



Scottish Paediatric and Adolescent Rheumatology Network (SPARN)

Annual Report 2024/25

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Lead Clinician: Neil Martin
Programme Manager: Jamie Nimmo
Programme Support Officer: Kirsty Young

1. Introduction

The aim of the Scottish Paediatric & Adolescent Rheumatology Network (SPARN) is to ensure that all children with rheumatological conditions in Scotland are diagnosed promptly and managed appropriately. Since its designation in 2009, the network has facilitated local delivery of specialist care. This means that children and their families no longer have to travel to tertiary centres to receive the care they need. Network clinics have been established in all health board areas and these are supported by local multidisciplinary teams including Nurse Specialists, Physiotherapists and Occupational Therapists. The network structure enables teams to work together across specialty and health board boundaries and develop flexible solutions to support local need.

To further support local delivery of care, the network has developed paediatric rheumatology service guidance, a suite of clinical guidelines and an education programme to facilitate sharing knowledge and expertise. The network ensures that the care delivered in each clinic meets agreed national standards and supports services to improve care through continuous quality improvement.

2. Current Position

The network achieved 14/14 (100%) of its 'Business as Usual' objectives and 3/3 (100%) of its 'Service Development Plan' priority objectives in 2024/25. It was anticipated that the network would be working on a three-to-five-year workplan, however, this was paused given the circumstances.

Dr Neil Martin's (Paediatric Rheumatologist, NHS Greater Glasgow and Clyde) tenure as Lead Clinician ended in March 2024. Dr Martin has continued to provide clinical leadership to the network throughout 2024/25 without a dedicated clinical session, ensuring continuity of activity while formal recruitment is aligned with national review outcomes.

In light of the ongoing Scottish Government review of national networks, planning has been adapted to focus on core priorities and ensure continuity of essential services. We await further guidance to inform future strategic development.

SPARN prioritised the continuation of the monthly education sessions, the development of a new service map for Scotland and the continued development of quality performance indicators (QPIs) and a Power BI dashboard that will benefit Clinical Audit System (CAS) users.

A Terms of Reference for the network replaced the service level agreement and covered the 2024/25 period.

3. Highlights

3.1 Effective Network Structure and Governance

Steering Group and Subgroups

The network Steering Group has remained active and has continued to be chaired by Dr Mary Brennan (Consultant Paediatric Rheumatologist, NHS Lothian).

3.2 Service Development and Delivery

Clinical Guidelines

Several clinical guidelines were due for review in 2024/25. A thorough refresh was done of the clinical guideline tracker to bring the information right up to date. The guidelines that were due for review have all been through the review process, however, new requirements have meant that additional sections have had to be added, which has delayed getting them back onto the SPARN website. Given that the content has been approved up until this point, it is anticipated that all of them will be back on the website in May 2025.

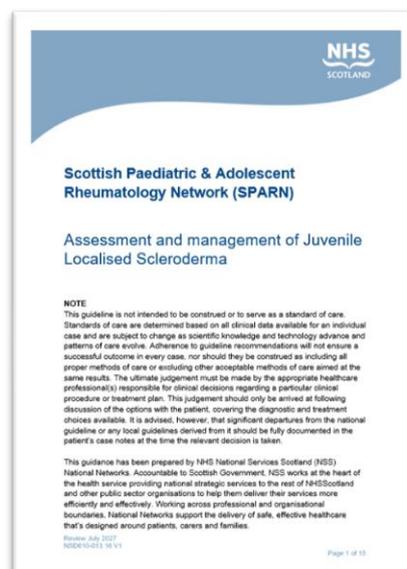


Image 1: Example of SPARN Clinical Guideline

The guidelines and pathways that have been reviewed in 2024/25 are as follows:

- Kawasaki
- The use of Janus Kinase Inhibitors (JAKi): Tofacitinib, Baricitinib, Ruxolitinib
- Assessment and management of Juvenile Localised Scleroderma
- Rituximab use
- Methylprednisolone use
- Chickenpox pathway
- Bisphosphonates
- Tocilizumab for rheumatology patients (for ward nursing staff)
- Tocilizumab for rheumatology patients (for rheumatology specialists)

Service Mapping in Scotland

A priority for SPARN this year has been to update the service map of paediatric rheumatology services available throughout Scotland. For each health board providing paediatric rheumatology services, this includes: network clinic sessions per annum, dedicated paediatric rheumatology clinics per month and personnel in place.

The service map will be made available on the SPARN website, which will allow anyone with an interest to identify what support and services are available where. The service directory should also be used to identify any inequity of access in Scotland, leading to quality improvement work for the network going forward.

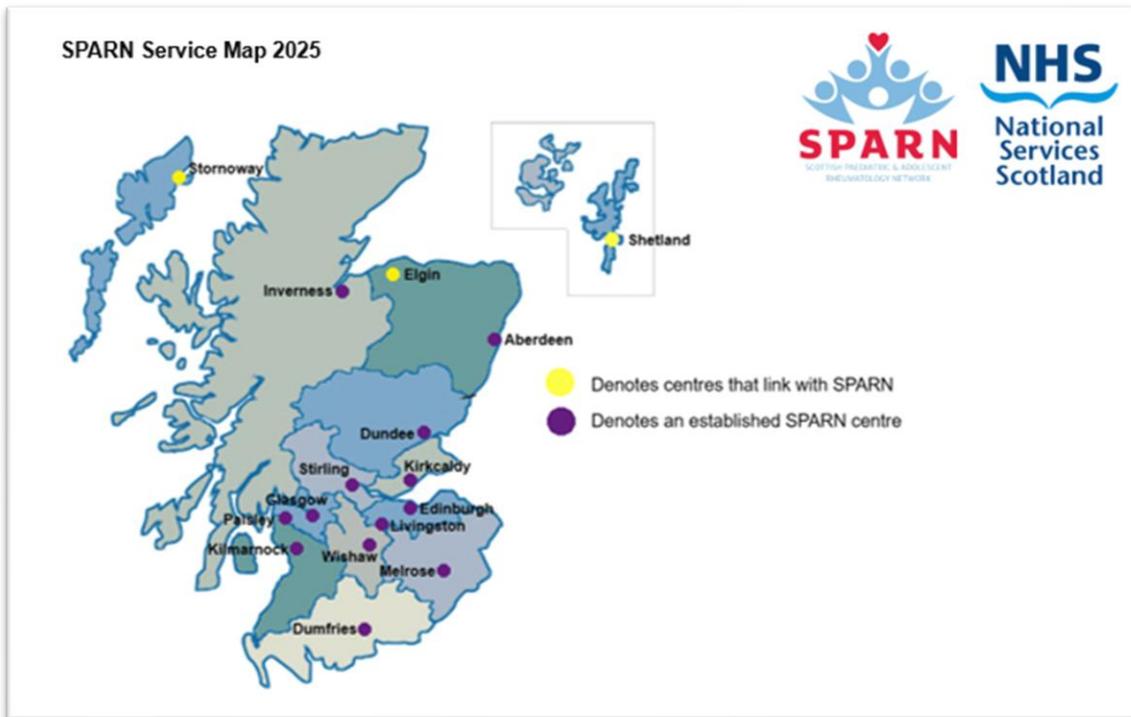


Image 2: An example page from the new SPARN service map.

3.3 Stakeholder Communication and Engagement

Website

The SPARN website remains a useful resource for staff and patients alike, with access to a range of resources including patient information leaflets, reports, newsletters, upcoming education events and clinical guidelines. A review was conducted in December 2024 to ensure the website remained up to date.

Newsletters

The network delivered two newsletters in 2024/25 as planned. The number of views jumped from 53 for the winter edition to 103 for the spring edition. The latter edition had a focus on education, with additional communications around the rollout of the Clinical Audit System (CAS) Power BI dashboard. More on this below.

Microsoft Teams

Microsoft Teams channels have continued to be utilised for meeting spaces, collaboration and sharing documents for editing and approving.



Image 3: SPARN newsletter example

3.4 Education

Annual Education Event

The Network facilitated its 15th Annual Education Event on Wednesday 12 June 2024. Due to the NHS Scotland directive to reduce discretionary spend, SPARN made the difficult decision to move the 2024 Annual Education Meeting to a virtual meeting. This session was open to the entire multidisciplinary team working within paediatric rheumatology, and beyond. The focus of the meeting was Juvenile Idiopathic Arthritis (JIA).

The following topics were covered at the meeting:

- Case studies
- Hypermobility/Ehlers-Danlos syndromes
- Feedback from the wrist service, 2 years on
- Research in JIA
- Transition
- Updates from third sector partners

The main aim of the event was to “increase knowledge in the management of patients with JIA”. Participants were asked about the extent to which they felt this aim had been met, 93% of attendees either strongly agreeing or agreeing, as shown below. Participants were also asked how they rated the content and educational value of the presentations? (5=excellent 1=poor). The event scored 4.6 out of 5 overall.

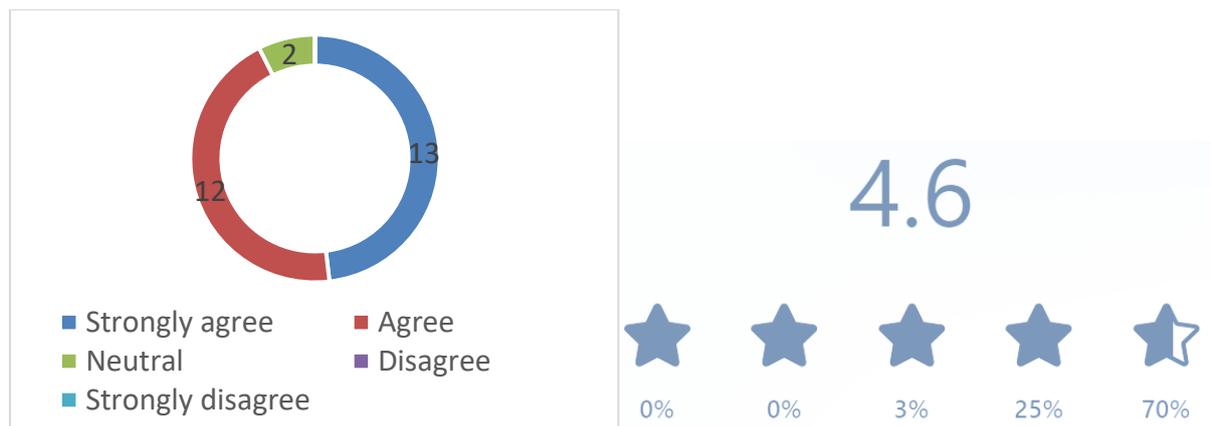


Figure 1: Feedback scoring from SPARN Annual Education Event

Monthly Education Sessions

The SPARN monthly education sessions were identified as one of the network’s key priorities for continuing with. These sessions are mechanisms for the collective knowledge and expertise in paediatric rheumatology care in Scotland to be continually shared. They are intended to enhance care for patients, support effective clinical succession and support revalidation requirements. Below is a table, which includes details of all the meetings that were held in 2024/25.

Date & Time	Topic	Lead
Tuesday 28th May 2024 (2pm to 4pm)	Adrenal Insufficiency	Dr Cat Anderson, Consultant Paediatric Rheumatologist
Wednesday 12th June 2024 (10am to 3pm)	***SPARN Annual Education Day on JIA***	
Thursday 15th August 2024 (2pm to 4pm)	Dentist session	Dr Cat Anderson, Consultant Paediatric Rheumatologist
Monday 23rd September 2024 (2pm to 4pm)	Lupus	Dr Eve Smith, Clinical Rheumatology, Alder Hey Children's Hospital Trust
Tuesday 29th October 2024 (2pm to 4pm)	Demyelination & ANTI TNF risks	Dr Mary Brennan, Consultant Rheumatologist
Wednesday 13th November 2024 (2pm to 4pm)	Should I wean or stop meds in JIA with inactive disease' and 'BAR-JDM	Dr Neil Martin, Consultant Paediatric Rheumatologist
Tuesday 10th December 2024 (1pm to 2pm)	Kawasaki	Dr Sarveshni Naidoo, Paediatric Consultant
Monday 13th January 2025 (2pm to 4pm)	Paediatric Sarcoidosis	Dr Sandrine Lacassagne, Consultant Paediatric Rheumatologist
Thursday 27th February 2025 (2pm to 4pm)	Complex Regional Pain Syndrome (CRPS)	Mandy Fanning, Advanced Specialist Occupational Therapist
Monday 10th March 2025 (2pm to 4pm)	Ankles, gait, JIA and untangling the overlap between Orthopaedics and Rheumatology	Dr Neil Martin, Consultant Paediatric Rheumatologist

A selection of some of the response highlights have been included below:

What have you gained as a result of attending this event?

- Techniques and options to try with patients.
- Good to have evidence with case study examples along with pain management advice and pharmaceutical intervention.

- Stressing the importance of pharmacological and non-pharmacological inputs as a means to enable the young person to engage with physio/OT which is the mainstay of treatment.
- Good understanding of physiotherapy and OT approach to managing pain and level of function in CRPS.
- Confirmed our service is trying to adhere to best practice.
- Important to try various treatment as 'one size doesn't fit all'. Biopsychosocial model is essential when working this group and their families.
- Importance of collaborative working as part of a wider MDT, seeing one patient from different professionals' viewpoints.
- Further knowledge of different potential trial options for patients and awareness of different treatment options and strategies across the globe.
- Knowledge, guideline awareness, anxiety about not missing a diagnosis especially the incomplete ones.
- Reminder of treatment pathways and diagnostic criteria for KD.
- Approach to investigation and treatment for erythromelalgia.
- Overview and understanding of Tx pathways and research which drives them.
- Good discussion around drug dosing and rationale behind clinical decision making.
- Discuss as a team how/if we can improve our clinics.

As a result of attending this event, would you say your practice will change?

- I think it helped to support the practice I deliver and emphasised the importance to ensure MDT working for the benefit of the patient.
- We do not have pain team in Fife but have worked with a pain team in other areas. I hope to have further conversations with the MDT to see if we can have some more co-ordinated care.
- Yes - plan to audit current dosing of hydroxychloroquine to see if we need to change practice if appropriate.

3.5 Audit and Continuous Improvement

Power BI Dashboard

One of the main concerns around utilising the CAS has been around the lack of a user interface for outputs. The SPARN Data Group have been working closely with the Information Management Service (IMS) to develop a new Power BI dashboard that will allow all CAS users to access their board's data outputs, including the new QPIs, in a user-friendly application that can be accessed easily through Microsoft Teams.

The dashboard also allows users to compare data with other boards in Scotland. The content has been refined and communications have gone out around its rollout. In 2025/26, users will be given their access to the dashboard and quarterly highlight reports will be circulated, which will provide high-level national data as well as health board specific data around missing information for completion.

SPARN Rheumatology Dashboard - Guidance

The SPARN Rheumatology Dashboard only includes patients with a diagnosis date from 1/1/2023.

Information about the pages and filters applied are described below:

QPIs 1- 7 - There is a page for each of the QPIs 1-7. QPI 8 does not currently have data available. Information on inclusion and exclusion criteria is listed on each of the pages.

Six-Month Assessment - This page shows details of the six-month assessment, including count of patients with active disease and joint count.

Steroid Eye Drops - This page shows steroid eye drop prescription numbers and average prescription length for patients diagnosed with Uveitis. Note that information on steroid eye drops can only be entered when 'Diagnosed with Uveitis' is selected in the CAS core dataset.

Transfer to Adult Services - This page contains information on transfer letters and appointments with adult services for patients aged 16+.

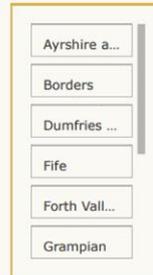
Medication - This page shows DMARD/Biologic information for patients with 'Diagnosed with Systemic JIA' selected in the CAS core dataset.

Generic Info - This page provides an overview of the number, condition and age bracket of all patients diagnosed with a rheumatological condition.

Missing Info - This page shows the number of patients who have missing information, by Healthboard. It includes missing information relating to QPIs, diagnosis/referral dates and also highlights date errors. Missing information prevents the QPIs from being calculated correctly and prevents the dashboard from showing accurate figures.

Interactive Filters

There are filters along the top or down the side of each page that can be used to view results for specific Healthboards.



Click on the name of a Healthboard to filter the results.

To remove the filter and show results for all Healthboards, click again on the highlighted Healthboard.

Multiple Healthboards can be selected by holding 'ctrl' as you click.

Further Information

Please note that some of the visuals on this dashboard will change over time as CAS is updated and more data becomes available.

Image 4: Landing page on the new SPEG PowerBI dashboard, linked to the SPARN Clinical Audit System

Quality Performance Indicators (QPIs)

In previous years, SPARN has collected information on patient diagnosis, condition, name, date of birth and CHI (Community Health Index) number on the CAS. As early as 2022, the network began working on a new set of QPIs to enable services to assess the quality of care they provide and identify quality improvement opportunities. Below is an outline of these.

1. % Of children and young people seen by the paediatric rheumatology team within 4 weeks of referral.
2. % Of children and young people diagnosed with systemic JIA given a biologic within 12 weeks of the onset of their symptoms.
3. % Of children under the age of 13 with a diagnosis of JIA who receive eye screening within 6 weeks of referral.
4. % Of children and young people with uveitis treated with a topical steroid for no more than 12 weeks continuously after initial presentation of uveitis before starting systemic therapy.
5. % Of children and young people diagnosed with JIA or Uveitis who have inactive disease 26 weeks after diagnosis.
6. % Of children and young people with a JIA or uveitis who have active disease 26 weeks after diagnosis and are on a biologic.
7. % Of children and young people with a rheumatological condition who are informed about opportunities to participate in clinical research (*currently focussing on JIA*)
8. % Of young people with a rheumatological condition who continue to engage with rheumatology services following their transfer to adult services.

With the further rollout of the dashboard, it is anticipated that the quality of the data will improve and the number of patients entered will increase. The QPIs are intended

to ensure consistent, high quality by monitoring outcomes. The QPIs are also intended to drive quality improvement through early and effective treatment.

Going forward, a quarterly highlight report will be sent to stakeholders, and individual health boards will also be sent a list of patients that have any missing information for them to action.

3.6 Value

Patient Information

SPARN has continued to host a number of useful patient information leaflets on the website.

Sustainability

All SPARN meetings in 2024/25 were moved online, which cut down on costs as well as reducing the network's carbon footprint.

All resources are accessible on the website and most forms are now completed online, reducing the need to print copies.

Looking forward – 2025/26

The network will continue with its 'business as usual' activity throughout quarter one in 2025/26, with further updates expected from the Scottish Government via NSD in the near future. The usual Business Plan will not be populated at this time.

Finance

The network operated within its allocated budget in 2024/25, focusing on low-cost, high-impact activities such as virtual education and digital resource development.

Risks and Issues

The network recognises the importance of maintaining national coordination in areas such as education, clinical guidance, and quality improvement. Continued support will be essential to sustain these benefits for patients and professionals.

Stakeholders have highlighted the importance of maintaining national coordination to sustain improvements in care. Continued support will be essential to build on existing progress and deliver future benefits.

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Contact email address: nss.sparn@nhs.scot