_20102011/health\\_pathways](http://www.hnehealth.nsw.gov.au/innovation_support/programs_for_20102011/health_pathways) both viewed 27/10/2013

<sup>iii</sup> Map of Medicine is a collection of evidence-based, practice-informed care maps that connect knowledge and services around a clinical condition and can be customised to reflect local needs and practices <http://www.mapofmedicine.com/solution/whatisthemap/>, viewed 27/10/2013



## 3. The patient journey

the complexity of the treatment – only rheumatologists and clinical immunologists are allowed to prescribe bDMARDs. These specialists are concentrated in metropolitan areas, so patients in underserved rural and remote regions face major logistical challenges just to access these medications.

There is the potential to use rheumatology nurses or other appropriately trained health practitioners, such as GPs or allied health professionals, to undertake triage for referral to paediatric rheumatologists, and this may be a useful strategy to adopt in underserved areas or to reduce paediatric rheumatology waiting lists. In one study, GPs and rheumatology nurses trained in assessing early inflammatory arthritis for referral achieved accuracy approaching that of a group of experienced rheumatologists.<sup>39</sup> In another, a nurse-led early arthritis clinic reduced delays in access to specialised rheumatology care from three months to three weeks.<sup>40</sup>

### Opportunities for improvement – Early diagnosis and treatment

- Increase public awareness of JIA and the need for early diagnosis and treatment
  - Implement public awareness-raising campaigns
  - Develop and implement JIA Information and education campaigns targeting GPs, physiotherapists, pharmacists, paediatricians and orthopaedic surgeons
  - Increase exposure to paediatric rheumatology in GP and allied health practitioner training
- Facilitate early referral to a paediatric rheumatology service
  - Develop or use existing online tools to support GPs, ensuring that these provide up-to-date information on diagnosis and management, clear referral pathways and guides to local services and resources
  - Establish a paediatric rheumatology telephone hotline/website to facilitate making appointments for urgent referrals
  - Establish early arthritis clinics for triage, assessment and diagnosis, face to face or online
  - Train rheumatology nurses or other health practitioners to undertake triage for referral to paediatric rheumatologists in underserved areas
- Increase access to paediatric rheumatologists and appropriately skilled multidisciplinary teams (see Workforce issues)

## 3.4 Ongoing management

The effective management of children and young people with JIA requires a holistic approach that addresses the clinical, functional, psychological and social needs of the affected child to support them in leading independent lives and reaching their full potential.<sup>2</sup> This approach needs to be adopted at every stage of treatment and care.

Best-practice international standards for optimal ongoing management of JIA are based on multidisciplinary care across a range of health care professionals led by a paediatric rheumatologist.<sup>2</sup> GPs have an important role within multidisciplinary teams, as they are responsible for initial assessment and ongoing treatment support, including monitoring compliance and the side effects of drug therapy. The RACGP guidelines provide guidance on primary care involvement in the management of JIA.

Once early and accurate diagnosis has been made, the goals of treatment are to:

- control disease activity and induce remission;
- preserve joint function and prevent long-term joint damage;
- preserve normal physical, social and emotional growth and development; and
- prevent or minimise deformity and disability.<sup>32,41</sup>

JIA affects each child differently, with substantial individual variation in the range of symptoms, number of joints affected and severity, so treatments must be matched to individual patient characteristics. However, key elements of treatment and care, based on existing treatment guidelines and models and standards of care<sup>1,2,5</sup> include:

- access to an appropriately skilled multidisciplinary paediatric rheumatology team for initial diagnosis, assessment and management, and regular review;
- information, education and support to improve patients' understanding of the disease and its treatment. and to support self-management;
- access to evidence-based pharmacological and non-pharmacological treatments; and
- appropriate transition to adult services.

### 3.4.1 Multidisciplinary care

Multidisciplinary care is beneficial in the ongoing management of JIA as it allows the best possible care to be provided, reducing patients' risk of developing the complications and disability associated with the condition.<sup>42</sup> Existing treatment guidelines, models and standards of care strongly support a multidisciplinary team approach to managing JIA. This holistic approach to care allows all aspects of a child's condition, including its impact on child and family, to be addressed.

Core members of a JIA multidisciplinary team should include a paediatric rheumatologist, a paediatric rheumatology nurse, a physiotherapist, an occupational therapist, a psychologist and a social worker. The extended multidisciplinary team would include but not be limited to:

- dieticians
- ophthalmologists
- orthopaedic surgeons
- pain management teams
- GPs
- general paediatricians
- adult rheumatologists
- community-based allied health practitioners
- podiatrists or orthotists, and
- school-based educational advisers.

Members of the multidisciplinary team should have appropriate training and experience in paediatrics and paediatric rheumatology.<sup>2</sup>

Existing guidelines and standards of care recommend that multidisciplinary team involvement should be managed by developing individualised multidisciplinary care plans. Family members should be involved in all aspects of care, and the support needs of family members should also be addressed.<sup>1,2</sup>

#### Barriers to multidisciplinary care

##### *Lack of appropriately skilled multidisciplinary teams*

Multidisciplinary teams trained in JIA management are not widely available in Australia, particularly in rural and remote areas.<sup>1</sup> Most of the services that do exist are attached to public tertiary hospitals in metropolitan areas, but even in these centres, dedicated funding for allied health services is limited. In 2011, dedicated funding for public multidisciplinary paediatric rheumatology services

Australia-wide consisted of just 2.7 FTE for nursing, 1.15 FTE for physiotherapy, 0.85 FTE for occupational therapy and 0.5 FTE for psychology.<sup>5</sup>

As well as restricting clinical capacity, limited availability of paediatric rheumatologists and specialised allied health practitioners hinders workforce development by restricting the capacity for teaching and education activities.

There is a pressing need to build workforce capacity in the field.

##### *Reliance on private services*

Around half of paediatric rheumatology practice in Australia occurs in private-practice settings, which do not normally have ready access to multidisciplinary team care.<sup>5</sup> As a result, many children and young people with JIA are required to access allied health services in community-based private practices. Appropriate skills in this sector are limited, as most practitioners receive little or no formal exposure to paediatric rheumatology as part of their training.<sup>5</sup> In addition, the lack of formal links between such practices and with paediatric rheumatologists can create issues around communication and the coordination of care.

The cost of accessing private services also creates a significant barrier to optimal access. Children and young people with JIA can access MBS rebates for allied health services under Chronic Disease Management items, but subsidised visits are currently limited to just five per year. This number is inadequate to enable JIA patients to access the range of allied health services they need for optimal care, and should be increased.

Moreover, under the MBS Chronic Disease Management items, only GP referrals to allied health services attract rebates, creating inequities in access to these services for people with conditions such as JIA that are primarily managed by specialists. A person in this position is required to visit their GP specifically to have a care plan developed and to get referrals to allied health professionals. It would make more sense if both care plans and referrals were handled by a person's main treating practitioner as part of routine patient management. This extra step simply adds unnecessarily to health care costs.

##### *Fragmentation of care*

The provision of coordinated multidisciplinary care is a key principle in the ARMA standards of care for JIA.

Care coordination has been shown to yield clinical and economic benefits in a range of musculoskeletal and chronic conditions, locally and internationally.<sup>43,44,45</sup>



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However, stakeholder consultations for this project consistently identified the fragmentation of services as a key issue affecting the delivery of quality care for JIA across the country. Service fragmentation is an issue at both primary care and specialist levels. Lack of service integration and of communication and coordination among specialists, GPs, paediatricians, orthopaedic surgeons and allied health professionals means that children and young people with JIA are likely to be managed poorly.

Parents report that they are left to navigate and coordinate services for their children with little to guide them. They often feel that they are the only link in the information chain across care providers. This is especially an issue for those who may lack the health literacy or English language skills to perform this role effectively. The issue of service fragmentation is exacerbated in the private system, where access to multidisciplinary teams is limited or non-existent.

Many stakeholders suggested a one-stop, family-focused multidisciplinary clinic, offering coordinated appointments with different service providers to prevent the need for multiple visits, as an ideal solution. This model would make it easier for children and young people with JIA to access multidisciplinary care and would facilitate communication across service providers. Clinics could be hospital-based or community-based, with the latter facilitated by Medicare Locals.

Providing each JIA patient with a case manager or care coordinator was also suggested as a solution to the fragmentation of care. In some hospital-based clinics, coordination of care is provided by a paediatric rheumatology nurse, and this may be a useful model for broader application (see Workforce issues).

### 3.4.2 Information, education and support for self-management

Self-management has been identified as a key strategy for managing chronic disease.<sup>46,47</sup> There is no consensus definition but the term is generally used to describe the activities undertaken by a person with a chronic condition, in conjunction with their family and care community, to manage the symptoms, treatments, psychosocial and lifestyle consequences of their condition so as to maintain optimal health.<sup>48</sup>

Effective self-management requires access to information, education and support from health professionals and carers.<sup>49</sup> Children and young people with JIA and their families require information about the disease and its

treatment, including drug and non-drug therapies as well as advice about maintaining general health. They also need information about multidisciplinary services and how to access them, and about any other social, financial and support services available to them.<sup>2</sup>

Interventions to support self-management vary in content and method of delivery but generally, they aim to improve the knowledge and skills that children and young people with JIA require to manage their condition effectively. Although the evidence base has limitations, self-management interventions in other forms of arthritis have been associated with small improvements in pain and disability.<sup>50</sup> One Australian study of participants in arthritis self-management courses showed small but sustained improvements in levels of pain, fatigue and health distress as well as self-efficacy and health-related behaviours.<sup>51</sup>

A recent systematic review of self-management interventions for children and youth with disabilities found only a few rigorously designed studies in this area. Of the six studies reviewed, four were for JIA; however, all the interventions reported at least one significant improvement in either overall self-management skills or specific health behaviours, such as improvements in knowledge and self-reported pain.<sup>52</sup>

For children with JIA, parents and carers play a pivotal role in self-management activities,<sup>17,52</sup> highlighting the need for family-based self-management education and support. Increasingly, however, as children mature into adolescence and adulthood, they need to develop the skills and knowledge required to self-manage their condition successfully. This requires access to age- and developmentally-appropriate information resources and support strategies as part of a managed transition to adult services (see Transition to adult services, below). In particular, the needs of adolescents for information and self-management support have been highlighted, in the literature<sup>53,56</sup> and through consultations for this project, as a major area of unmet need.

Internationally and in some local clinics, paediatric rheumatology nurses play a pivotal role in providing information, education and self-management support for children with JIA and their families.<sup>6,57</sup> A nurse-led education program for JIA in Melbourne has been shown to substantially improve parental satisfaction regarding their knowledge of issues integral to caring for children with JIA.<sup>58</sup>

Internet-based strategies also appear to offer a feasible and acceptable mode of delivery for the provision of information and self-management support for both families and adolescents.<sup>59,60</sup>

Arthritis organisations across Australia are an important source of information and support services in the community, including:

- information sheets and booklets on the disease and its management;
- self-management education programs; and
- patient support groups and camps.

However there appears to be no systematic approach to referring those newly diagnosed to these organisations for support. There is also scope to develop more comprehensive national information resources and tools to better meet the needs of families of children and young people with JIA. Stakeholder consultations particularly highlighted the lack of adequate information and support at the time of diagnosis.

### 3.4.3 Pharmacological treatments

Medications used for JIA may include one, some or all of the following:

- Non-steroidal anti-inflammatory drugs (NSAIDs) to control inflammation and provide symptomatic relief. Topical NSAIDs are not recommended.
- Corticosteroids. Corticosteroid joint injections are often used as first-line treatment early in the disease course, especially in children who have arthritis in four joints or fewer. They can be used with or without other medications, and are likely to reduce inflammation and improve symptoms for at least four months.<sup>3</sup> They may also reduce growth abnormalities and allow discontinuation of systemic medications.<sup>61</sup> Typically, injections are administered under sedation or anaesthesia and require hospital admission, especially for younger patients. Systemic steroids may also be prescribed.
- Disease-modifying antirheumatic drugs (DMARDs) that modify the abnormal immune response to slow or stop joint destruction. There are two types: conventional synthetic DMARDs (most commonly, methotrexate) and biologic DMARDs (bDMARDs), a newer class of drugs that target individual molecules in the immune system. Conventional DMARDs can be taken orally but bDMARDs are delivered either by injection or by intravenous infusion.

DMARDs are recommended for use if NSAIDs and corticosteroids fail to adequately control JIA symptoms. They require close medical monitoring for efficacy and side effects, which can be serious.<sup>23</sup> Under PBS restrictions, bDMARDs can be prescribed only by rheumatologists and clinical immunologists, and only after treatment with other conventional

synthetic DMARDs has failed. Usually, bDMARDs are used in conjunction with conventional synthetic DMARDs, especially methotrexate.

- Short-term simple analgesics to reduce pain.

Response to these medications varies across patients and needs to be monitored closely and adjusted as required. Patients may need to try a number of therapies to optimise benefit.

Historically, NSAIDs were used as the first line of treatment for JIA, but evidence now shows that earlier and more aggressive treatment with DMARDs can improve disease control and positive long-term outcomes.<sup>13</sup> Methotrexate and bDMARDs in particular have been shown to improve outcomes in more than 50 per cent of children treated.<sup>11</sup>

However, a recent systematic review concluded that there is not enough high-quality research evaluating the comparative effectiveness of different DMARDs in children with JIA to enable practitioners to determine if any of the conventional or biologic DMARDs work better than the others, how effects differ across different subtypes of JIA, or the long-term safety implications.<sup>62</sup> There is a view that earlier treatment with bDMARDs may lead to improved outcomes for JIA over other therapies but as yet, there is insufficient evidence to support superiority over methotrexate.<sup>63</sup>

New therapeutic agents are likely to become available, providing additional treatment options for JIA. It is important to ensure timely access to these treatments in Australia.

While bDMARDs are expensive, the patient population is relatively small, limiting the overall cost of their use in JIA. Pharmaceutical benefits paid for bDMARDs to treat juvenile arthritis totalled just \$4.7 million in 2011.<sup>23</sup>

## Barriers to accessing medications

### *Limited prescribing authority*

Under PBS rules, and in recognition of the complexity of treatment, only paediatric rheumatologists and clinical immunologists are able to prescribe bDMARDs for JIA. As a result, and given the serious shortage of paediatric rheumatologists in Australia (see Workforce issues), access to these medications is difficult for children and adolescents with JIA who live in rural and remote regions or in other areas with limited or no access to these specialists.

### *Eligibility criteria and application processes*

Patients with JIA must fulfil detailed eligibility criteria relating to disease severity, prior therapy and treatment response to qualify for treatment with bDMARDs. In



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particular, bDMARDs can be prescribed for severe JIA only after other drug treatments have failed. In order to meet the criteria, children and young people with JIA must fail a three-month trial of the conventional DMARD methotrexate before bDMARDs can be prescribed, potentially compromising future outcomes. Stakeholder consultations identified this as an important issue, with a number of parents reporting that they were paying tens of thousands of dollars to access these medications when their children failed to meet the eligibility criteria.

There is a view that earlier treatment with bDMARDs may result in improved outcomes for those with certain subtypes of JIA, with the prospect that medication can be withdrawn earlier, but the evidence is not yet clear-cut. As more evidence becomes available, current PBS prescribing restrictions may need to be reviewed.

An additional issue is the burdensome and time-consuming authority application process for PBS subsidy required to initiate and continue bDMARD treatment. Detailed application forms must be completed and sent to Medicare for approval, and this adds to delays in initiating and continuing appropriate treatment.

### *Limited availability of bDMARDs*

Currently, three bDMARDs – etanercept, adalimumab and tocilizumab – are PBS-listed for poly-articular course JIA, and these can be prescribed only once all other treatments have failed.<sup>64</sup> Other biologics may be available through some hospitals, but access depends on the willingness of the individual hospital to fund supply.

Notably, the most recent treatment recommendations for JIA from the American College of Rheumatology specifically recommend other bDMARDs, including abatecept (not currently reimbursed via the PBS), for the treatment of certain types of JIA.<sup>3</sup>

### 3.4.4 Non-pharmacological treatments

#### Physiotherapy/occupational therapy

Physiotherapy and occupational therapy are widely accepted as important elements of JIA treatment. Physiotherapy is used to control pain, prevent and correct joint contractures, preserve range of motion in affected joints, maintain and improve muscle strength, minimise the effects of inflammation and ensure normal growth and development.<sup>65</sup>

Both land-based and a combination of land-based and water-based (hydrotherapy) physiotherapy have been shown to improve short-term disease outcomes in JIA, with the combined option also leading to greater improvements in health-related quality of life and cardiovascular fitness.<sup>66</sup>

In Australia, however, access to appropriately skilled paediatric physiotherapists, especially in rural and regional areas – and, to some extent, in the private, community-based sector – is limited. Parents of children with JIA often report difficulties in finding appropriately skilled physiotherapists as well as issues with fragmentation and costs of care.<sup>53</sup> Access to hydrotherapy pools is also limited. These issues have been reinforced in stakeholder consultations for this project.

As highlighted previously, there is a pressing need to increase access to integrated multidisciplinary care delivered by appropriately skilled practitioners, both generally and in the private sector where most services for JIA are provided. Education and information programs to upskill physiotherapists and others delivering exercise-based therapy to children with JIA are also required.

#### Psychosocial services

A diagnosis of JIA can have a devastating and bewildering impact on a child or young person and their family. Difficulty managing the challenges of JIA can lead to emotional and behavioural difficulties including anxiety, depression, social isolation, low self-esteem and poor body image.<sup>2,11</sup> Parents can also experience emotional, physical and financial strain as a result of the need to care for and support their child.<sup>11</sup>

More severe physical disability may be associated with poorer psychological outcomes but studies addressing this correlation show mixed results.<sup>67</sup>

The ARMA standards of care suggest a tiered approach to the provision of psychosocial support for children or young people affected by arthritis and their families, comprising three levels of intervention. All children and families should receive general information and support with screening for indicators of higher risk. Those in acute distress should receive interventions and services appropriate to their symptoms, with monitoring for any escalation of distress. Those with persistent and escalating distress should receive assistance from clinical psychologists.

An Australian study of parent and adolescent perspectives on paediatric rheumatology care emphasised the need for psychosocial support including social and financial aid,



mental health services, vocational guidance and peer support. Most participants believed that psychological services were a vital resource in addressing chronic pain and depression, mood changes and aggression related to steroid use, low self-esteem, sibling support and family functioning.<sup>53</sup>

These issues were raised consistently in stakeholder consultations. In particular, consultations highlighted the lack of support for parents, the need for more psychological support for carers and the need to recognise the financial burden for affected families.

A common theme raised in stakeholder consultations for this project was the lack of person-centred holistic care. Parents report that the provision of services for JIA tends to be focused primarily on medical management of the disease rather than consideration of the children and their overall needs. This likely reflects limited access to multidisciplinary care and psychosocial support services.

School and vocational support is particularly important for children and young people with JIA, who may experience absences from and difficulty participating in school (e.g., difficulty sitting, writing, concentrating and/or participating in sports)<sup>11</sup> that affect their educational attainment and employment prospects. Stakeholder consultations highlighted the need to provide schools with information and resources so that teachers and the school community can better understand JIA and how to support children and young people with the condition.

The need for access to age-appropriate peer support for affected children/young people and their families was also raised.

## Opportunities for improvement – Ongoing management

- Improve access to coordinated multidisciplinary care
  - Establish comprehensive centres of excellence in paediatric rheumatology in major centres across Australia, to provide best-practice multidisciplinary care and support education and training for health professionals in the field
  - Develop multidisciplinary clinical networks at regional/state level to link service providers and provide training and support
  - Build multidisciplinary teams in both the public and private sectors
  - Increase access to publicly funded multidisciplinary services
  - Conduct 'one-stop shop' multidisciplinary clinics
  - Provide care coordinators
- Develop an electronic patient-controlled tool to assist patients and carers to coordinate patients' own care and support
- Provide services in rural/underserved areas through outreach clinics and/or telehealth services, extending out in a hub-and-spoke model from comprehensive centres of excellence
- Increase the number of annual Medicare-subsidised allied health visits available under Chronic Disease Management items, and extend these to cover referrals to allied health professionals by specialists and consultant physicians
- Provide age-appropriate information and support to children and young people with JIA and their families
  - Use rheumatology nurses/nurse educators or other allied health professionals in the multidisciplinary teams to provide patient information, education and self-management support as well as coordination of care
  - Develop a comprehensive information package and tools for parents and families of children and adolescents newly diagnosed with JIA, to help them understand the condition and its treatment and navigate their way around available services and supports
  - Develop national age-appropriate resources and tools for adolescents with JIA
  - Develop national JIA resources for schools and childcare centres
  - Refer those newly diagnosed with JIA to the arthritis organisation in their state or territory for access to information resources, self-management education, support groups and activities such as kid's camps
  - Provide improved psychosocial support for children with JIA and their family members, including better access to psychologists
- Improve access to biologic medications
  - Review existing restrictions on PBS access to biologics and streamline application processes
  - In underserved areas, extend prescribing authority for bDMARDs to other health practitioners managing patients with JIA, in consultation with paediatric rheumatologists
  - Ensure timely access to new and effective therapies as they become available



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### 3.5 Secondary prevention

Children and young people with JIA may be at increased risk of developing other health conditions as a result of their disease or its treatment, so maintaining a healthy lifestyle and healthy weight is important.

#### 3.5.1 Exercise

Children and adolescents with JIA generally have lower physical activity levels and aerobic fitness than their healthy peers.<sup>68,69</sup> Reduced levels of physical activity do not seem to be related to either periods of disease activity or the severity of the disease, suggesting that other factors, such as poor conditioning or anxiety about the potential adverse effects of exercise, may be at play.<sup>70</sup>

Exercise has been shown to be beneficial in other forms of arthritis, but research regarding the effects of exercise in JIA or the types of exercise likely to be most beneficial is limited. A Cochrane review found that results favoured exercise therapy in terms of function, health-related quality of life and aerobic capacity, but were not statistically significant, possibly due to the small number of studies and participants considered. Importantly, however, the review found that even very intense physical activity did not exacerbate symptoms, although the long-term effects were unclear.<sup>71</sup>

Physical activity and fitness are important contributors to good health. Physical activity is likely to be particularly valuable in those with JIA, who tend to be deconditioned and who may already face increased risk of longer-term health issues associated with inactivity as a result of their condition and its treatment.<sup>68</sup> Participating in physical activity also offers psychosocial benefits relating to fitting in and feeling normal, and can help to establish active habits that carry into adulthood.<sup>72</sup>

So while in the past, it was believed that children with JIA were harmed by engaging in physical activity, the literature increasingly recommends that they be encouraged to engage in regular physical activity, in line with public health recommendations.<sup>68,73</sup> The RACGP guidelines also recommend that children with JIA engage in regular physical activity compatible with their abilities and disease restrictions.

Children and young people with JIA, however, face particular barriers to participation in exercise and physical activity, because of pain and fatigue as well as fear of adverse effects.<sup>68</sup> Adherence to exercise programs can also be an issue.<sup>69</sup> Education strategies

and innovative programs such as online strategies, to support and encourage children with JIA to be more active, are required. Parents have been identified as pivotal facilitators of children's involvement in treatment regimens, including home exercise programs, so parents of children and young people with JIA should also be encouraged to support their children's participation.<sup>71</sup>

#### 3.5.2 Maintaining healthy weight

The tendency to reduced physical activity associated with JIA and the effects of steroid medication mean that children with JIA may be at increased risk of becoming overweight or obese and of developing associated conditions. These include heart disease and diabetes, and such risks are exacerbated if there is poorly controlled systemic inflammation.

Excess weight can also increase pressure on joints that are already painful; however obesity does not appear to be associated with disease activity.<sup>74</sup>

### Opportunities for improvement – Secondary prevention

Encourage children and young people with JIA to be more physically active

- Provide access to exercise therapists for advice on appropriate forms of exercise and physical activity and/or any modifications required to enable participation
- Develop information resources about exercise for children and adolescents with JIA for patients, carers, schools and sports coaches
- Develop age-appropriate exercise programs for children and young people with JIA, including online programs, apps and video games
- Provide children and young people with JIA and their carers with access to dieticians for advice on healthy diet and weight management, if required

### 3.6 Long-term care

While complete clinical remission is increasingly becoming a realistic treatment goal, many children experience JIA as a chronic condition characterised by periods of fluctuating disease activity, requiring ongoing care. For children with the milder forms of JIA, transition to a more severe form can also occur over time.

Careful ongoing management and monitoring of the progression of JIA is crucial to maximising health outcomes. The aims of long-term care for JIA are to minimise the physical, emotional and social impact of the condition, and to monitor and manage complications and comorbidities associated with the disease and its treatment.<sup>2</sup>

Ongoing multidisciplinary care and support, as outlined previously, is required. Care and support needs to be age- and stage-appropriate over the course of the disease. Currently, however, limited access to appropriate specialist and multidisciplinary paediatric rheumatology care in Australia, as noted previously, is likely to result in sub-optimal ongoing management of the condition.

#### Remission

While early diagnosis and treatment increases JIA patients' chances of achieving inactive disease, complete clinical remission is more difficult to attain. One study showed that periods of inactive disease were achieved in nine out of 10 cases. However, in around two thirds of cases, disease activity recurred within two years and nearly all patients experienced a recurrence within five years. Outcomes varied by subtype. Most of the disease course for children with disease in just a few joints was characterised by inactive disease while, for most others, the majority of the disease course involved active disease.<sup>75</sup>

The most appropriate time to withdraw potentially toxic treatment in those with JIA who achieve remission is not clear. Most clinicians wait one year before withdrawing DMARD therapy but evidence suggests that extending therapy beyond six months does not reduce the risk of relapse once medication is stopped.

Agreement on defining remission criteria and research into optimal timing of medication withdrawal will help to attain consistent clinical practice<sup>76</sup> and may help to limit the costs and side effects associated with unnecessary treatment.

#### Ongoing monitoring

Regular reviews of children with JIA by paediatric rheumatologists and multidisciplinary teams at least annually, and more frequently for those with more active disease, is recommended in international and local guidelines.<sup>1,2</sup> Quick access to the specialist team is also required for the management of major flares.

GPs have a major role in the ongoing management of JIA in conjunction with regular reviews by paediatric rheumatologists. The RACGP guidelines include recommendations for the GP's role in ongoing management of JIA. Their role includes monitoring disease activity, medication toxicity and side effects; managing comorbidities; and assessing a child's overall wellbeing, including progress at school and age-appropriate activity.<sup>1</sup>

Information and education programs to upskill GPs in the management of JIA, especially in areas where access to a paediatric rheumatologist is limited, will help ensure the provision of best care. As most GPs will see very few cases of JIA over the course of their careers, and treatment regimens are evolving rapidly, it is important that they have ready access to education and up-to-date information on managing JIA, e.g. through online modules that they can access if and when required.

A possible barrier to effective monitoring of medication safety and side effects by GPs is the lack of easy access to information on the medications used, which are usually prescribed by paediatric rheumatologists. This information is not provided in the RACGP guidelines.

#### Managing complications

Children with JIA may experience significant complications of both the disease and its treatment that require ongoing screening, treatment and management.

Uveitis (inflammation of the eyes) occurs in five to 20 per cent of children with JIA, depending on their subtype.<sup>1</sup> Uveitis in JIA is often asymptomatic and if left untreated can cause permanent eye damage or blindness, requiring regular screening and interdisciplinary management with ophthalmologists for those at high risk. Inter-specialty clinics have been shown to improve the quality and efficiency of treatment for children with rheumatic conditions and are recommended for managing complex cases.<sup>77</sup>

Other potential complications include growth abnormalities and flexion contractures, which occur much less frequently with early disease treatment; severe infections as a result of treatments that suppress the immune system; and the involvement of other organs such as the heart and lungs. Establishing clear local



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referral pathways and protocols, e.g. through Medicare Locals, will help support appropriate and timely care by specialists and other health practitioners when required.

### Long-term impacts

Little is known about the long-term impact of JIA under current DMARD and bDMARD treatment regimens. Establishing patient registries and supporting research to monitor outcomes in JIA will help to answer critical questions regarding current therapies, and will help to inform effective and cost-effective care in future.

### Opportunities for improvement – Long-term care

- Provide annual review by a paediatric rheumatologist and multidisciplinary team, and quick access to specialists for management of major flares
- Develop information and education programs in easily accessible formats (e.g. online) for GPs assisting in the care of children/young people with JIA
- Develop an easily accessible, easy-to-use medication guide for JIA to assist GPs in monitoring medication safety and side effects
- Develop referral pathways and protocols to facilitate access to other specialist care providers, such as ophthalmologists, and provide access to inter-speciality clinics for complex cases
- Establish patient registries and support research to improve effective and cost-effective use of DMARD and bDMARD therapies, including timing of the withdrawal of medications following remission

### 3.7 Transition to adult services

Around half of all children and young people with JIA will continue to have active disease or sequelae into adulthood, requiring ongoing medical treatment. As a result they will need to transition from paediatric to adult rheumatology services.

The transition period can be challenging physically and emotionally for young people and their families, as well as for the health professionals who support them.<sup>78</sup> If not managed effectively, transition is associated with a high risk of non-compliance with medications or of dropping out of the health system, increasing the risk of disease flares or complications.<sup>79</sup>

Good transitional care supports a young person in developing the skills they need to self-manage their condition successfully, a responsibility that previously rested with their parents/carers. The ARMA Standards of Care recommend individualised transitional care for children and young people with JIA that is age- and developmentally appropriate; addresses their medical, psychosocial, educational and vocational issues; and reflects early, middle and late phases of adolescent development. They recommend that transition planning begins in early adolescence, is coordinated by a nominated member of the paediatric rheumatology team, and involves primary care providers, especially GPs.

There are a number of models for transition care for young people with chronic conditions. Some adopt a disease-specific approach; others favour primary-care-based, coordinated care spanning adolescent to adult care; and some advocate generic adolescent health services.<sup>79</sup>

McDonagh (2007) trialled a structured, multidisciplinary, JIA-specific model that was shown to significantly improve health-related quality of life, adolescent and parental knowledge and satisfaction, and pre-vocational readiness markers.<sup>80</sup> The model used a framework for the provision of transitional care comprising:

- a written transition policy developed collaboratively between paediatric and adult rheumatology service providers to guide action;
- a local coordinator to manage transitional care for patients;
- individualised transition plans for both young people with JIA and their parents that addressed issues relating to health, home and school during the early, middle and late phases of adolescence; and
- resources to support adolescents, parents and health professionals.

Another model of transition care adopted in Vancouver, Canada, is based on providing a clinic for young adults aged between 18 and 24 years with childhood-onset rheumatic disease. The model includes the provision of shared care by paediatric and adult rheumatologists in the same clinical setting, supported by a clinical nurse specialist and social worker, and having established links with physiotherapy, occupational therapy and counselling services.<sup>79</sup>

In Australia, the transition to adult rheumatology services usually takes place when a young person finishes secondary school at around 17 or 18 years of age. Typically, however, there is little in the way of formal transition planning for children with JIA, although newer models of care may be addressing this for a small percentage of patients. Young people and their parents identify the provision of effective transition care as an important aspect of care that needs to be addressed<sup>31,55</sup> and this issue was reinforced during stakeholder consultations.

## Opportunities for improvement – Transition to adult services

- Improve transition planning and care for young people with JIA moving to adult services, commencing in early adolescence
  - Identify key principles to guide the development of transition services for young people with JIA
  - Develop resources to support young people, parents and health professionals prepare for transition, including resources for early, middle and late adolescence
  - Provide a coordinator to manage transitional care

## 3.8 Surgical treatment

Surgery is rarely used to treat juvenile arthritis in the early course of the disease. In a few severe cases, surgery may be used to relieve pain, correct a leg length discrepancy, straighten out a bent or deformed joint, or replace a damaged joint when medical therapy has failed.<sup>81</sup>

Advances in treatment of JIA in recent years have reduced the need for surgical intervention.<sup>81,82</sup> In adults with childhood-onset arthritis, however, joint replacement surgery is common and often occurs at a relatively young age. The procedure is associated with significant improvements in pain and function. In adolescents and young adults, however, joint replacement is associated with poorer short-term outcomes and prosthetic survival than it is in older patients.<sup>83</sup>

Data from older cohorts show that up to 50 per cent of patients who've had the disease for an average of between 25 and 30 years, and 75 per cent of patients with disease durations of more than 40 years had undergone joint replacement surgery.<sup>82,84,85</sup> Furthermore, one study found that around 50 per cent of adults with JIA attending a specialist adult JIA clinic required revision hip replacement surgery within 19 years of the original procedure.<sup>86</sup>

It is not yet clear what impact new treatment paradigms for JIA will have on joint replacement rates in adults with JIA in future, but it's likely that the need for surgery will be further reduced or delayed in current younger cohorts who receive appropriate, timely medical management.



## 4. Australian health care environment

### 4.1 Supporting multidisciplinary care in Australia

A number of broad structural factors within the Australian health care environment affect the implementation of best-practice care for JIA. Many of these factors reflect the difficulties of providing ongoing, integrated, multidisciplinary, patient-centred care for those with chronic health conditions within a health system that's still predominantly structured to deliver acute care.

The creation of Medicare Locals to plan, integrate and coordinate primary health care services on a local basis provides significant opportunities for improving multidisciplinary care for JIA. Medicare Locals could provide a locus for community-based multidisciplinary clinics for JIA, support the development of local referral pathways, and facilitate telehealth and outreach services.

A number of tools, including Map of Medicine<sup>87</sup> and Health Pathways<sup>88</sup>, have been developed to assist in establishing local referral pathways and are being implemented in some Medicare Locals.

Inadequate funding for allied health services in both public and private sectors is an important barrier to accessing multidisciplinary care for JIA, and needs to be addressed. In particular, under MBS Chronic Disease Management items, only five Medicare-subsidised allied health visits per patient, per year are provided, which is inadequate to cover the range and frequency of allied health visits required to support optimal care.

### 4.2 Workforce issues

The most significant barrier to best-practice treatment of JIA in Australia is the shortage of specialist paediatric rheumatologists and appropriately skilled allied health professionals to support multidisciplinary care.

A 2012 survey identified 13 paediatric rheumatologists in Australia, working six full-time equivalents (FTE) in clinical rheumatology, with approximately 3.4 FTE in public hospitals.<sup>89</sup> Three or four paediatric rheumatologists plan to retire over the next five years. Some states/territories have no paediatric rheumatologists.

International guidelines recommend having one paediatric rheumatologist per paediatric population of 300,000 to 500,000, just for clinical care, with more required for additional work, such as teaching and research. Based on international guidelines, 10 to 17 FTE

paediatric rheumatologists would be a more appropriate number to meet the clinical needs of children around Australia with JIA and other rheumatic conditions.<sup>89</sup>

Currently, there are only three paediatric rheumatology trainees in Australia and just two accredited training centres.<sup>90</sup> Nor is there any dedicated funding for paediatric rheumatology training, which is a major disincentive for physicians seeking to specialise in the field.

Limited access to paediatric rheumatologists increases delays in achieving accurate diagnoses and in initiating the early treatment that is critical to good outcomes. Furthermore, it results in children and young people with JIA being managed by other health practitioners, such as general paediatricians, orthopaedic surgeons and adult rheumatologists, who are not optimally trained to deliver best-practice care for JIA, risking inadequate or inappropriate treatment and poor outcomes. Management by other health practitioners also limits access to bDMARDs, as only rheumatologists and clinical immunologists are authorised to prescribe bDMARDs on the PBS.

In addition to restricting access to appropriate clinical care for JIA, the shortage of paediatric rheumatologists limits capacity for providing teaching, education and research in the field, narrowing the scope for quality treatment, improvements in care, and the timely delivery of services.

### Increase the supply of paediatric rheumatologists

Expanding the paediatric rheumatology workforce is critical if Australia is to address the current problems with access to appropriate care, although this is likely to take some years.

Dedicated funding for a training position in paediatric rheumatology is an essential first step. There is also scope to expand training options for paediatric rheumatology in the private sector through the Specialist Training Program<sup>91</sup> as, in Australia, the case mix in private and public paediatric rheumatology clinics has been shown to be similar.<sup>92</sup>



## Upskill other medical practitioners

Often, children with JIA are cared for by health practitioners other than paediatric rheumatologists, including adult rheumatologists and paediatricians. There is scope to develop education and training programs for upskilling these practitioners so they're equipped to provide appropriate care for children and young people with JIA, either on a shared care basis with paediatric rheumatologists or as an equivalent qualification.

Paediatric rheumatology could be included as a component of existing training programs for adult rheumatologists and/or paediatricians, or could be offered as a separate module. Innovative models for delivering training, including online modules, could help upskill practitioners in rural, remote and other underserved areas.

There is also scope to upskill GPs and allied health practitioners, enabling them to provide shared care for children and adolescents with JIA in underserved areas, reducing the frequency of travel required to attend specialised paediatric rheumatology clinics. Telehealth services could be a valuable support to this model.

## Build allied health workforce capacity

There is a dearth of allied health practitioners with the skills to work as part of multidisciplinary teams in the management of JIA, especially in the community sector. Increasing students' exposure to paediatric rheumatology during medical training, and developing education and training programs targeted at specific practitioner groups, would help to address this skills shortfall.

## Increase the use of rheumatology nurses

Paediatric rheumatology nurses have a central role in providing comprehensive, coordinated multidisciplinary care, as well as education and psychosocial support to children and their families, liaising with other services (e.g. schools) and helping JIA patients prepare for transition to adult services.<sup>2,6,93</sup> In some centres, a paediatric rheumatology nurse provides care across inpatient and outpatient settings and through a telephone/email advice service, as well as being involved in research.<sup>6</sup>

Internationally, advanced-practice nurses and nurse practitioners are playing increasingly key roles in delivering rheumatology care and services.<sup>94,95</sup> An extension of the scope of practice for the paediatric rheumatology nurse at the Royal Children's Hospital in Melbourne has been proposed to allow innovative, flexible delivery of care to children and adolescents with JIA (see Models of care). As yet, however, there has been no progress in implementing this model.

In Australia, access to paediatric rheumatology nurses is limited. In 2011, there were only 2.7 FTE publicly funded nursing positions for paediatric rheumatology in tertiary hospitals.<sup>5</sup>

There is substantial scope to develop the existing rheumatology nursing workforce so as to provide improved care for children and adolescents with JIA, and to support paediatric rheumatologists, freeing them to focus on patient care. An appropriately skilled nursing workforce could also support the delivery of services in currently underserved areas. The recent development of an online Graduate Certificate in Musculoskeletal and Rheumatology Nursing, which has been available through the Australian College of Nursing since 2012, will assist in building this workforce.

## 4.3 Services in regional and rural areas

Issues of limited access to specialist and multidisciplinary paediatric rheumatology services are exacerbated in rural and regional areas, and in states and territories in which there are no paediatric rheumatologists. Some limited outreach paediatric rheumatology clinics are conducted in rural and regional areas, but these are not supported by funded multidisciplinary services.

As a result, people in underserved areas face the added stress and costs of needing to travel long distances to receive appropriate care – or go without.

Reviews of outreach specialist services are scarce but have generally been positive with regard to overall effectiveness and cost-effectiveness. In addition to improving access to specialists in rural and remote areas, the benefits of outreach services include upskilling local primary care practitioners, improving continuity in patient management and reducing costs to patients, their families and the health system through a reduction of the travel time needed to access specialist JIA care.<sup>96</sup>

An extension of the existing outreach paediatric rheumatology clinics, including multidisciplinary providers, through a hub-and-spoke model, is a feasible option for improving clinical services in areas that are currently underserved. In addition, outreach clinics help to establish professional networks and upskill local health practitioners in relation to JIA and its management. The Australian Rural Rheumatology Service, an outreach model combining clinical care and education services in rheumatology, is being piloted in the New England Medicare Local Region; if successful, it could provide a blueprint for services delivery for JIA. However, workforce constraints are likely to limit the range of outreach services that could be provided in the short term.



## 4. Australian health care environment

Telehealth services are considered viable for rheumatology<sup>97,98</sup> and offer great potential to increase access to paediatric rheumatologists and multidisciplinary teams by people in underserved areas. In the Australian context, telehealth services (including paediatric services) have been reported to improve access to and quality of care for patients, support local professional development, and be cost-effective and acceptable to patients and clinicians.<sup>99,100</sup> Dedicated local support and training would be required to maximise the benefits of this model. Such support could be provided by GPs and/or rheumatology nurses, who could provide assistance with medication monitoring, patient education and engagement with other local health care providers, for JIA and for other inflammatory forms of arthritis.

As some states/territories have no paediatric rheumatology services, models of cross-border provision of outreach/telehealth services need to be developed.

Developing more efficient, better-coordinated referral pathways to existing paediatric rheumatology services – for example, by establishing national or state-based networks – may also help to reduce delays and unnecessary travel for children with JIA and their families.

### 4.4 Disadvantaged groups

Special attention needs to be given to the needs of culturally and linguistically diverse (CALD) and other disadvantaged groups, including those with low health literacy. Information resources should be made available in a range of languages, and the potential need for greater assistance with care coordination and support should be recognised. A culturally matched peer support program should also be considered.

### Opportunities for improvement – Australian health care environment

- Work with Medicare Locals to improve access to multidisciplinary services for JIA management
  - Assess and plan for local needs
  - Provide a locus for multidisciplinary clinics and for telehealth and outreach services
  - Develop local referral pathways
- Increase funding for allied health services in the public sector
- Increase the number of annual Medicare-subsidised allied health visits allowed per patient under Chronic Disease Management items and extend them to include referrals to allied health professionals by specialists and consultant physicians
- Build workforce capacity to provide best-care management of JIA
  - Provide dedicated funding for training paediatric rheumatologists in JIA management
  - Provide training and education programs to upskill other medical practitioners, such as adult rheumatologists and paediatricians
  - Develop education and training programs to upskill allied health practitioners
  - Build a cadre of rheumatology nurses to support JIA management and provide education, psychosocial support and coordination of care for patients and their families
- Provide outreach and telehealth services that combine clinical care and education components to rural, remote and other underserved areas
- Develop resources and programs to target CALD and other disadvantaged groups, including culturally matched peer support programs



## 5. Existing models of care

Currently, two models of care developed in Australia specifically address the provision of care for JIA. In addition, the WA Model of Care for Inflammatory Arthritis is relevant to the provision of services for JIA as well as other juvenile and adult forms of inflammatory arthritis. These models of care align well with international standards of care for JIA and have formed the basis for the national model of care recommendations.

### 5.1 Paediatric Rheumatology Best Practice Model of Care, Royal Children's Hospital, Melbourne

The paediatric rheumatology model of care that operates through the Royal Children's Hospital is outlined in Figure 2.<sup>101</sup>

The model comprises the following key components:

- a best-practice model that is child-centred and family-focused; and
- services, delivered in a coordinated manner by a multidisciplinary team, that encompass:
  - disease management and physical therapy;
  - patient and family education and self-management;
  - psychosocial support and intervention; and
  - community liaison.

Implementing this model has enhanced dedicated paediatric rheumatology services, providing coordinated multidisciplinary care by appropriately skilled practitioners.

Formal assessment of the model has shown improvements in clinical care and care coordination, greater knowledge of the disease and its management by children and parents, and reduced delays in the initiation of appropriate treatment.<sup>5</sup>

A new model of care for paediatric rheumatology nursing has also been proposed, although to date, there has been no progress in its implementation. Under the proposed model, paediatric rheumatology nurses would progress to nurse practitioners whose role would include disease management and advanced clinical assessment, with authority to order radiology, pathology, prescriptions and referrals. Nurse practitioners would be able to practice autonomously, for children and adolescents treated with NSAIDs or in clinical remission, and to co-manage with paediatric rheumatologists in more complex cases.<sup>6</sup>

**Figure 2: Paediatric Rheumatology Best Practice Model of Care, Royal Children's Hospital, Melbourne**



### 5.2 NSW Paediatric Rheumatology Network

This model was released in May 2013<sup>5</sup> and has yet to be implemented.

The model aligns with international best practice and is based on the establishment of a tertiary centre of excellence linked to a statewide network of collaborative partnerships with other stakeholders, including tertiary paediatric services, local health districts, GPs, Medicare Locals, Local Health Districts and consumer organisations.

The centre of excellence would provide a single point of access and a one-stop shop for coordinated clinical care from a multidisciplinary team, and would also have the education and training resources required to build workforce capacity. Expanded services, coordinated from the tertiary centre and based on a hub-and-spoke pattern, would include outreach services, a virtual ward and satellite services, with a strong emphasis on engaging local services.

The proposed model is similar to the existing Victorian model, but goes further by proposing the establishment of a statewide paediatric rheumatology network.



## 5. Existing models of care

### 5.3 WA inflammatory arthritis model of care

The WA Model of Care for Inflammatory Arthritis<sup>8</sup> addresses care for a range of adult forms of inflammatory arthritis as well as JIA.

It makes a number of recommendations to support:

- early diagnosis and intervention, including early synovitis clinics to expedite diagnosis referral and treatment;
- improved management, including:
  - consumer education, advice and self management tools;
  - improved access to multidisciplinary care;
  - the development of transition pathways and protocols for adolescents moving from paediatric to adult rheumatology;
  - improved monitoring of disease activity, and effectiveness and side effects of DMARD treatment;
- workforce professional development and education, including training for rheumatology nurses, extended-scope allied health practitioners and chronic disease-management teams; and
- rural rheumatology clinics and telehealth services for rural areas.

## 6. Stakeholder consultations

A series of stakeholder consultations was held across Australia, including people with arthritis, carers, medical practitioners, nurses, allied health workers and researchers, to identify key issues and priorities to be addressed as part of the Time to Move: Arthritis strategy. These consultations were hosted by state and territory arthritis organisations and were held in the capital cities of each state and territory.

Several key issues were raised in relation to JIA:

- the need to increase community, GP and policymaker awareness of JIA;
- delays in diagnosis and referral/access to paediatric rheumatologists;
- lack of access to paediatric rheumatologists, specialist allied health professionals and multidisciplinary care, especially in some states/territories and in regional areas;
- inequity of access to services generally, and particularly to publicly funded services;
- the need for better coordination of care – including ‘one-stop shop’ multidisciplinary clinics;
- restrictions on access to biologics: “...children have to go through the process and suffer side effects and misery to get access to the needed medication”;
- lack of a planned transition process for adolescents moving from paediatric to adult health care services;
- the importance of psychosocial support for children and young people with JIA and their family members, including access to psychological services, and peer support;
- recognition of the financial burden on families of children and young people with JIA; and
- the need to increase understanding of JIA for those interacting with affected children, such as teachers, school nurses, sports coaches and the school community.

A number of solutions were suggested:

- conduct community awareness-raising campaigns;
- increase the number of paediatric rheumatologists;
- educate/train GPs and allied health professionals to better recognise JIA;
- establish standardised referral pathways to paediatric rheumatologists and other appropriately skilled practitioners;
- improve access to coordinated multidisciplinary care, including by establishing centres of excellence/one-stop multidisciplinary clinics;
- establish hub-and-spoke arrangements extending out from specialist paediatric rheumatology centres to underserved areas, including outreach clinics and telehealth services;
- develop services to cater for adolescents with JIA, including support for the transition to adult services and improved peer support;
- improve information and support for children and young people with JIA and their families, including greater psychological support for parents; and
- improve the information on JIA that is provided to school communities, including students, teachers, school nurses, coaches and PE teachers.



## 7. Conclusions

There is substantial scope for delivering improved and more equitable care to children and young people with JIA in Australia, in line with international best practice.

The objectives of the national model of care will be to deliver the following key elements of care to children and young people with JIA:

- early diagnosis and referral to a paediatric rheumatologist for initiation of appropriate treatment, as soon as possible and ideally within 10 weeks of symptom onset;
- access to integrated, coordinated multidisciplinary team care by appropriately skilled practitioners led by a paediatric rheumatologist, for the development and implementation of an individualised care plan;
- age-appropriate, culturally sensitive information, education and support for self-management;
- better coordination of care and psychosocial support for children and young people with JIA and their families;
- equitable access to appropriate, evidence-based pharmacological and non-pharmacological treatment;
- effective ongoing management, including the monitoring of drug compliance, toxicity, safety and side effects, and managing complications and comorbidities; and
- planned and managed transition from paediatric to adult health services commencing in early adolescence.

## 8. Recommendations

### 1. Develop and implement strategies to increase awareness and understanding of JIA, and of the importance of early diagnosis and treatment, by the public, health practitioners and policymakers

### 2. Support early diagnosis of children with JIA and urgent referral to paediatric rheumatologists for prompt initiation of therapy

- 2.1 Utilise existing telephone hotlines/website booking services (e.g. HealthDirect, HealthEngine) to facilitate urgent referrals to paediatric rheumatologists for early diagnosis and treatment
- 2.2 Support improved education of health care professionals in paediatric musculoskeletal conditions, to promote early diagnosis and treatment of children with JIA
- 2.3 Conduct early arthritis clinics in underserved areas to provide triage and improve early access to specialist care

### 3. Provide equitable and timely access to individualised, coordinated multidisciplinary team care by appropriately skilled practitioners led by a paediatric rheumatologist

- 3.1 Establish comprehensive centres of excellence in paediatric rheumatology in major centres across Australia, to provide best-practice multidisciplinary care and support education and training for health professionals in the field. Core members of the multidisciplinary team should include a paediatric rheumatologist, a paediatric rheumatology nurse, a physiotherapist, an occupational therapist, a psychologist and a social worker.
- 3.2 Develop multidisciplinary clinical networks at regional/state levels to link service providers and provide training and support
- 3.3 Establish community-based multidisciplinary clinics/teams providing public and private services, in collaboration with Medicare Locals and other stakeholders
- 3.4 Develop system incentives/funding models to support the delivery of multidisciplinary care in the private sector, including increased access to Medicare-subsidised allied health visits under Chronic Disease Management items, in line with clinical requirements



- 3.5 Provide services in rural and other underserved areas through outreach clinics and/or telehealth services that include clinical and educational components

#### **4. Improve age-appropriate and culturally suitable information, education, coordination of care and psychosocial support to children and young people with JIA and their families**

- 4.1 Utilise rheumatology nurses and other allied health professionals as part of multidisciplinary teams providing patient information, education, and self-management support, psychosocial support and coordination of care
- 4.2 Develop a comprehensive information package and tools for parents and families of children and adolescents newly diagnosed with JIA to help them understand the condition and its treatment, navigate their way around available services and supports, and coordinate their care
- 4.3 Develop national age-appropriate resources and tools for adolescents with JIA
- 4.4 Develop JIA resources for schools and childcare centres
- 4.5 Refer children and young people newly diagnosed with JIA and their families to arthritis organisations in their state or territory for access to information resources, self-management education, support groups and activities such as kids camps.

#### **5. Optimise pharmacological treatment for JIA**

- 5.1 Review existing restrictions on PBS access to biologic DMARDs to ensure they allow appropriate, timely, evidence-based access to these therapies for those who would benefit from them
- 5.2 Streamline the application process for access to biologic DMARDs through the PBS
- 5.3 Develop information materials to support effective medication management by other health professionals providing care for children and young people with JIA

#### **6. Improve transition planning and care for young people with JIA moving to adult services, commencing in early adolescence**

- 6.1 Identify key principles to guide the development of transition services for young people with JIA
- 6.2 Develop resources to support young people, parents and health professionals prepare for transition, including resources for early, middle and late adolescence
- 6.3 Provide coordinators to manage transitional care

#### **7. Build workforce capacity to support early diagnosis and effective treatment for children and young people with JIA**

- 7.1 Provide dedicated funding for training paediatric rheumatologists
- 7.2 Build a cadre of rheumatology nurses/nurse practitioners to support JIA management, including in rural and remote regions and other underserved areas
- 7.3 Develop information and education materials programs and tools for GPs, paediatricians, orthopaedic surgeons, nurses and allied health practitioners, including pharmacists, to support the early diagnosis and effective management of children and young people with JIA
- 7.4 Develop or use existing online tools (e.g. Health Pathways, Map of Medicine) to provide an information portal, enabling easy access by GPs and other health practitioners to information about JIA diagnosis and management, and clear referral pathways, as well as a guide to local services and resources



## 9. Priorities and implementation

The following priority areas for implementation have been identified by the Steering Committee as offering the greatest scope for reducing the burden of JIA and being the most feasible in the short term:

- strategies to support early diagnosis and urgent referral to paediatric rheumatologists;
- provision of equitable access to specialist services and multidisciplinary care;
- improved transition planning and care; and
- dedicated funding for paediatric rheumatology training.

Implementation of these recommendations will require collaboration between stakeholders across all sectors of the health system, as well as the education and disability sectors. Arthritis Australia will work with relevant stakeholders to encourage and support the implementation of the Time to Move strategy.

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