May 2024

Australian Paediatric Rheumatology Group (APRG)
2023 Updated Standards of Care for children and young people with Juvenile Idiopathic Arthritis

GUIDING PRINCIPLES

1. Children and young people with Juvenile Idiopathic Arthritis (JIA), including those in regional, rural and remote areas, have access to health services that are safe, effective, timely, efficient, co-ordinated, person-centred, accessible and equitable.

2. Care for children and young people with JIA addresses the evolving physical, emotional, social, developmental, educational and vocational needs of each child and young person, as well as the impact of JIA on their families.

3. Care for children and young people with JIA must be culturally safe and free from racism, discrimination and prejudice.

4. Treatment goals and therapeutic strategy for each child and young person with JIA are based on shared decision-making between the child and young person, their carer(s) and the paediatric rheumatology healthcare team in response to the child and young person's preferences, needs and values.

5. Paediatric Rheumatology Service (PRS) are adequately funded to provide healthcare, undertake continuing education and professional development and to participate in research and quality improvement initiatives.

6. PRS undertake to improve outcomes in populations known to be at risk of poor health outcomes including, but not limited to, Aboriginal and Torres Strait Islander people, those living regional and rurally in Australia, those who are Culturally and Linguistically Diverse (CALD), refugee populations, Lesbian, Gay, Bisexual, Trans, Intersex, Queer (LGBTIQ+), and those living with disability.

QUALITY STATEMENTS

DOMAIN 1: EARLY CARE

1. Healthcare professionals who are likely to encounter children and young people with JIA have the appropriate knowledge and clinical skills to recognise JIA and facilitate prompt referral to a PRS.
2. Where there is a strong clinical suspicion of JIA, a child and young person is seen by a PRS within 30 days of initial referral.
3. Children and young people with JIA have access to an appropriately skilled specialist paediatric rheumatology multidisciplinary team (MDT) (see Table 1). The structure of the MDT will vary depending on local arrangements and referral will depend on clinical need.
4. Children and young people with JIA and their families receive appropriate information and education from their PRS within 2 weeks of diagnosis.
5. Children and young people with JIA and their families are adequately informed about expected benefits and potential risks prior to commencing any new disease modifying therapy.
6. Children and young people with JIA have access to support and educational resources for childcare settings, schools, colleges and other educational / vocational institutions.
7. Where clinically indicated children and young people with JIA have access to paediatric rheumatology allied health care services within 30 days of referral to that service.
8. Children and young people with JIA have timely access to necessary investigations as determined by their treating clinician(s).
9. A written care plan (e.g. a letter documenting the clinic outcome) is communicated to families, referring doctor, GP and other HCP involved in the child and young person's care within 2 weeks of diagnosis.
10. Children and young people with JIA have timely access to treatment options, specifically:
    a. Corticosteroid joint injections including appropriate analgesia, sedation and/or anaesthesia within 4 weeks of recognising the need for this procedure;
    b. Paediatric infusion centre within 2 weeks of prescription of an intravenous infusion;
    c. Disease Modifying Anti-Rheumatic Drugs (DMARDs) and other pharmacological therapy in line with currently accepted best practice and contemporary guidelines.

TABLE 1: Composition of the paediatric rheumatology multidisciplinary team (MDT)

- Paediatric rheumatologist
- Paediatric rheumatology advanced practice nurse
- Paediatric rheumatology physiotherapist
- Ophthalmology / eye care service
- General Practitioner
- Paediatric rheumatology occupational therapist
- Psychology and/or other mental health professionals
- Administrative support
- Interpreters and cultural support workers
- Pharmacist
- Radiologist

The MDT may also include other health practitioners:

- Social work
- Child life therapy
- Podiatry / orthotics
- Dietetics
- Pain specialist
- Aboriginal and Torres Strait Islander Health Practitioner
- Exercise physiologists

DOMAIN 2: ONGOING MANAGEMENT

11. Children and young people with JIA have timely access to review appointments in line with the clinical decisions of their treating team.
12. Children and young people with JIA and their families have access to ongoing disease and treatment education tailored to their individual requirements throughout the evolving stages of their care.
13. Children and young people with JIA have a clear and reliable pathway for accessing advice and support from their specialist team between scheduled appointments.
14. Children and young people with JIA have access to pharmacological and non-pharmacological pain management options for the prevention and management of acute flare related pain, procedural pain and chronic pain.
15. Children and young people and their families have access to an individualised plan for transition to adult care prior to transfer to adult services.

DOMAIN 3: EYE HEALTH

16. Children and young people with JIA are screened for uveitis by a specialist eye service within 6 weeks of referral for eye screening.
17. Where symptoms or signs of eye disease are present, the child and young person is assessed by a specialist eye service within 1 week.
18. Children and young people with JIA have access to ongoing uveitis screening as determined by contemporary clinical practice guidelines.

DOMAIN 4: WORKFORCE

19. Healthcare services ensure public workforce is provided, at a minimum, in line with the following ratios:
    - 1 Full Time Equivalent (FTE) paediatric rheumatologist per 200,000 children
    - 1 FTE paediatric rheumatology advanced practice nurse per 200,000 children
    - 1 FTE paediatric rheumatology physiotherapist per 200,000 children

    and pro-rata for small populations, which may be achieved through links with larger PRS as appropriate.

DOMAIN 5: WELLBEING

20. Children and young people and their families have access to appropriate emotional, psychosocial and mental health support in accordance with their evolving needs.
21. Children and young people with JIA are supported to participate in all domains of daily life including educational, vocational, sporting, leisure, community and self-care activities in accordance with their capabilities and interests.
22. The specific healthcare needs of adolescents and young adults with JIA including contraception and risk-taking behaviours are addressed and referred as appropriate.

DOMAIN 6: CARE EXCELLENCE

23. Children and young people with JIA are given the opportunity to participate in research, which may include clinical trials and/or biobanking.
24. Children and young people with JIA are given the opportunity to participate in a national JIA registry.
25. PRS have a program of local and national audit and quality improvement, including audit against these Quality Standards.
26. Each member of the MDT has dedicated non-clinical time to undertake research, teaching, professional development, advocacy and/or quality improvement.
27. PRS partner with children and young people and their families in service development and quality improvement processes.

DOMAIN 7: PRIORITY POPULATIONS

28. PRS work in partnership with Aboriginal and Torres Strait Islander families, communities and healthcare services to ensure that care and support is provided in a culturally appropriate manner.
29. Children and young people with JIA from priority populations and their families, as required, have access to support services including liaison officers, interpreters, social workers, care coordinators and any other supports necessary to facilitate equitable healthcare.
30. PRS provide support to children and young people with JIA living in rural, regional and remote areas through clinical care networks, outreach clinics and the use of virtual technologies.