From the Chief Medical Officer
Professor Sir Michael McBride

Department of Health
An Roinn Sláinte
Männystrie O Poustie
www.health-ni.gov.uk

HSS(MD) 31/2026

For Action by:

Chief Executives, HSC Trusts for cascade to:
Medical Directors
Directors of Acute Hospital Services
Directors of Nursing
Governance Leads
Chief Executive, PHA
Chief Operating Officer, SPPG for cascade to:
General practices
Chief Executive, NIMDTA
Chief Executive, RQIA

Castle Buildings
Stormont Estate
Belfast BT4 3SQ

Tel:
Email: cmooffice@health-ni.gov.uk
Our Ref: HSS(MD) 31/2026
Date: 28 July 2026

For Information to: see full distribution list overleaf

Dear Colleagues

NCEPOD REPORT: Joint Care? A review of the quality of care provided to children and young adults with juvenile idiopathic arthritis

On the 13 February 2025, the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) published its report 'Joint Care?' available here: Full report_JIA_Joint Care.pdf The report is based on a review of the care of children and young adults presenting to hospital with a diagnosis of juvenile idiopathic arthritis across England, Wales and Northern Ireland.

The aim of the report is to identify priority areas for improvement in the treatment pathway of patients with juvenile idiopathic arthritis. A summary of the key messages and recommendations are set out in **Annexes 1 and 2.**

ACTION

Chief Executives of HSC Trusts should:

- Consider the key findings and recommendations set out in this report and bring these to the attention of relevant staff to further inform service improvements and developments in your organisation.

Chief Operating Officer, of Strategic Performance and Planning Group should:

- Disseminate this letter to all relevant staff to further inform commissioning and improvement of services.

- Report on the required actions through the established arrangements of the "SPPG Overarching Comprehensive Report on SPPG Safety and Quality Processes."

Chief Executive Officer PHA should:

- Disseminate this circular to all relevant PHA staff.

- Ensure relevant professionals work with colleagues in SPPG to further develop and inform commissioning and service improvements.

Chief Executive, RQIA should:

- Disseminate this letter to all relevant Independent Sector providers.

Chief Executive, NIMDTA should:

- Disseminate this letter to doctors in training in all relevant specialties.

Please thoroughly consider this Report and action in line with the above, to further inform service improvements and developments in your organisation and across the HSC system.

Kind regards

Professor Sir Michael McBride
Chief Medical Officer

For Information to:

Executive Medical Director/Director of Public Health, PHA
Director of Nursing & AHPs, PHA
Safety and Quality, PHA
Director of Performance Management, SPPG
Safety and Quality Alerts, SPPG
Donna Britton, SPPG
Cara Toner, SPPG
Paula Tweedie, SPPG
Prof Kenda Crozier, Head of School of Nursing & Midwifery, QUB
Prof Pascal McKeown, Head of Medical School, QUB
Andrea Shepherd, Head of School of Nursing, UU
Prof Peter Bazira, Head of Medical School, UU
Post Graduate Dean, NIMDTA
Staff Tutor of Nursing, Open University

Annex 1

Key Messages – Joint Care? A review of the quality of care provided to children and young adults with juvenile idiopathic arthritis

- **Raise awareness of JIA and its symptoms with those who might see patients.**

  Better recognition would encourage faster referral to rheumatology which may prevent joint damage.

  23/101 (22.8%) of GP practices reported having protocols for the investigation and care of patients with suspected JIA. 20/54 (37.0%) of parents/carers felt that they were not taken seriously by the GP during the consultation.

- **Streamline your local referral pathway, with clear timelines for patients with suspected JIA.**

  Pathways exist but vary between hospitals. It is not always clear who is involved, leading to incorrect referrals.

  The most common reason for delay in being seen by a rheumatologist was initial referral to the wrong speciality. 71/266 (26.7%) of patients had a delay in assessment by a rheumatologist. Only 12/58 (20.7%) of patients were referred directly to a rheumatologist.

- **Provide prompt training to patients/parents/carers on how to inject medications for JIA.**

  Patients/parents/carers do not always get trained to administer methotrexate, which can lead to a delay to treatment starting. 22/118 (18.6%) of patients and parents/carers had no evidence of being trained in how to give methotrexate injections. 26/298 (8.7%) of patients had inappropriate medications given while patients and parents/carers waited for training on how to give injections.

- **Ensure ongoing access to physiotherapy, occupational therapy, pain and psychology services**

  Many patients have JIA as adults and so equivalent access to care needs to exist from diagnosis through to adulthood.

  193/290 (66.6%) of patients saw a physiotherapist – 54 not seen should have. 62/290 (21.4%) of patients saw an occupational therapist – 67 not seen should have. There was a trend towards less involvement of physiotherapy, occupational therapy and psychology from paediatrics into adulthood.

- **Provide a holistic, developmentally appropriate rheumatology service for patients with JIA.**

  Being diagnosed with JIA at a young age, impacts all aspects of well being and education, which is not always addressed. Only 48/101 (47.5%) of adolescent clinics were in an age-appropriate environment. Being seen out of school hours was reported for 2/114 (1.8%) of patients. Only 114/262 (43.5%) of patients had their holistic health supported. Signposting to peer support decreased with age.

No	Recommendation	Target audience
1	**Raise awareness of juvenile idiopathic arthritis and its symptoms with the healthcare professionals who will see this group of patients.** • Painful, swollen or stiff joint(s) • A fever that keeps returning • Joint(s) that are warm to touch • A limp but no injury • Increased tiredness Patients were not being referred to rheumatology services early enough. There was an absence of standardised protocols for treating juvenile idiopathic arthritis (JIA). There was also a lack of opportunity for continuing professional development in this disease.	Royal College of General Practitioners, Royal College of Paediatrics and Child Health, Royal College of Physicians, British Society for Children's Orthopaedic Surgery, British Orthopaedic Association, Royal College of Ophthalmologists and Royal College of Emergency Medicine, Getting it Right First Time Supported by: Musculoskeletal leads with a responsibility for children and young people working with integrated care boards, commissioners, executive boards, NHS England, Welsh Government, Department of Health Northern Ireland, Government of Jersey.
2	**Streamline and publicise local referral pathways with clear measurable timelines for patients with suspected juvenile idiopathic arthritis.** Ensure that this includes: • The ability to refer patients with suspected JIA directly from primary care to a secondary/tertiary care rheumatology service where a diagnosis can be made and ongoing care provided • Access to advice from rheumatology services regarding the need for/appropriateness of investigations at the time of referral • Agreed referral pathways within secondary care from specialties such as orthopaedics and emergency medicine to age-appropriate rheumatology services • Agreed referral pathways from rheumatology services to ophthalmology clinics (including same day/combined clinics) with clear standards for referral and follow-up timeframes • Direct access to age-appropriate services if the patient should have a disease flare or other urgent disease-related issue.	Medical Directors and healthcare professionals treating patients with JIA. Supported by: Integrated care boards, commissioners, executive boards, Getting It Right First Time

No	Recommendation	Target audience
	Clearer lines of referral are needed to ensure that treatment starts promptly and that all necessary multidisciplinary input is arranged. Discussion amongst the clinical groups involved in the study showed that getting referred to rheumatology quickly was often based on luck, with many clinicians reflecting on how parents had to advocate for their child based on their own research or after multiple visits to their GP. This recommendation aims to reduce healthcare inequalities; consideration needs to be given to the populations accessing the services, distance travelled, and costs involved as well as seldom heard and 'at risk' groups.	
3	**Provide timely access to appropriately trained physiotherapy, occupational therapy, pain and psychology services at the diagnosis of juvenile idiopathic arthritis, and then as needed through adolescence and adulthood.** There was a decline in access to these services as the young person moved to adulthood, however it shouldbe noted that many patients have JIA as adults and so equivalent access to care needs to exist.	Medical directors and healthcare professionals treating patients with JIA. Supported by: Integrated care boards, commissioners, executive boards, Getting It Right First Time
4	**Offer age-appropriate information about juvenile idiopathic arthritis and medication risks and benefits to patients and their parents/carers at diagnosis and on an ongoing basis.** Improving understanding and empowering patients and their carers to be involved in making informed decisions about their management will reduce unnecessary delays in starting a treatment due to patient/carer concerns and improve subsequent adherence and ensure treatment starts promptly and continues effectively. Ongoing education and training should be accessible to all patients and carers, and provided in developmentally appropriate formats, and departments. Both online and physical resources are still very important to patients and families.	Healthcare professionals treating patients with JIA

No	Recommendation	Target audience
5	**Provide training to the patient, if age-appropriate, and/or their parents/carers on how to administer subcutaneous injections for juvenile idiopathic arthritis at the point treatment is initiated.** There were delays to treatment starting as a lack of training meant the medication could not be administered.	Healthcare professionals responsible for training on administration of medications for JIA Supported by: Integrated care boards, commissioners, executive boards, Getting It Right First Time
6	**Ensure timely access to intra-articular steroid injections by staff who have been trained to deliver age-appropriate care in units where local or general anaesthesia can be delivered.** Access to medical treatments and home care service should be equitable and not subject to social determinants of health or distance to travel to appointments. Patients needing intra-articular joint injections required a general anaesthetic but could often not access theatre lists.	Integrated care boards, commissioners, medical directors and healthcare professionals treating patients with JIA. Supported by: Orthopaedic surgeons, anaesthetists, theatre booking staff
7	**Provide a holistic, developmentally appropriate rheumatology service for patients with juvenile idiopathic arthritis.**	Medical directors and healthcare professionals treating patients with JIA. Supported by: Integrated care boards, commissioners, executive boards, Getting It Right First Time
8	**Develop NICE guidance for the management of juvenile idiopathic arthritis.** There are no standard national guidelines for juvenile idiopathic arthritis. Many hospitals have their own pathway but there is no overarching standardisation.	National Institute of Health and Care Excellence