



# **Scottish Paediatric and Adolescent Rheumatology Network (SPARN)**

## **Annual Report 2023/24**

**Lead Clinician:** Dr Neil Martin

**Programme Manager:** Michael Durkan

**Programme Support Officer:** Kirsty Young / Anna Suszko

## 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.

## Current position

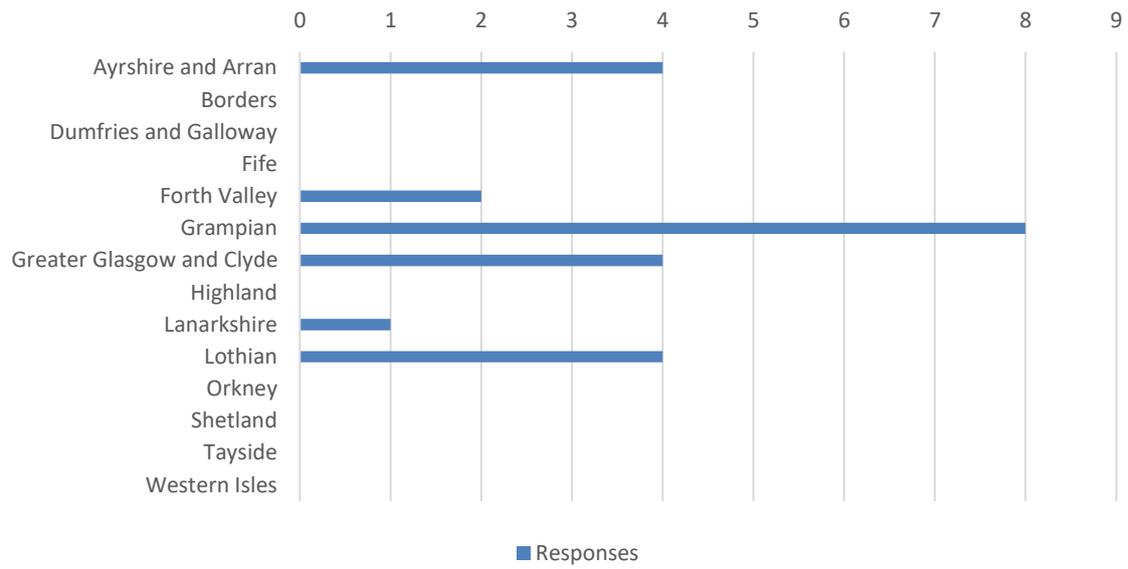
SPARN achieved 20 of 22 (91%) objectives set for 2023/2024. One objective to develop a 3 - 5 Year Strategic Workplan has been carried forward to 2024/2025 this is in part due to outstanding objectives from the previous strategic workplan and in part due to logistics. The other incomplete objective was to review the uveitis guideline. The initial guideline was developed as part of the now decommissioned Scottish Uveitis Network. The review process is taking longer than normal due to an audit of the previous guideline taking place. The initial guideline has been removed while the audit and review takes place.

## Highlights

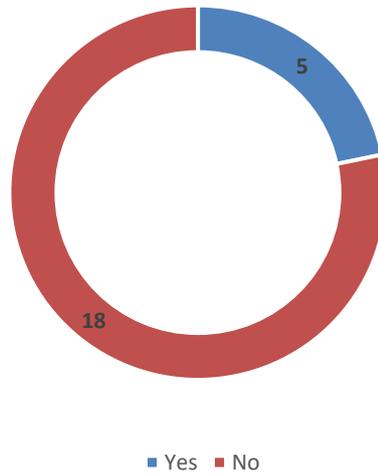
### Transition questionnaire

Following a number of unsuccessful attempts to seek feedback on the transition process from recently transitioned patients, a feedback questionnaire was circulated. In total there was 23 responses to the survey. A snapshot of the data is below.

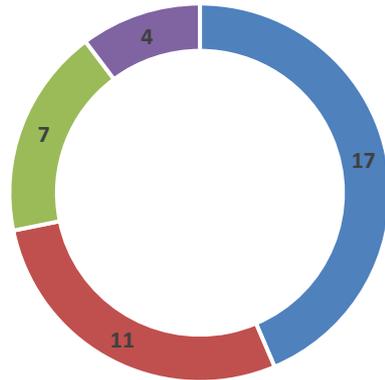
## Responses



Did you do Ready, Steady, Go at any point prior to transition?

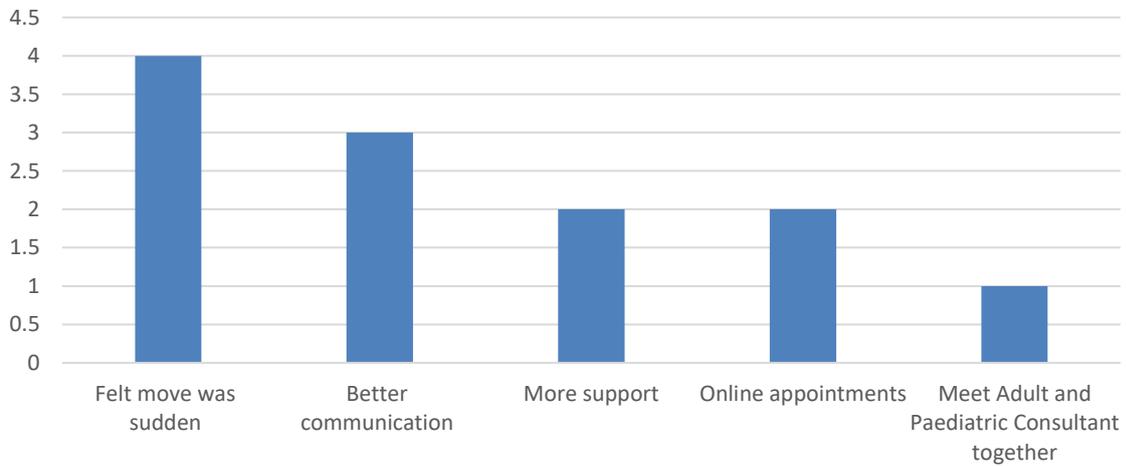


## What was good about your transition?



- I felt more listened to and treated like an adult
- Good communication from new consultant
- Relationship With the adult rheumatology team
- Other

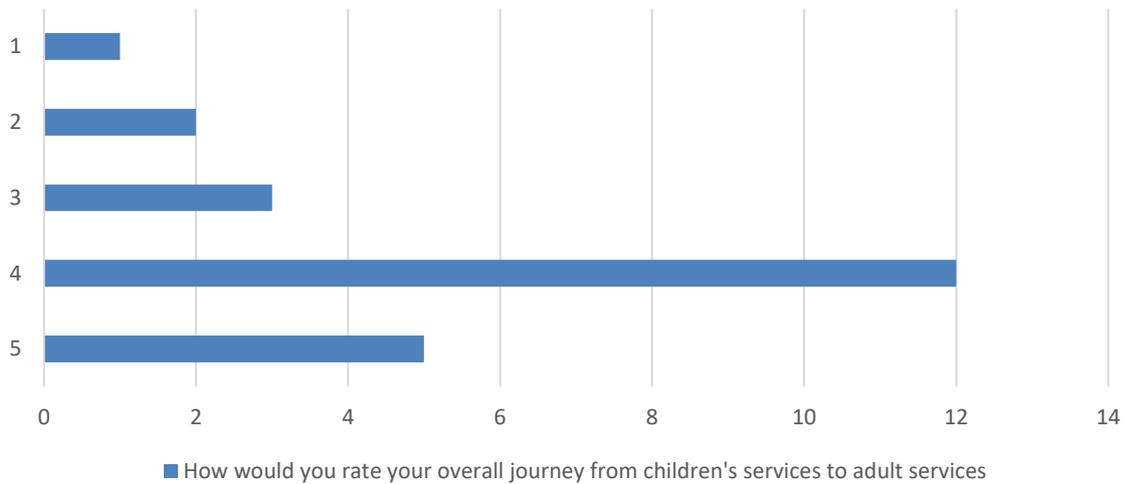
## What could we improve for future young people moving from children to adult services?



- What could we improve for future young people moving from children to adult services?

## How would you rate your overall journey from children's services to adult services

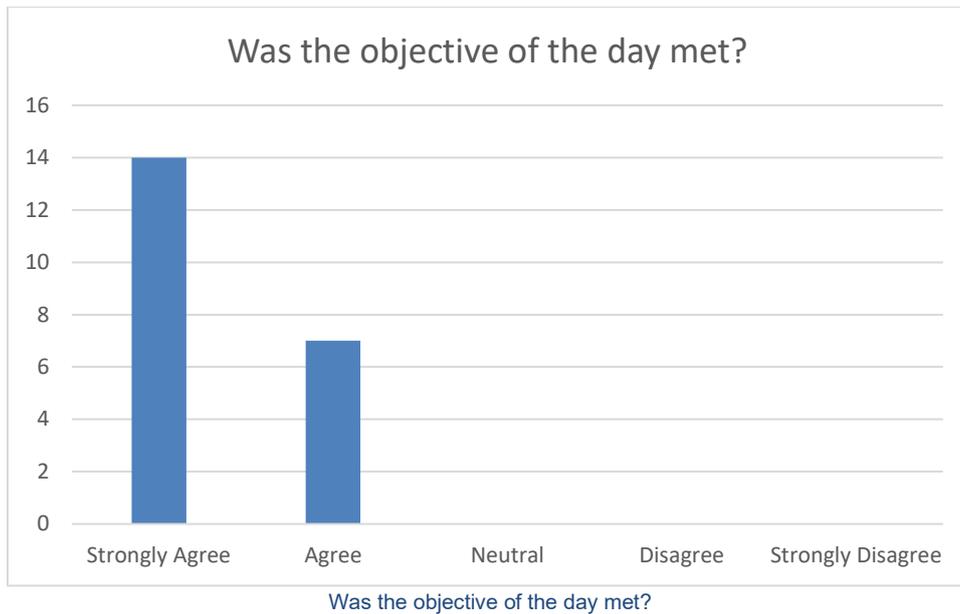
5 - excellent, 1 - poor



The transition group will take review the responses to the survey and develop an action plan to better support patients and local teams and aim to improve the transition process.

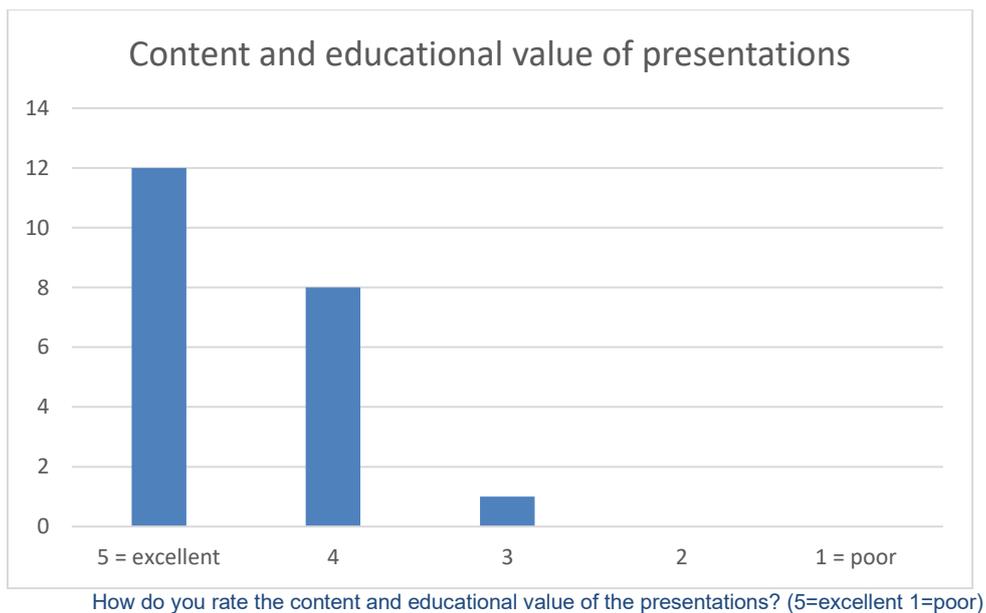
### Education

This year's Annual Education Meeting was held in Glasgow on 5<sup>th</sup> June. This year's topic was MCDT, Myositis & Arthritis. In total 37 delegates attended the event. A total of 21 responses were received to the post event evaluation. Delegates where asked a number of questions on the event. Below is a snapshot of the event feedback.

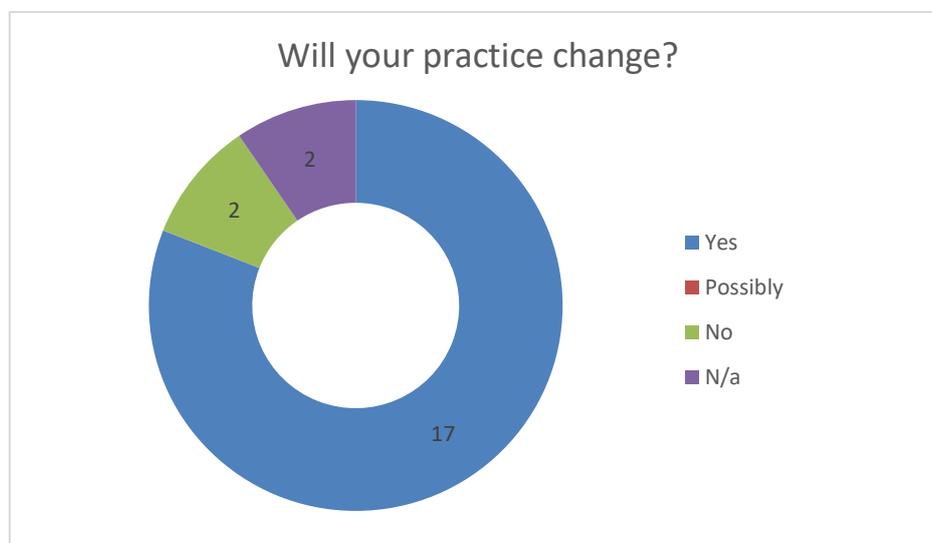


The first question above was used to understand whether or not the meeting met its purpose to increase knowledge of the management of patients with MCDT, Myositis and Arthritis. All 21 responses agreed that this objective had been met.

The next question asked was to understand the content and value of presentations, below. 20 of 21 respondents advised that the meeting was at least 4/5, with the final respondent rating it 3.



Further questions were asked to try to understand the impact to practice following the event. 17 of 21 responses advised that practice would change as a result of this event, with the most popular impacts being increased confidence in managing these patients and increased awareness of these conditions.



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

### Monthly education sessions

SPARN continues to provide multidisciplinary education for those involved in the care of children and young people with rheumatological conditions. 7 2 hour sessions are delivered via Microsoft teams, with recordings available to view after the sessions. The table below shows the date, topic and attendance at each session and the subsequent views:

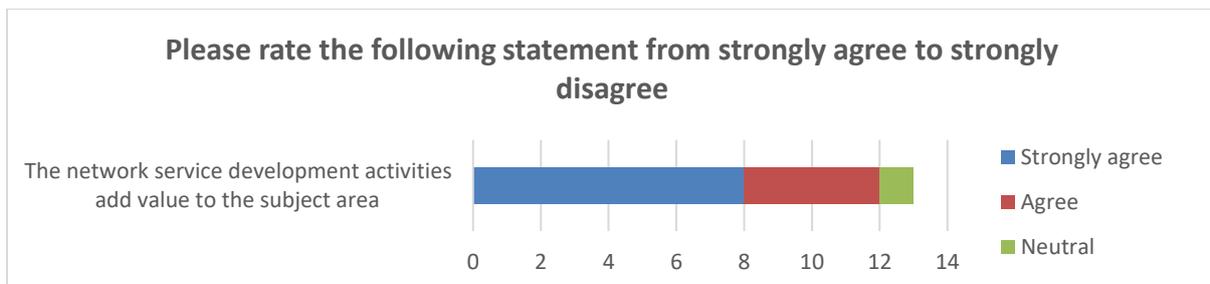
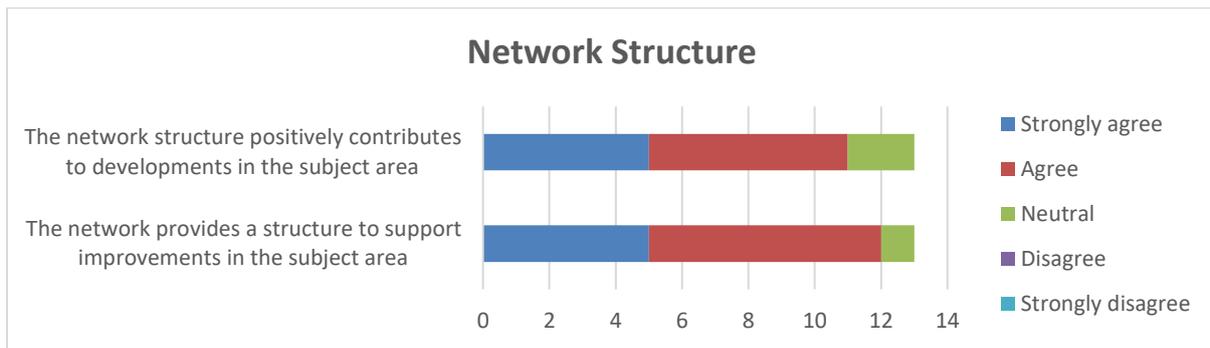
Date	Title	Attendees	Views
30/05/23	Joint session with SPRUN on glomerulonephritis	49	N/A
August	Pre-recorded update on the ISSAID conference	N/A	
27/09/23	Lyme Disease		
26/10/23	Paediatric Sjogren's Syndrome	25	4
20/11/23	Raynaud's Disease		
31/01/24	Post-pandemic role of the Paediatric Rheumatologist in PICU	26	8
28/02/24	Tofacitinib	22	4
27/03/24	CAP update, Drug contract changes, device changes including updates on Tocilizumab, adalimumab and Methotrexate	32	2

Each individual education session is evaluated to ensure that the sessions continue to provide high quality education and meet the needs of stakeholders.

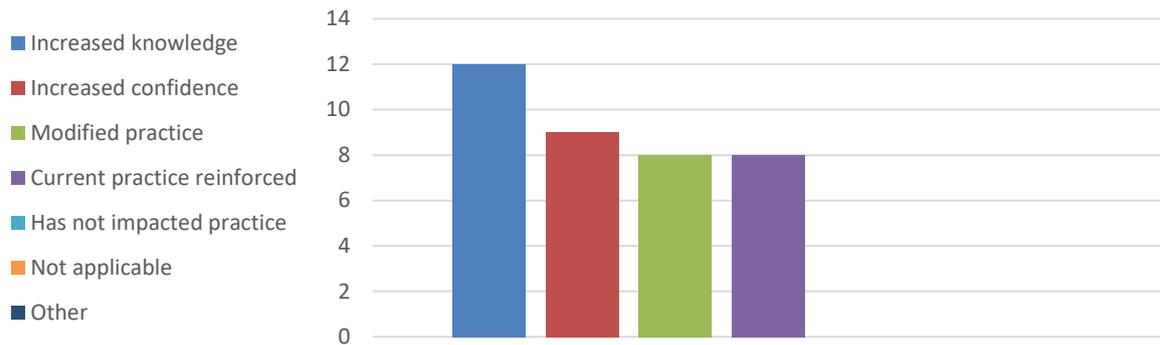
### Stakeholder survey

In order to seek feedback from stakeholders a National Network Survey was developed on MS Forms and open for responses from 18-29 March 2024. The survey was issued to all those stakeholders deemed to be actively participating in the network. Active participants ranged from Steering Group members to those who occasionally attend education events.

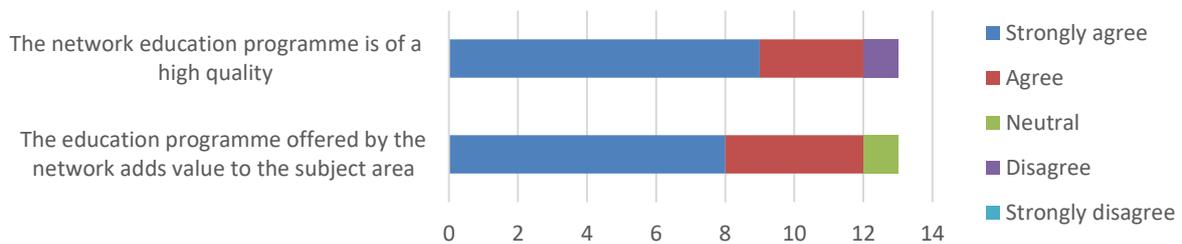
A snapshot of the responses is below;



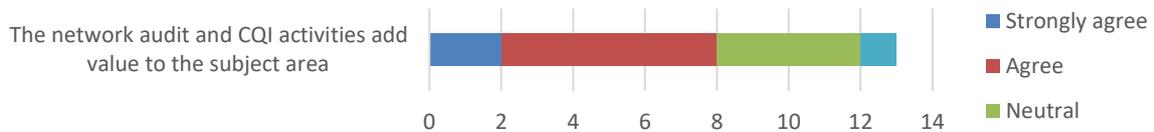
**In what ways has participation in the network's education programme or events had an impact on your practice?.**



**Please rate the following statement from strongly agree to strongly disagree**



**Please rate the following statement from strongly agree to strongly disagree**



**Strengths**

- As a nurse new to the rheumatology team, it has given me a network of support and a platform to be able to reach out to others in the same role for support and advice.
- Collective working and discussion
- Communication
- Communication and approachable. It's like we are one huge team, offering support,

**Areas for Improvement**

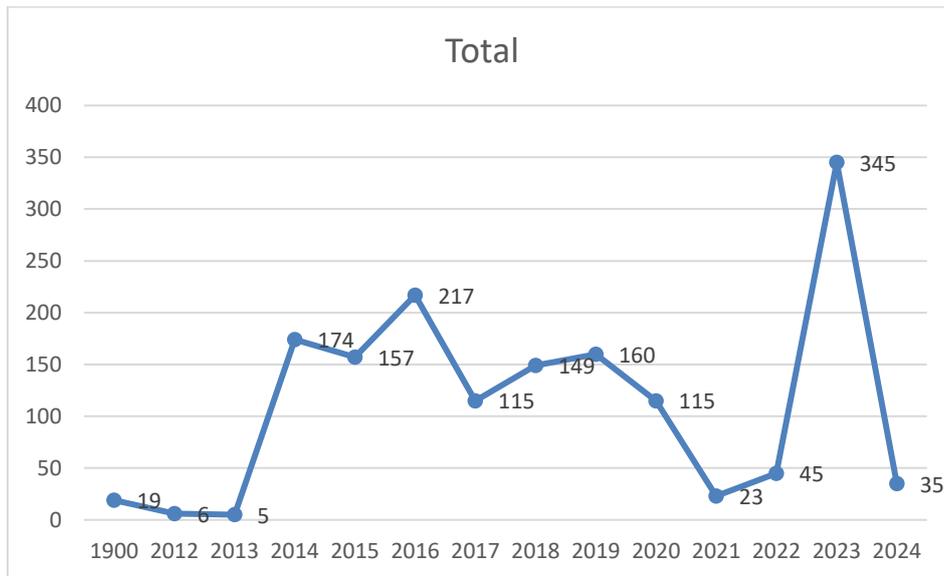
- Ensuring all receive same access to psych, OT, Physio etc..
- Trying to ensure staffing at each network centre is what is required i.e. huge discrepancies in access to OT, psychology support, physio support in different network centres. Securing more CNS time
- Website update essential

<p>reassurance and troubleshooting where requires</p> <ul style="list-style-type: none"> <li>• Well organised and focused</li> <li>• Standards of care and links to colleagues</li> <li>• 'Opportunity to meet and work together with others across the country. Working towards common goals and collect national data to inform decisions and assess actions</li> <li>• Flexibility, excellent communication between professionals, patient centred care wherever the child is in Scotland</li> </ul>	<ul style="list-style-type: none"> <li>• Keep it up</li> <li>• Becoming stable over time, no major change recently</li> </ul>
<b>Suggested Future Priorities (3-5 years)</b>	<b>Network Challenges/Threats</b>
<ul style="list-style-type: none"> <li>• Streamlining patient care across Scotland with protocols for medications, blood monitoring etc as each health board does different</li> <li>• Build AHP services across network</li> <li>• Trying to ensure staffing at each network centre is what is required i.e. huge discrepancies in access to OT, psychology support, physio support in different network centres. Securing more CNS time</li> <li>• Improving transition and improved working with adult teams</li> <li>• Maintain same</li> <li>• Embed the need for centres to engage in regular high quality audit to confirm equity of service provision across all network clinics. At the moment we cannot see that the network has provided an improved service as we don't have any real data. There are no sanctions for non-engagement or requirements to prove standards are met so gaps in engagement are hidden.</li> <li>• Maintain what we have, advocate for more AHP support, succession planning</li> </ul>	<ul style="list-style-type: none"> <li>• Limited budgets</li> <li>• Funding and staffing</li> <li>• Financial implications for health boards and money saving as a priority above clinical need</li> <li>• Staffing/funding as usual</li> <li>• Many retirements coming up for network leads which will leave a number of gaps that need filling at a very similar time. We need more trainees with SPIN in paed rheum to fill these in the near future, and better succession planning.</li> <li>• 'Lack of Face to face meetings. TEAMS meeting are valuable but the opportunity to meet up occasionally is also extremely beneficial</li> <li>• 'Gaps in service provision due to individuals retiring or changing job plans, financial constraints in maintaining a complete MDT in a particular area</li> </ul>

## Data

Following the refreshed quality indicators, a revised CAS core data set was developed alongside the IMS. This has now been in use by teams across the network. The network is currently working alongside the IMS to agree a suite of reports and to allow for an initial audit of the networks CQIs. The charts below show the increased CAS engagement from the networks since the initial introduction of

CAS until the refreshed instance launched in June 2023. Since the relaunch of CAS 380 patients have been added from across the country.



## Looking forward – 2024/25

Looking ahead to 2024/25 priorities for the network include:

- Develop a strategy for supporting a sustainable paediatric rheumatology workforce to inform service planning
- Engage with patients with rare rheumatic conditions to understand their priorities for improvement
- Set up a process for monitoring and review of cost savings by moving rheumatology patients to new biosimilars
- Develop an action plan to improve transition from paediatric to adult care
- Audit revised clinical indicators and identify areas for improvement
- Refresh of strategic workplan

## Finance

The 2023/2024 finance summary is:

## Risks and issues

### Face to face meetings

The stakeholder survey circulated this year highlights the important role SPARN plays in providing development opportunities, peer support and advice to teams across the country. A vital part of this is the Annual Education Meeting which provides an opportunity for all professional groups across the Multidisciplinary Team involved in paediatric rheumatology care to come together and network with colleagues. The event also provides education and workshops which are opportunities to provide education to a wider audience and take forward some of the network's key deliverables. There is no other event in Scotland which provides the opportunity for colleagues to meet with their peers, especially AHPs.

*“The MCN has facilitated my learning and competence at managing cases of paed rheum - from a very low knowledge base to where I am now. Without the network we would not have a local paed rheum service. We do have a local service, which provides a very good service to our population.”*

*“As a nurse new to the rheumatology team, it has given me a network of support and a platform to be able to reach out to others in the same role for support and advice.”*

*“Communication and approachable. It's like we are one huge team, offering support, reassurance and troubleshooting where requires”*

*“Lack of Face to face meetings. TEAMS meeting are valuable but the opportunity to meet up occasionally is also extremely beneficial”*

Having to host this event online has remove the networking aspect so highly regarded by colleagues and the ability to host workshops which have proven to be difficult in MS Teams. Removal of Face to Face meetings has the potential to have a detrimental effect on the long term future of SPARN.