Scottish Paediatric and Adolescent Rheumatology Network (SPARN)

Annual Report
2022/23

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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 has achieved 19 of 21 (90%) objectives set for 2022/23. One objective to undertake a first audit of the Clinical Quality Indicators has been delayed due to an intention to develop and use a refreshed CAS core data set. This is now complete, and work has moved to rolling out this refreshed data set and undertaking a first audit. The second uncomplete objective was to gather feedback on transition. An initial survey was developed which received minimal response. A second survey has now been developed alongside Versus Arthritis; it is hoped that this survey will receive a better response.

Lead Clinician update

2022-2023 has had a number of challenges and opportunities. Moving back towards “normal” ways of working after 2 years affected by COVID related measures we have tried to use and build on new skills and strengths gained within our teams such as improved use of video technology with teams and attend anywhere. At the same time we have been glad to restart previous activities such as research and audit which had been greatly reduced during the pandemic.

We have worked hard to create an effective update to the clinical audit system “CAS” with the aim of auditing our newly agreed Quality Indicators.

We have worked together within SPARN to ensure access to joint injections under general anaesthetic despite reduced theatre lists, particularly in Glasgow.

As always the education programme has been popular and effective. The first patients came through our new national clinic for patients with treatment resistant wrist arthritis and arthroscopic synovectomy has become a real option for a small, carefully selected group of patients. We are looking forward to our first fully face to face meeting for several years to be held in Glasgow in June 2023 and in the year ahead we plan to use CAS to assess our new Quality indicators across the country and roll out an updated transition questionnaire.

Highlights

Patient engagement

Juvenile Dermatomyositis (JDM) family day

A family day for patients with JDM (and their families) was held on 3rd September 2022 in Crieff Hydro. The event was attended by 7 families, with 6 responding to the post event evaluation.

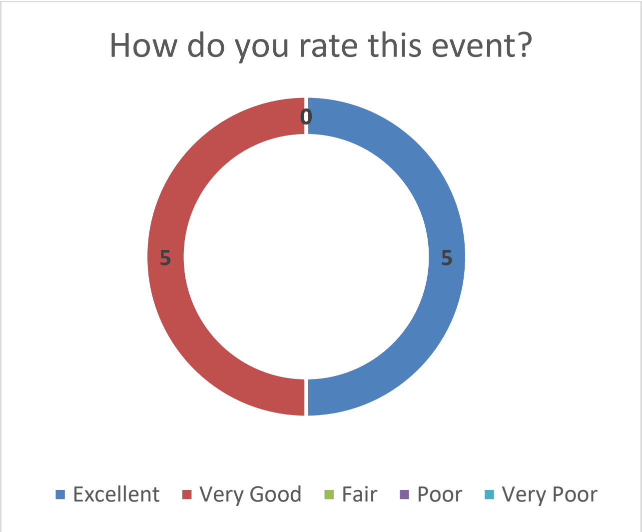


Figure 1 – families rating of JDM day

Of the 6 responses, all 6 families rated the event as Excellent or Very Good. As part of the post event analysis, families were also asked in what way the event had been of benefit to them. Of the 6 responses, 4 families advised that getting to meet other families and sharing experiences was a key benefit to them. 1 family also reported feeling more knowledgeable and informed about their condition and 1 family were better informed about studies due to the event. A key part of these events is to remove the isolation often associated with rare conditions.

Although the event overall was well received, there was some feedback on the venue. An alternative venue is to be sought for future events. It was also agreed that a future event would include a psychology presentation.

Patient experience survey

A patient experience questionnaire was circulated to patients and families via local teams at paediatric rheumatology clinics. In total, 173 responses were received. A breakdown of these responses by health board is below in figure 2.

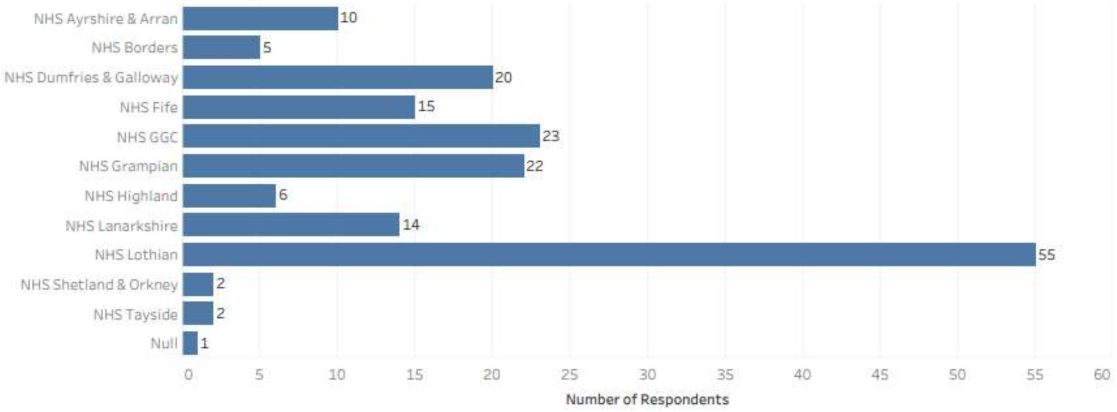


Figure 2 -responses by HB

A full analysis of the responses is being finalised; a snapshot of the responses is below:

Respondents were asked “What three things would help you and your family the most living with a rheumatic condition?”. Responses could be broken down into 4 main categories; appointments, information, medication and support. Although many responses mentioned support, 24 responses referred to the good support their local team already provided.

Patients were then asked “Thinking back over your/ your child’s experience so far of living with a rheumatic condition, what went well?”. Again responses could be broken down into 4 main categories; appointments, diagnosis and treatment, staff and support. Respondents praised the support received locally, this included praise for the support received from local teams and from local links to charities and support groups such as SNAC and the Teapot Trust.

Finally, respondents were asked “Overall, how well do you think the service met your needs?”

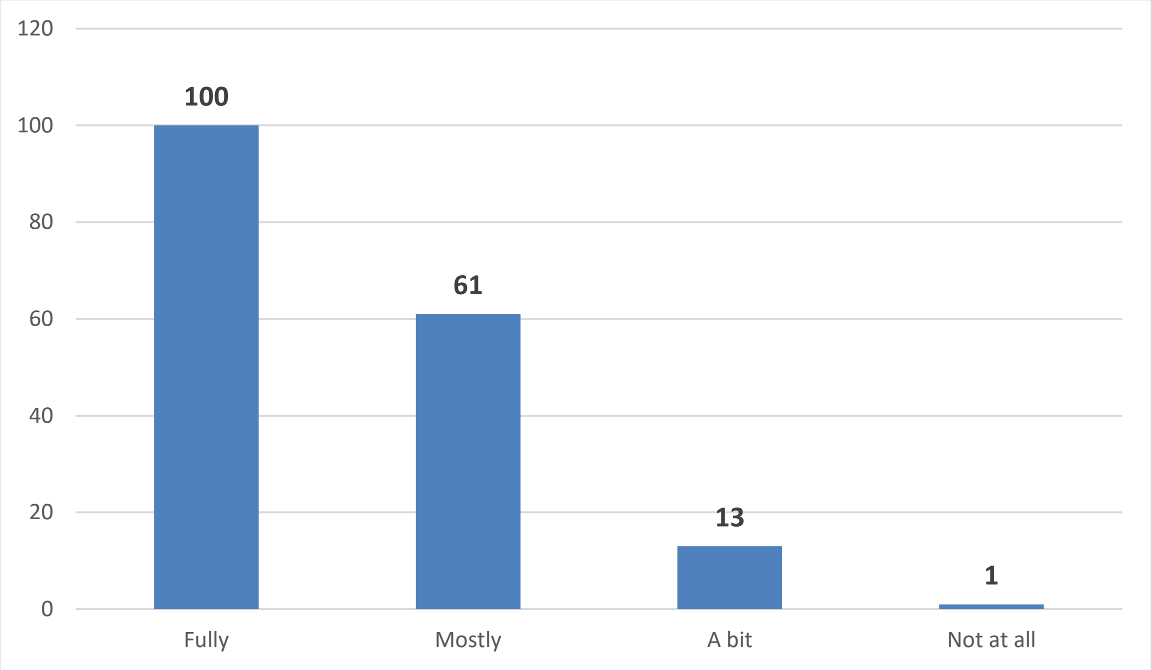


Figure 3 - how well do you think the service met your needs?

100 of 173 (58%) responses thought that the service fully met their needs, with 61 (35%) responses advising that the service mostly met their needs. In total 93% of responses felt that their local service currently at least mostly met their needs.

Each local team will also be provided with a report for their health board areas responses. This report can then be used to support local teams to either make improvements or celebrate successes.

An initial action plan has been developed based on the pan Scotland report. Further actions may be added following discussions with local teams and development of local reports.

Identified Issue	**Solution**	**Rationale**
Families struggled with knowing what information/ support was available around DLA applications, financial and travel support	Collate and signpost to existing resources on where support can be accessed and included in the new JIA patient packs	New rheumatology patients and their families can be overwhelmed with information when newly diagnosed and it was felt that an insert in the patient pack with all the

		relevant information would be useful
How useful has the JIA new patient information pack been for patients and families?	Evaluate the pack with 10 newly diagnosed patients at/ around their first appointment	To ascertain the impact of the existing JIA patient information pack and if any additional information resources were required.
Does every patient/ family receive the new patient information pack ? Do any updates need to be made to the information packs?	Audit to be completed alongside rheumatology nurses	To ensure the information given out to patients and their families was up to date and useful
Show patients/ families that the network has listened to their views and are actioning where appropriate	Develop a ‘you said, we did’ poster to be displayed in clinic areas to demonstrate to patients/ families that their views were considered and work was being done to address them	To provide evidence to patients and their families that the questionnaire was worthwhile and show that each board was taking their feedback into consideration when looking at service provision.

Education

This year’s Annual Education Meeting was held in Dumfries and Galloway Royal Infirmary on 9th June 2022. This year’s topic was JAK inhibitors. This event was the first to utilise a hybrid model, while the meeting physically took place in Dumfries there was an option to dial in virtually via Microsoft teams for those unable to travel. Networking is a vital part of SPARN, this is not as easy in a virtual setting, so this meeting is the one meeting each year where travel is encouraged where possible. In total 53 delegates attended the meeting, 29 in person and 24 virtually.

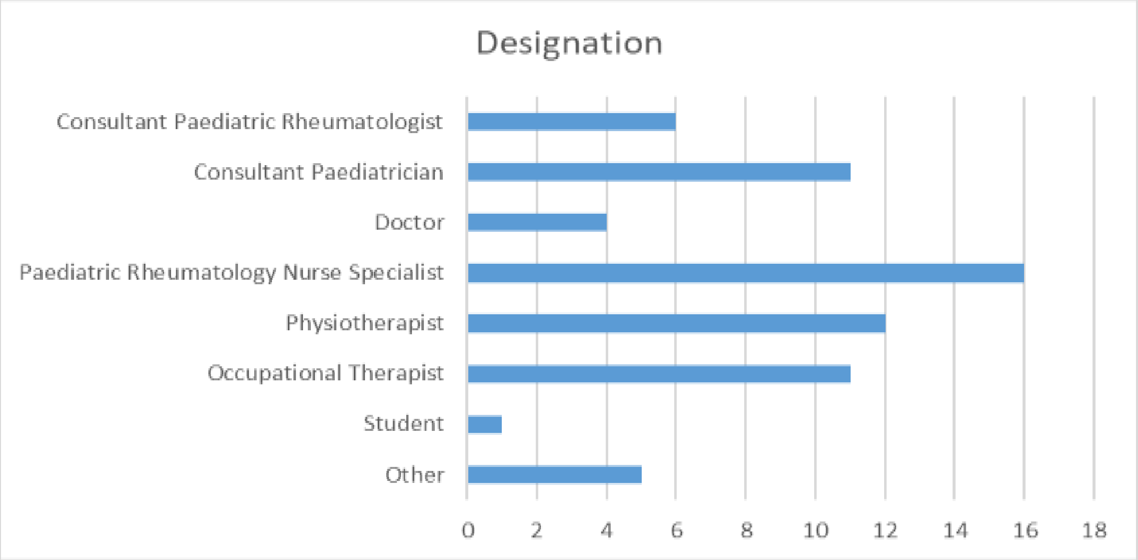


Figure 4 -AEM delegates by profession

The chart above (figure 4) identifies the profession of attendees at this year’s meeting, highlighting that the meeting continues to be attended by all parts of the paediatric rheumatology Multi-disciplinary team.

Figure 5 -AEM delegates by HB

The chart above (figure 5) identifies the split of delegates by their host board. There was a good mix of attendees from almost all health boards, ensuring that this event (and the network) continues to benefit from pan Scotland engagement.

In total, 33 delegates completed a post event evaluation. Delegates where asked a number of questions on the event. A full analysis is available from the SPARN website, a snapshot is included below to evidence the impact of this event.

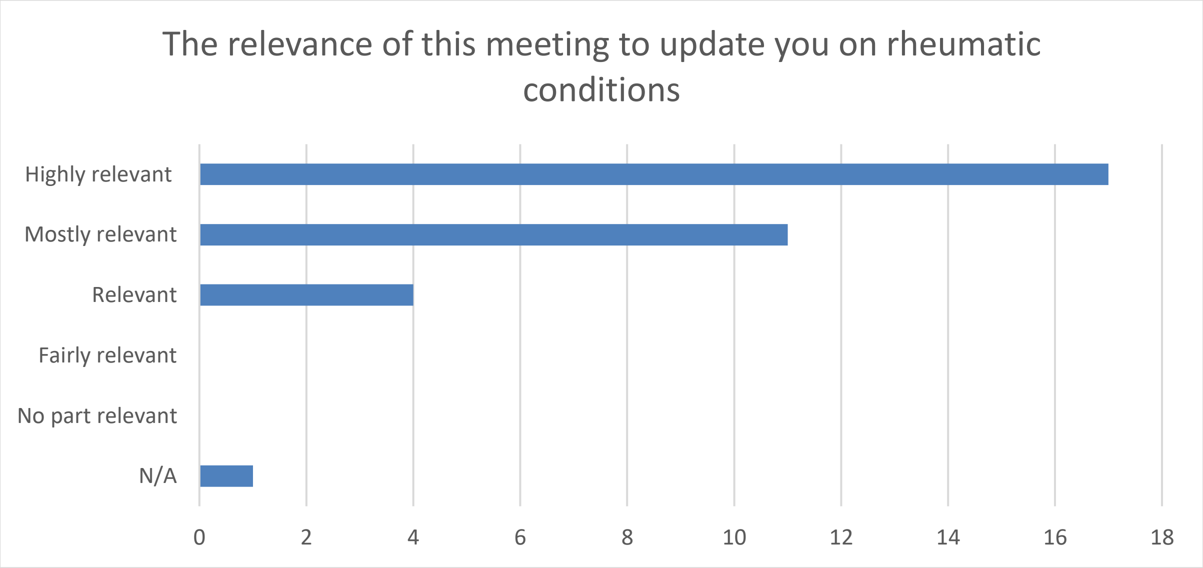


Figure 6 - Relevance of this meeting to update on rheumatic conditions

The first question above (figure 6) was used to understand whether or not the meeting met its purpose of providing an update on paediatric rheumatology conditions to clinicians working with this patient group. 32 out of 33 (97%) responses advised the meeting was at least relevant, with 28 (88%) rating the meeting as mostly or highly relevant.

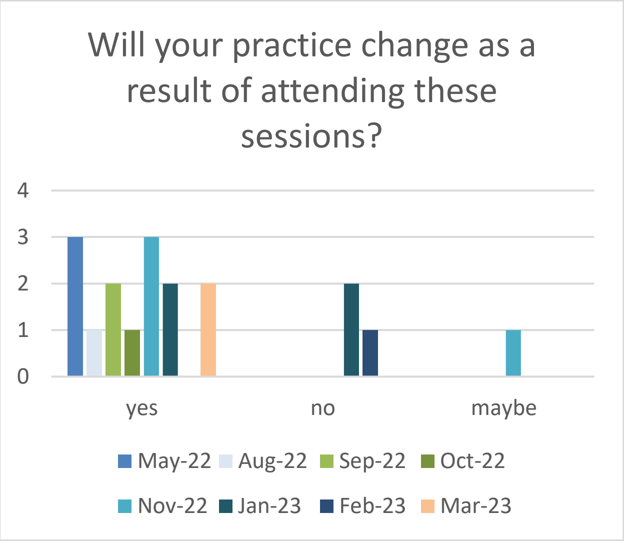
Further questions were asked to try to understand what impact there was to practice following the event. The most common response to this question was “improved knowledge and confidence in managing these patients”. Other responses included “increased awareness of treatment options” and “increased awareness of the Scottish wrist service which was due to be set up”.

Monthly education sessions

SPARN continues to provide multidisciplinary education for those involved in the care of children and young people with rheumatological conditions. 10 2 hour sessions are delivered each year via Microsoft teams, with recordings available to view after the sessions. The table below shows the attendance at each session and the subsequent reviews:

Date	Title	Attendees	Views
22/3/22	JIA ‘Back to basics’	17	6
16/5/22	Young Person’s experience	49	42
29/8/22	TV & Anti TNF Treatment	14	5
21/9/22	Fatigue pacing & how to promote physical activity in our patients	12	5
25/10/22	NES Tips-AH Anxiety Module (not recorded)	9	n/a
14/11/22	Sclerodermous GVHD	28	3
19/1/23	Oral manifestations of rheumatological disease & a practical approach to mouth ulcers	16	2
28/2/23	Bone Tumours	27	2
27/3/23	Neurology for Rheumatologists	27	1

Each individual education session is evaluated to ensure that the sessions continue to provide high quality education and meet the needs of stakeholders. An aggregate score for the two questions “Did the session meet its purpose” and “Will you practice change” from across 2022/2023 is included below:



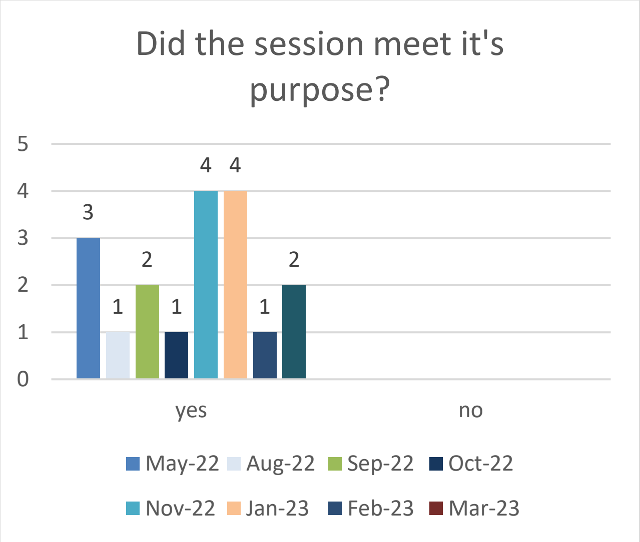


Figure 7 - did the session meet its purpose?

Figure 8 – will your practice change?

Guideline use / impact

SPARN has produced a number of guidelines throughout the years however no work had been done to monitor the uptake of these guidelines in local services or the impact they have had to patients / services. In order to begin this piece of work a survey was developed to audit the use of SPARN guidelines across the country. 9 responses were received from 8 boards. Results of this audit are below:

Q. Were you aware that SPARN guidelines are hosted on the SPARN website

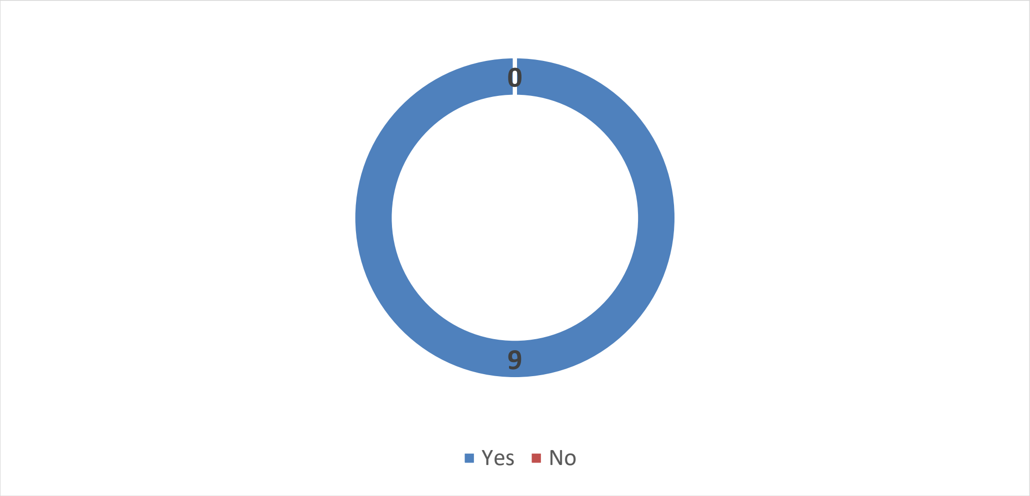


Figure 9 – awareness of SPARN guidelines hosted on SPARN website

All 9 respondents were aware that SPARN guidelines were hosted on the SPARN website, indicating that SPARN had succeeded in ensuring that local teams were aware of the guidelines which had been developed.

A question was then asked around the use of guidelines to understand how often each guideline was utilised.

Q. How often are patients presenting with rheumatology conditions treated according to these guidelines?

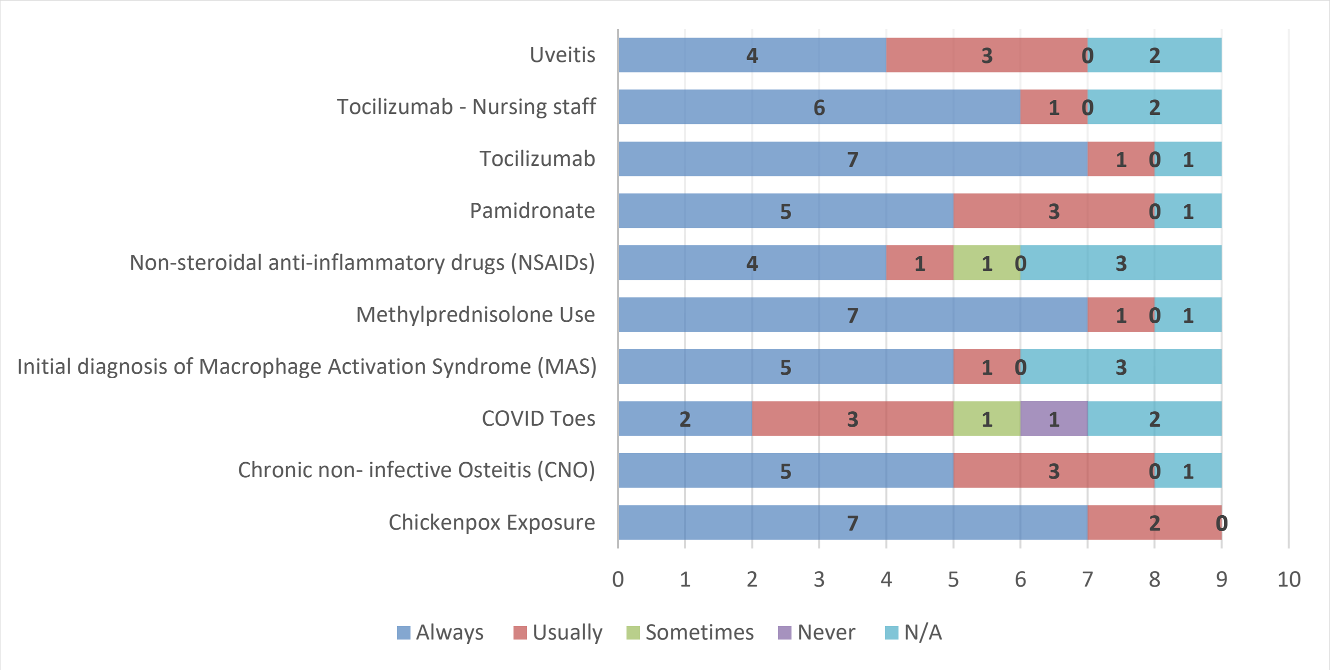


Figure 10 – use of SPARN guidelines

Almost all responses indicated that patients were always or usually treated according to SPARN guidelines. Where this wasn't the reported response a common reason for this was that the condition, such as COVID toes, had not been treated in that clinic. This accounted for the N/A responses.

A final question was asked to try to understand any barriers to following the SPARN guidelines. Only a small number were reported, this included:

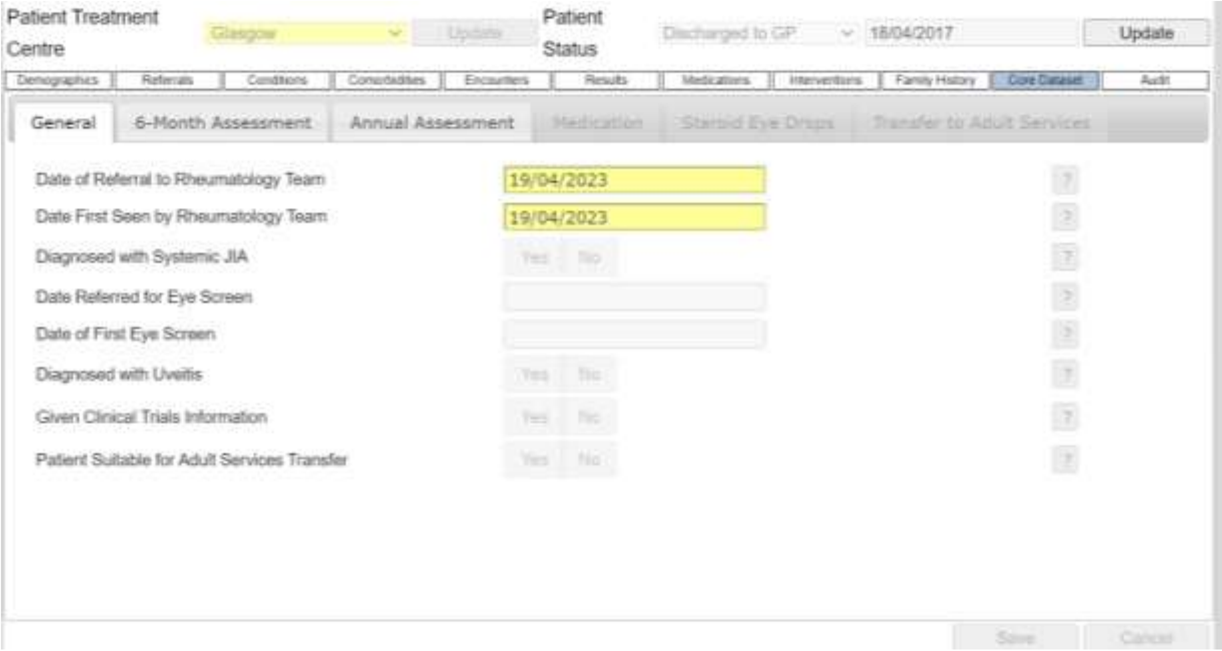
- Uveitis which relied on Ophthalmology being available which was not always the case
- Junior doctors not always being aware of guidelines
- Geographic spread of patients means they can present at A&E out with paediatric rheumatology care

- While there was general awareness of SPARN guidelines being hosted on the website, there was not always awareness of which specific guidelines were available

An action plan is being developed to investigate what can be done to better support the uptake of these guidelines and begin to evaluate their impact. This will be taken forward in 2023/2024.

Data

Following the refreshed quality indicators, a revised CAS core data set has been developed alongside the IMS. Once signed off, this core data set page will allow for the refreshed quality indicators to be audited. The core data set page is split into 6 screens, general, 6-month assessment, annual assessment, medication, steroid eye drops and transfer to adult services. The general screen is included below:



Patient Treatment Centre: Glasgow

Patient Status: Discharged to GP 18/04/2017

Date of Referral to Rheumatology Team: 19/04/2023

Date First Seen by Rheumatology Team: 19/04/2023

Diagnosed with Systemic JIA

Date Referred for Eye Screen

Date of First Eye Screen

Diagnosed with Uveitis

Given Clinical Trials Information

Patient Suitable for Adult Services Transfer

Figure 11 – SPARN CAS core data set page

Looking forward – 2023/24

Looking ahead to 2023/24 priorities for the network include:

- Rollout of new CAS instance and initial audit of CQI’s
- Gathering feedback on transition care to identify what is important to young people and use this to identify key improvement projects to be taken forward.

Further add to this by developing a process to audit current transition processes across Scotland.

- Support the establishment of a new wrist service to treat patients with erosive arthritis for arthroscopy under GA in theatre.
- Delivering action plan developed following patient experience questionnaire and roll out of individual board reports
- Supporting the continuing professional development of staff involved in supporting children and young people with rheumatological conditions
- Continue work to evaluate the impact of SPARN guidelines
- Refresh of strategic workplan

Finance

The 2023/2024 finance summary is:

Catering for SPARN education event -	£ 540
JDM Families Day costs -	£ 900
SPARN Nurses meeting costs -	£ 480
CAS Development -	£2532
Total spend	**£4552**

Risks and issues

There are currently no ongoing risks or issues