

Scottish Paediatric and Adolescent Rheumatology Network (SPARN)

Annual Report 2025/26

This document has been prepared by the National Services Directorate (NSD) of Public Services Delivery Scotland (PSD Scotland) on behalf of the Scottish Paediatric and Adolescent Rheumatology Network (SPARN). Accountable to Scottish Government, PSD Scotland works at the heart of the health service providing national strategic services to the rest of NHS Scotland and other public sector organisations to help them deliver their services more efficiently and effectively. The SPARN network is a collaboration of stakeholders involved in the care of children and young people with rheumatological conditions, who are supported by a PSD Scotland Programme Team to drive improvement across the care pathway

The network is supported by a dedicated programme team within Public Services Delivery Scotland (PSDS), consisting of:

Programme Manager: Jamie Nimmo

Assistant Programme Manager: Laura Craig

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. 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 guidance 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

Activity during 2025/26 reflected national prioritisation set during a period of review. Alongside evolving national planning arrangements, Managed Clinical Networks were asked to focus activity on a number of core priorities.

Looking ahead, and consistent with the direction set by the Health and Social Care Service Renewal Framework and Scotland's Population Health Framework (June 2025), and recognising that Chief Executive Letter (CEL) 29 (2012) *Managed Clinical Networks: Supporting and Delivering the Healthcare Quality Strategy* remains the extant mandate for Managed Clinical Networks, SPARN will build on its established approach by undertaking a Strategic Needs Assessment to inform the 2026/27 workplan and ensure priorities remain aligned to population need, current pathways, available data and stakeholder perspectives.

The priorities for SPARN in 2025/26 were:

- Continue to deliver monthly education sessions for professional stakeholders
- Deliver an in-person annual education event for professional stakeholders
- Develop and rollout a Power BI user dashboard to allow clinical colleagues to access their own data on the Clinical Audit System (CAS)

3. Highlights

3.1 Effective Network Structure and Governance

Steering Group and Subgroups

The network Steering Group has remained active and continues to be chaired by Dr Mary Brennan (Consultant Paediatric Rheumatologist, NHS Lothian). Membership of the Steering Group evolved during 2025/26, reflecting a combination of retirements and the appointment of new members from across the network.

Following the end of the formal Lead Clinician appointment in March 2024, Dr Neil Martin continued to provide expertise and support to the network, helping maintain continuity of activity while future clinical leadership arrangements were considered in line with national recommendations.

3.2 Service Development and Delivery

Clinical Guidance

Clinical guidance documents are essential for ensuring children and young people with rheumatological conditions are receiving safe, consistent, evidence-based care, regardless of where they are treated. In 2025/26, a huge amount of work went into updating the SPARN clinical guidance. As well as updating content, the review ensured all the governance processes and standards were being met.

Several documents were refreshed and four new documents were developed. All of these were put onto new templates and added to the website. The table below includes updates on all the documents that have been reviewed this year.

Document	Current position
Joint Injection Request Form	New – on SPARN website
Iloprost	New – on SPARN website
Infliximab	New – on SPARN website
Rituximab	Reviewed – on SPARN website
Methylprednisolone	Reviewed – on SPARN website
Flu Statement	Reviewed – on SPARN website
SPARN Checklist	Reviewed – on SPARN website
Bisphosphonates Protocol	Reviewed – on SPARN website
Chronic Non-infective Osteitis	Reviewed – on SPARN website
COVID Digits	Risk Assessed (extended) – on SPARN website
Macrophage Activation Syndrome	Risk Assessed (extended) – on SPARN website

Table 1: SPARN clinical guidance updates 2025-26

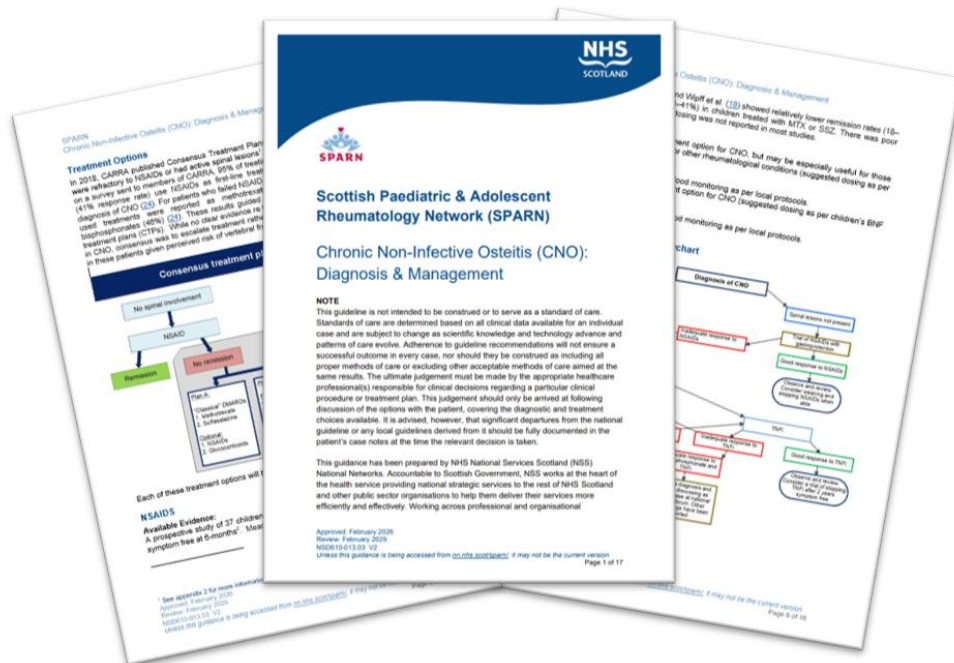


Image 1: Example of new SPARN clinical guidance template

Transition from Paediatric to Adult Services

The SPARN Transition subgroup reconvened towards the end of the year to start planning a new dedicated page for transition on the SPARN website, with dedicated resources for professionals and patients. The work aims to support a smoother transition from paediatric to adult services, improve continuity of care and support positive patient outcomes.

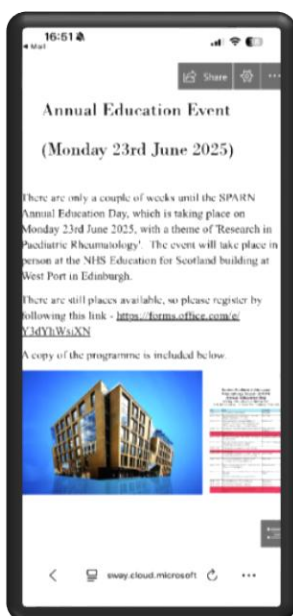
Physiotherapy

The Physio subgroup split into two separate short life working groups in 2025/26 to focus on two separate workstreams. Group 1 is focussed on chronic pain resources and Group 2 is focussed on hypermobility. Both sets of resources are currently being reviewed by the wider Steering Group.

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, details of upcoming education events and clinical guidance. A review was conducted in November 2025 to ensure the website remains up to date.



Newsletters

The network delivered two newsletters in 2025/26. The average number of views jumped from 78 in 2024/25 to 118 in 2025/26. The newsletters are designed to ensure stakeholders are kept informed about changes and developments within, and beyond, the network. They also provide useful information around access to resources and learning and development opportunities.

News items this year included: advertising education events, rollout of the Clinical Audit System (CAS) PowerBI dashboard, staff spotlights, new SPARN resources and third sector updates.

Image 2: Example of SPARN newsletter on mobile device

Microsoft Teams

Microsoft Teams channels have continued to be utilised for meeting spaces, collaboration and sharing documents for editing and approving. The monthly education sessions are also recorded and stored securely in a dedicated channel. Access to the recordings can be made available to other stakeholders upon request. A new channel was also set up this year for “SPARN CAS Users”, giving them quick and easy access to the Clinical Audit System (CAS) and the PowerBI user dashboard.

3.4 Education

Annual Education Event

The network delivered its 16th Annual Education Event on 23 June 2025 at the West Port building in Edinburgh. The event was open to the multidisciplinary teams involved in the care of children and young people with rheumatological conditions, as well as other interested healthcare professionals. The theme of the event was research and its role in improving patient care and service delivery.

A total of 49 delegates attended the event, including speakers and participants who joined remotely

A breakdown of attendance by health board can be found in figure 1 below.

SPARN Annual Education Day 2025 Attendance by Health Board

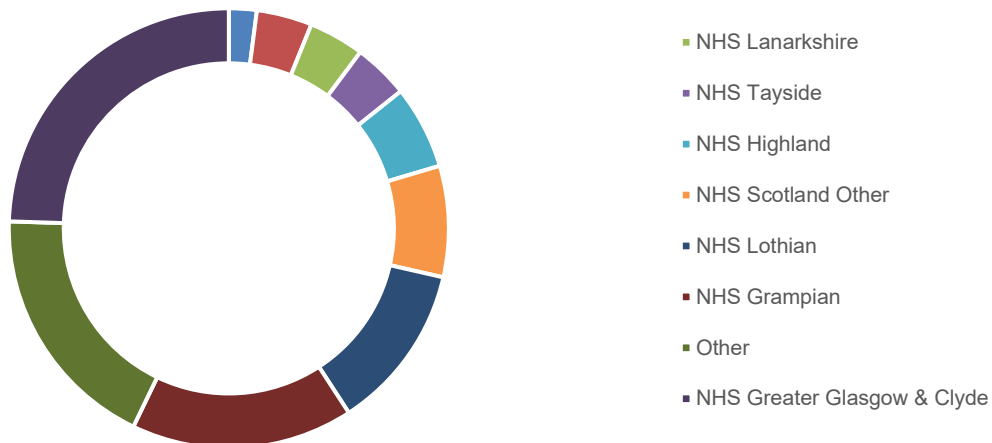


Figure 1: SPARN Annual Education Day 2025 - attendance by health board

The following topics were covered at the meeting:

- Building CAIRN: Shaping the Future of Paediatric Rheumatology Research in Scotland
- Can a Hub-and-Spoke Model improve Scotland's delivery of paediatric clinical trials?
- Unveiling the new SPARN quality indicator dashboard
- The power of research – Active AHPs: One Career, Many possibilities
- Balancing Care and Curiosity: My career in Physiotherapy & research at GOSH
- MSK Research Across the Life Course: Adult Rheumatology research in Glasgow and opportunities for aligning across Scotland
- MSK research in Scotland: Building networks, broadening access and delivering impact
- Better Evidence, Better Services: Turning research into action in Rheumatology
- Paediatric Gastroenterology Research Network
- Paediatric Respiratory Research Network
- Paediatric Epilepsy Research Network

Feedback was received from 15 delegates, who were asked to rate each of the talks from "poor" to "excellent". The scores are included in figure 2 below, with all eleven averaging a "very good" score.

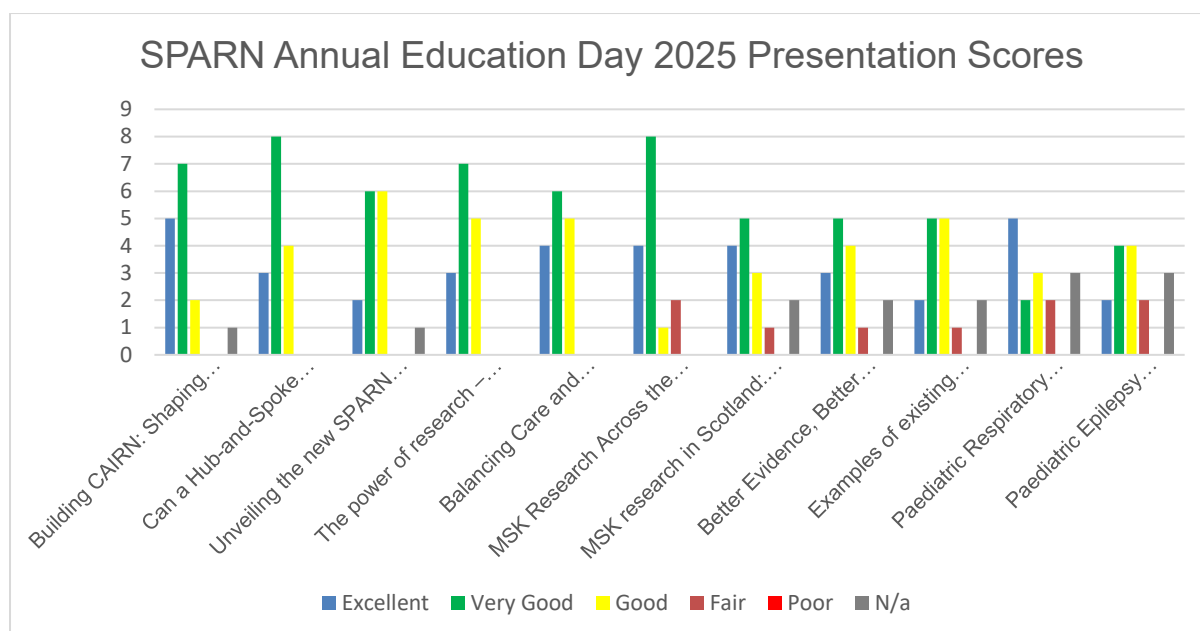


Figure 2: SPARN Annual Education Day 2025 - presentation scores

Delegates were also asked about the extent to which the day's objectives were met. Details can be found in figure 3 below. "Agree" was the average response for all but one of the objectives. There was less consensus about the "next steps" objective, which reflects the degree of uncertainty networks were facing at the time.

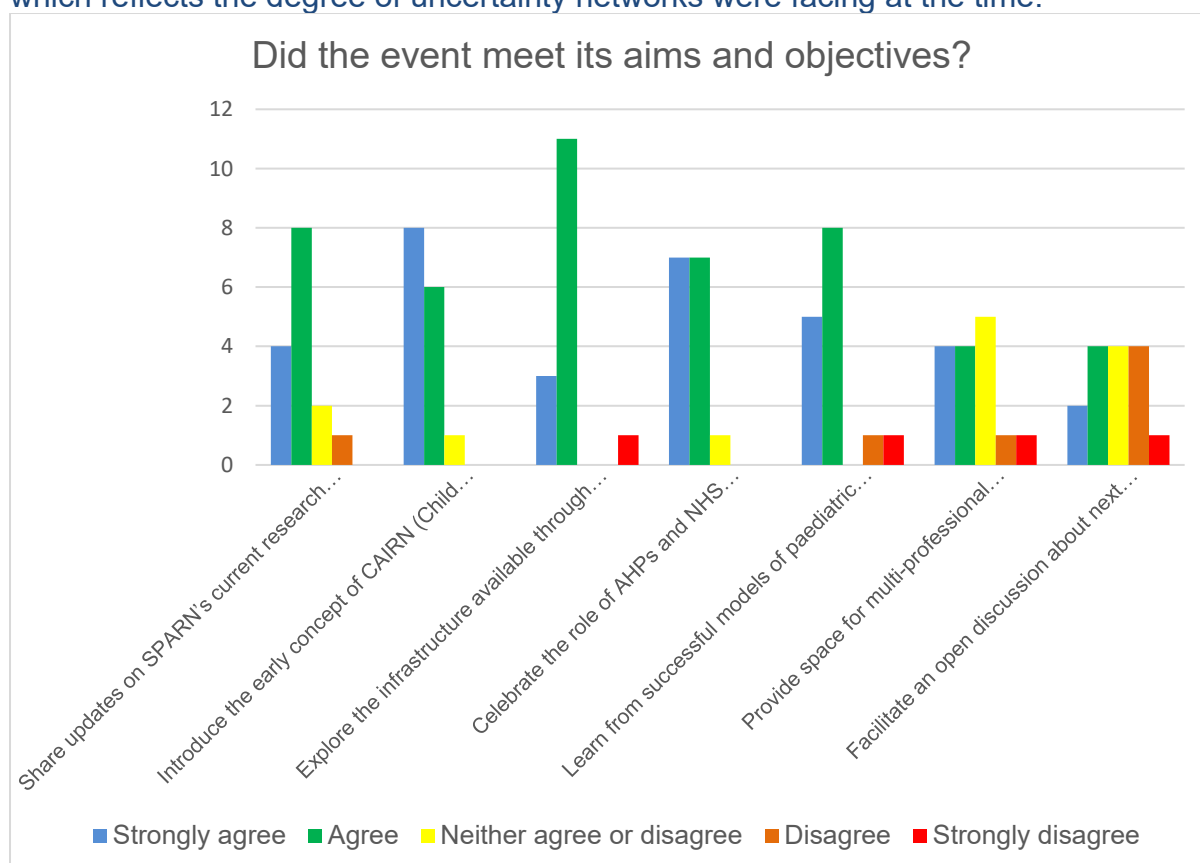


Figure 3: SPARN Annual Education Day 2025 - extent to which objectives were met

Delegates were asked to provide qualitative responses around what they valued most, as well as key takeaways. They were also asked to provide suggestions for future research topics. Some of the highlights are included below.

What did you value most about the event?

- “The opportunity to think about ways to embed research into clinical practice”
- “Face to face discussions and speciality subgroup time”
- “A better understanding of the complexities of research and how I can contribute to research without being PI in big studies”
- “The importance of doing research for our patients and how Scotland could be ideally set up to aid this”

What are the key takeaways and insights you gained from the event and what impact will these have on your work going forward?

- “Research does not have to be big, funded pieces of work, it can be part of everyday clinical practice”
- “Potential direction of travel for research within SPARN going forwards”
- “The importance of reaching out to people already involved in research and utilising the support available”
- “Possibilities to increase research opportunities for our patients and families”

Do you have any suggestions as to how we should develop research across Scotland, or have any research ideas?

- “How to embed research into physiotherapy clinical practice and how this may direct future treatment”
- “Engaging with the CYP and their families in order to hear their priorities and discuss how they would best like to be informed”
- “Ask the Scottish government to insist that all boards use the same Trak system so patient records can be shared, this would help from a safeguarding issue and potentially future research”

80% of respondents either “agreed” or “strongly agreed” that the event sparked an interest to get involved in future paediatric rheumatology research.

Monthly Education Sessions

The SPARN monthly education sessions provide a mechanism 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. An average of 19 delegates attended throughout the year. Below is a table, which includes details of the nine sessions that were held in 2025/26.

Date	Topic	Presenter(s)
Wed 25 Mar 26	Case presentation BAR-JDM trial information	Dr Neil Martin, Paediatric Rheumatologist

Wed 11 Feb 26	Reflections on a Career as a Paediatric Rheumatologist	Dr Jo Walsh, Paediatric Rheumatologist
Thu 22 Jan 26	Paediatric Nutrition	Helen McLeod, South CAMHS Dietitian
Wed 10 Dec 25	Vascular EDS + Case Presentation	Glenda Sobey, National EDS Centre + Dr Kirsty McLellan, Paediatric Rheumatology Consultant
Wed 26 Nov 25	Feedback from PReS + Projects on Flu Vaccination & Biologics in JIA	Drew Fell, CNS, Rheumatology & Lucy Paterson-Brown, Paediatric Rheumatology Registrar
Wed 22 Oct 25	Chronic Pain (role of OT)	Anne Marie van Es, Occupational Therapist, Oxford University Hospitals NHS Trust
Mon 22 Sep 25	Antiphospholipid Syndrome + Case Presentation	Dr Sarah Clarke, Haematologist Dr Elizabeth Twynam-Perkins ST6
Mon 18 Aug 25	Juvenile Localised Scleroderma	In-person event at RHCYP, Edinburgh Clare Pain, Consultant Paediatric Rheumatologist, Alder Hey Children's Hospital Trust
Mon 28 Apr 25	Autoinflammation	Dr Kirsty McLellan, Paediatric Rheumatology Consultant

Table 2: SPARN Monthly Education Sessions 2025-26

Feedback form returns remain low, with some sessions not receiving any responses. Some of the highlights, however, are included below.

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

- “A greater understanding of how genetic testing can aid diagnosis, prognostication and treatment for patients with inflammatory phenotypes”
- “Reassurance that current interventions are in line, some additional strategies or approaches that can be used”
- “More ways of discussing pain and treatments for those with chronic pain”
- “A reminder of how to approach patients with chronic pain and accept that we need some motivation for change to happen”

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

- “I will be more likely to seek genetic testing for patients with uncertain diagnosis and ask for advocate for re-analysis where patients remain diagnostic enigmas”

- “A reminder of how to approach some more challenging situations”
- “Better able to explain PPS to young people”
- “I will consider motivation and readiness to change more”

3.5 Audit and Continuous Improvement

Clinical Audit System (CAS)

The Clinical Audit System (CAS) has been established as the platform for SPARN audit data collection for the past few years. The aim of this data collection is to have audit data including patient numbers of children and young people with rheumatological conditions across each health board, and to capture service delivery in Scotland. The data can then be utilised for service planning, monitoring, quality improvement and research.

One of the challenges of the CAS in previous years has been the ability to easily access outputs for users. The SPARN Data Group has continued to work closely with the Information Management Service (IMS) over the past year to finalise, and roll out, the new PowerBI dashboard.

Power BI Dashboard

The PowerBI dashboard provides CAS users with access to their health board's data outputs, including Quality Performance Indicators (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.

This new tool has been extremely well received, and improvements are continuing to be made. One such improvement has been the introduction of “missing information” reports to allow users to address missing patient information.

The first quarterly highlight reports have been circulated, which provide high-level national data as well as health board specific data.

Below is a snapshot of the dashboard landing page, which provides an overview of the filters and QPIs.

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+.

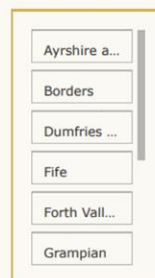
Medication - This page shows DMARD/Biologic information for patients with 'Diagnosed with Systemic JIA' selected in the CAS core dataset.

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 3: SPARN PowerBI CAS user dashboard landing page

Quality Performance Indicators (QPIs)

As well as collecting a core dataset, SPARN also collects Quality Performance Indicator (QPI) data as outlined below. The QPIs are intended to drive quality improvement through early and effective treatment.

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.

Below is an example of what the QPIs look like on the SPARN PowerBI dashboard.

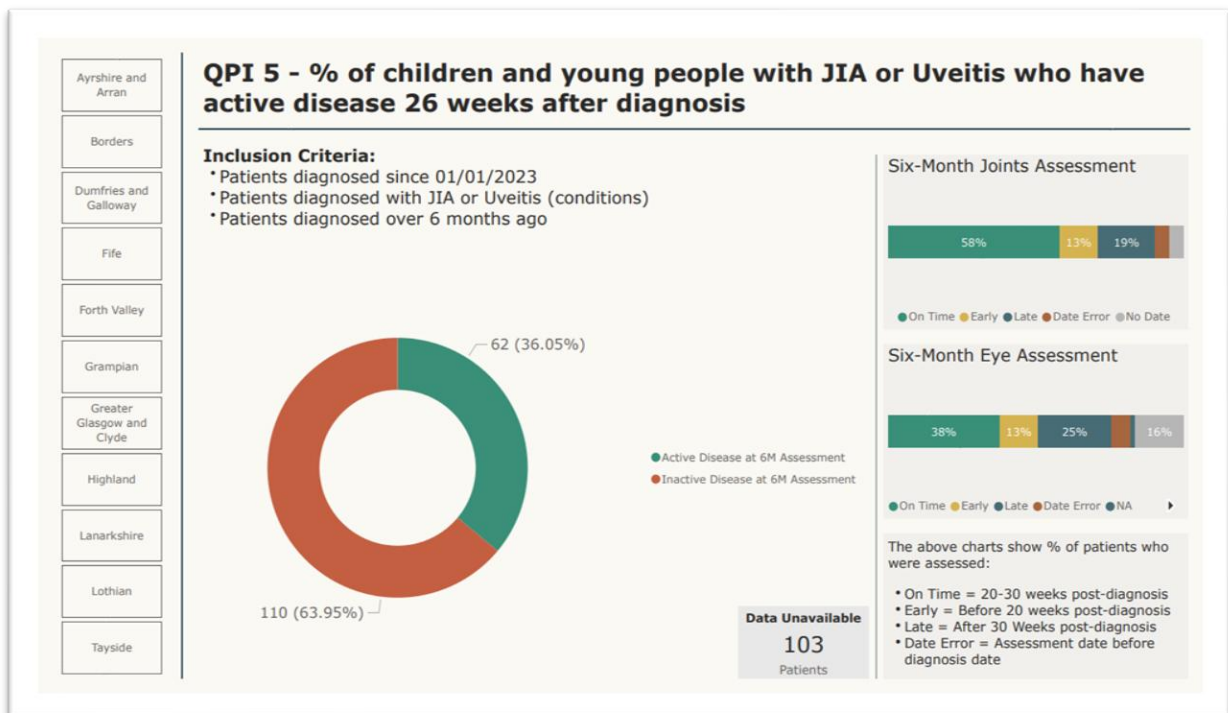


Image 4: SPARN PowerBI CAS user dashboard example of a QPI

The first quarterly highlight report was circulated for quarter 3 (October 2025 to December 2025), with the next one covering quarter 4 (January 2026 to March 2026). The inclusion of the “missing information report” is already leading to some signs of improvement as seen in figure 4 below. It is expected that this trend will continue into next year and beyond.

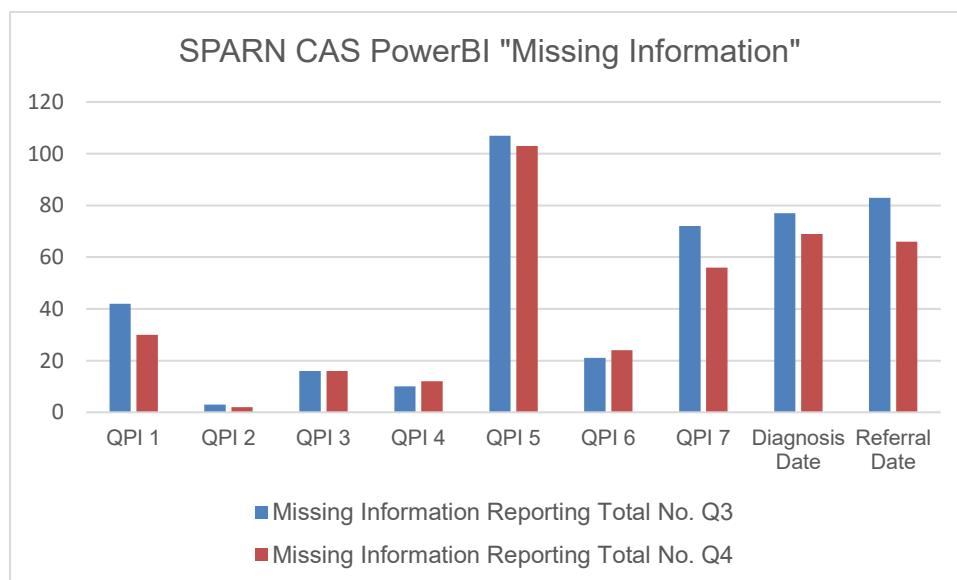


Figure 4: SPARN PowerBI CAS user dashboard – number of patients with missing information Q3 to Q4

The network will continue to roll out the dashboard in 2026/27 and will continue to monitor progress against the QPIs.

3.6 Value

Patient Information

SPARN has continued to host a number of useful patient information leaflets on the website. These are due to be reviewed and moved to new templates in 2026/27.

Third Sector

The Steering Group continues to have representation from third sector organisations, SNAC and Arthritis UK. SPARN members often provide support for their events, and the representatives provide valuable patient insight to the group.

Sustainability

SPARN has continued to run its monthly education sessions, as well as Steering Group and subgroup meetings, online. This has cut down on costs as well as reducing the network's carbon footprint. The Annual Education Day took place at a free NHS venue (West Port, Edinburgh) in 2025.

All SPARN resources are accessible on the website, reducing the need for paper copies.

Looking forward – 2026/27

The network has already outlined its workplan objectives for 2026/27, detailed below.

- **Strategic Needs Assessment** - The network should assess its impact and how it benefits service users. This will include looking at the patient pathway, a review of available data, a look at workforce requirements and engagement with all stakeholders. This will help shape the future priorities of the network.
- **Transition** - A new dedicated (paediatric to adult) transition page will be set up on the SPARN website, with dedicated resources for professionals. This will include useful information, guidance and a checklist. A resource will also be produced for patients and families, with information around transition.
- **Clinical Audit System (CAS)** - There should be a measured improvement in the use of CAS through the amount of data captured. Gaps in data should be identified and addressed. The network should work towards doing an audit of a 5-year dataset from 2020 to 2025.
- **Physio Resources** - The Physio Group will be split across two distinct workstreams to develop physio resources. One with a focus on hypermobility and the other with a focus on pain management.
- **Annual Education Day** - The network will deliver an in-person Annual Education Day in Glasgow, with dedicated topics based on requirements and previous feedback. This should offer professional development and networking opportunities.
- **Clinical Guidance** - As well as reviewing current clinical guidance under business as usual, the network will develop and rollout new guidance on GP referrals and will also adapt current guidance on COVID Digits and Macrophage Activation Syndrome (MAS). All guidance will also begin to move across to the Right Decision Service platform.

- **Patient Information** - The network will review all of its current patient information resources and create a plan to update and replace existing resources with newer versions that adhere to current governance requirements.

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.

Finance

The Network is funded through Public Services Delivery Scotland and operated within its approved budget during 2025/26.

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