

Scottish Paediatric and Adolescent Rheumatology Network (SPARN) ANNUAL REPORT 2018/19

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1. Executive Summary

2018/19 has been another successful year for SPARN. The network continues to work ably with its stakeholders and its focus has evolved to provide support for the more complex and rarer rheumatic conditions, such as Uveitis.

The network has once again implemented an excellent, diverse programme of education events for clinicians, including the SPARN national meeting.

A new guideline on Chronic Non-Infective Osteitis (CNO) has been produced; others will be completed in 2019/20 alongside a programme of reviewing existing ones.

Looking ahead to 2019/20, the network will continue to implement its agenda relating to data and information, delivering high quality information to support patient care.

Two important audits (on medication and Uveitis) have been completed in the west and will be rolled out nationally.

SPARN will also continue to progress its work in improving transition processes and services for rarer rheumatic conditions.

The network will continue to work to improve its understanding of what users think of the service, through surveys and links with the third sector.

2. Introduction

The Scottish Paediatric and Adolescent Rheumatology Network (SPARN) was designated as a National Managed Clinical Network (NMCN) in April 2009. Formal designation was preceded by a period of informal networking and the MCN was officially launched on 27th April 2009.

Juvenile Idiopathic Arthritis (JIA) is the most common rheumatic condition affecting children. The known prevalence of this condition in the UK is 1 in 1,000 children. In areas where the network clinics are well established the number of known cases is in line with this. Early recognition and optimal treatment of JIA is known to be associated with improved outcome and the network aims to ensure that all children with JIA in Scotland, including those with JIA associated Uveitis, are diagnosed promptly and managed appropriately.

Complex autoimmune inflammatory conditions such as Juvenile Systemic Lupus Erythematosus, Juvenile Dermatomyositis, Scleroderma and Systemic Vasculitis are individually rare but together represent a significant workload for paediatric rheumatology services. These children have complex diseases often requiring access to multiple specialties for optimal care.

Hypermobility and other non inflammatory musculoskeletal conditions affecting children are also recognised as a part of paediatric rheumatology workload. Initially the network has necessarily focussed on JIA. More consideration is now being given to these other patient groups.

SPARN has achieved great progress in developing paediatric rheumatology services since its designation. The biggest impact for the network has been in facilitating local delivery of specialist care. There is evidence 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 board areas and these are supported by local multidisciplinary teams including nurse specialists, physiotherapists and occupational therapists. Work has begun to ascertain the extent to which these clinics adhere to the SPARN standard for a network clinic.

The network has increased the focus on family and stakeholder engagement. SPARN provides ongoing support and resource for patient events in conjunction with support groups such as Scottish Network for Arthritis in Children, Versus Arthritis and Teapot Trust. Feedback from these events provides evidence that families affected by rheumatic conditions are feeling less isolated and more knowledgeable. Two of the organisations are represented on the Steering Group.

3. Report on Progress against Network Objectives in 2018/19

National networks have agreed core objectives that reflect the Scottish Government's expectations for managed clinical networks, as described in CEL (2012) 29¹. The network's core objectives are:

1. Design and ongoing development of an effective Network structure that is organised, resourced and governed to meet requirements in relation to SGHSCD Guidance on MCNs (currently CEL (2012) 29) (Annex) and national commissioning performance management and reporting arrangements.
2. Support the development, design and delivery of services that are evidence based and aligned with current strategic and local and regional NHS planning and service priorities.
3. Effective Stakeholder Communication and Engagement through design and delivery of a written strategy that ensures stakeholders from Health, Social Care, Education, the Third Sector and Service Users are involved in the Network and explicitly in the design and delivery of service models and improvements.
4. Improved capability and capacity in services for children with CF and their families through design and delivery of a written education strategy that reflects and meets stakeholder needs.
5. Effective systems and processes to facilitate and provide evidence of continuous improvement in the quality of care (CQI).
6. Generate better value for money in how services are delivered.

This report gives an overview of progress against these objectives in the year 2018/19.

3.1. Effective Network Structure and Governance

The network Lead Clinician is Dr Neil Martin, a Consultant Paediatric Rheumatologist from NHS Greater Glasgow and Clyde. Dr Martin has been in post since September 2017 and his tenure is until 2020/21. The Steering Group has representation from all professions involved in the network including specialist nursing, AHPs, pharmacy, and the Voluntary Sector. The purpose of the steering group is to direct and support the development of the network and the services it encompasses. It has the remit to establish work streams and support implementation of recommendations/guidelines which will enable delivery of the networks' designated objectives.

Rather than working with traditional sub-groups the network has instead opted to work with various work streams allowing for more fluidity and for much of the work to be done virtually.

The work streams are:

- Education and Training
- Working with families
- Quality Outcomes and Audit
- Service Development and Guidelines
- Transition

The network was supported through the National Network Management Service (NNMS) in NHS NSS with access to a Network Manager, Greg Fearn, and a Programme Support Officer, Michael Durkan (March 2018-August 2018) and then Laura Craig (December 2018 onwards). Data support has been provided by Mike Gunn, Data Analyst (NNMS Information Management Service).

The Terms of Reference for the network are being updated and will be endorsed at the SPARN Steering Group meeting in June 2019.

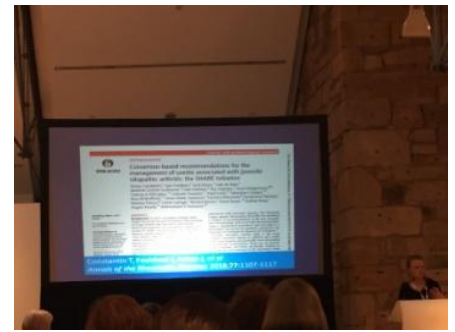
¹ Please see: https://www.sehd.scot.nhs.uk/mels/CEL2012_29.pdf

The network agreed a new service level agreement with NHS NSS in July 2018 for the three years to 2021.

3.2. Service Development and Delivery

Transition

One of the key priorities for the network in 2018/19 has been transition. The network planned and held a successful Transition Day in Glasgow on the 15th March 2019. The event was organised in partnership with the Scottish Society for Rheumatology (SSR) and targeted adult as well as paediatric clinicians. The aim was to promote the need for better coordination between adult and paediatric services and the keynote talk was on the Ready Steady Go transition process by Dr Arvind Nagra of Southampton General Hospital. 75 clinicians attended from across Scotland. 33 evaluations from the event have been received. The evaluation demonstrated high levels of satisfaction among delegates.



Dr Jo Walsh addressing speakers at the Transition event

How did you rate the relevance of this event to your educational needs?

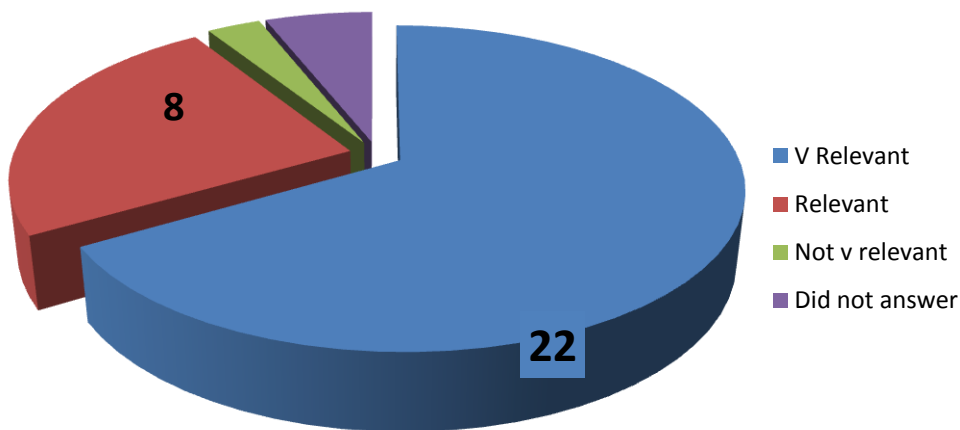


Fig 1 – Relevance of the event

What was your overall impression of the event programme? (5 - excellent - 1 - poor)

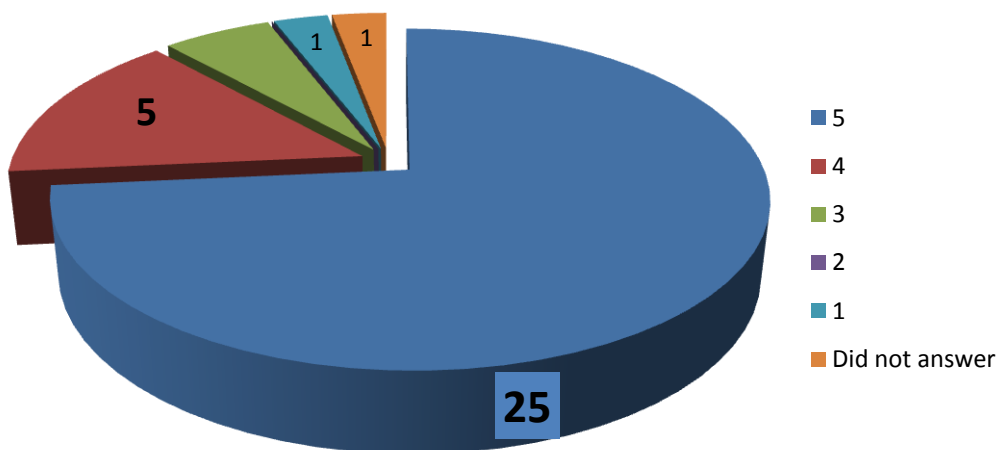


Fig 2 – Overall impression of the event programme

Additionally the evaluation gave delegates an opportunity to comment on what impact the event will have on future practice. A selection of the responses are listed below;

- I will have improved communication skills when seeing adolescents in clinic
- This will inform a research project for a prospective PhD student evaluating transition processes in Scotland.
- We are organising a meeting between adults and children to think about evaluating what is currently happening and measuring improvements that we make for the future
- Will consider developmentally appropriate health care. Different ways of working virtual clinics , text
- It will enhance my clinical approach to evaluating and managing adolescents with rheumatic disorders.
- I will be more patient and understanding of my teenage/early 20's patients.

Guidelines

The network has approved its new guideline for Chronic Non-Infective Osteitis (CNO). Additionally a number of guidelines have been developed by the NHS Lothian pharmacist on behalf of the network who has worked closely with the networks Guidelines Lead (a consultant from NHS Lothian also). Regular updates have been provided to the network via the guidelines lead. They are to be distributed to the network with a view to approval at the Steering Group meeting in June 2019. The guidelines are listed as follows:

- Rituximab
- Cyclophosphamide
- Tocilizumab
- Illoprost
- Pamidronate

Additionally the SPARN flu guidance was updated in 2018 and the network is in the process of working with radiologists to produce a radiology guideline.

Network Audit

SPARN has piloted an audit of the network standards in two services. The audit showed that these two (non-specialist) centres had appropriate levels of compliance against the network standards. Of the two sites audited one was a medium sized service with high levels of compliance to the standards in terms of the MDT team and access to specialist services locally. The other board was a small service in a rural health board. This had less access to specialist staff locally and some specialist services. The project will be rolled out nationally in 2019/20 and the findings reviewed to measure whether network standards are being met. Where this is not the case, SPARN will seek to work with paediatric rheumatology services and health boards to address gaps in provision.

3.3. Stakeholder Communication and Engagement

Uveitis event

On the 15th September 2018 the network organised, as part of its strategy to focus on rarer conditions, an information and engagement day for families affected by Uveitis. The event was held at the Mitchell Library in Glasgow. Around 30 parents, carers and children participated. Delegates were split into three groups;

- Parents / carers
- Older children
- Younger children

Specific programmes and activities were developed for each group, overseen by clinicians and specialists in activities such as storytelling and art. There was a session for parents to network with clinicians on relevant aspects of management and services. The event was very positively received with all eight families who completed an evaluation rating it 5/5.

For example, in response to the question, *in what ways has today been of benefit to you and your family*, the following responses were received;

- Better understanding is good. We are family of 5 and all of us are affected but knowing and understanding will allow us to talk about more.
- Learnt more about xxxx's eyes
- To meet other families and children in the same position it can feel quite isolating you think you're the only one in this position
- Answered all the questions I had
- Refresher for long-term families and inform re updated treatments
- Meeting others
- Improved awareness, understanding, knowledge

Uveitis books

Two books have been produced by a SPARN specialist nurse in conjunction with the Scottish Network for Arthritis in Children (SNAC). The books are specifically targeted and younger and older children and are available from the Network Team. The books are listed below;

- Polly's Sore Knee & Sore Eyes (younger children)
- Seeing Through the Snow (older children)

1st SPARN National Family Survey

In the second half of 2018/19 the network initiated its first SPARN Annual Family Survey. A questionnaire was developed by a short life working group and was distributed to specialist nurses across Scotland. It was agreed at the 2018 SPARN Annual Education Meeting that all teams would take part in the survey. However only five of eleven services distributed and collated the questionnaires. A number of services stated that they were too stretched to distribute and collate the questionnaires. A sixth service provided data too late for it to be included in the initial analysis for the presentation at the British Society for Paediatric Rheumatology Nursing Conference in Edinburgh in May 2019. The additional responses will be included in the final SPARN report. One other board did not participate as it completes its own family survey. Yet, they hadn't raised objections when all services had signed up to the SPARN survey. The network will address this in 2019/20, through the Nursing Lead, with the service in question. A request has gone to the service for the aggregated results of their survey.

A total of 169 responses were received and they are broken down by health board in the table below.

Health Board	Number of Responses
Ayrshire & Arran	20
Borders	7
Fife	25
Greater Glasgow & Clyde	91
Tayside	26
Total	169

Responses were only collated in March 2019 and results have not yet been analysed. A full report on the survey will be available in time for the June 2019 Steering Group meeting.

Increased 3rd Sector Representation

The network has three charitable organisations represented within the network now that Versus Arthritis has a member on the Steering Group (the other two being SNAC and The Teapot Trust). Versus Arthritis has prioritised transition and are working with the network on this issue.

Ongoing Support for Third Sector

SPARN continues to provide support through the network and its clinicians raising awareness of events and contributing content and support. These have included in 2018/19:

- SNAC Information Day – November 2018
- SNAC Family Weekend – March 2019
- Supporting the Versus Arthritis 10th Anniversary meeting at the Musculoskeletal Cross Party Group to be held at the Scottish Parliament in May 2019.

These events are crucial for the third sector, as the expertise provided by SPARN clinicians enables the success of these events and promotes good links with the network. The gains from the strength of these relationships enable SPARN to work closely towards mutual goals in delivering events and resources for families affected by paediatric rheumatological conditions.

Communication Strategy

The network will update its Communication Strategy as a priority in 2019/20.

Website

The SPARN website statistics are included in Appendix 3. This is the first year this data has been collected and there is a clear increase in activity in quarter 4, suggesting increased use of the site during the course of the year.

3.4. Education

Monthly Educational Sessions

Monthly education sessions have continued into their 9th year. These sessions continue to be a cornerstone of the work of SPARN allowing free, easy to access education for a broad range of clinicians. Attendance at the sessions is by videoconference and each session continues to be attended by at least five to eight sites. A total of 62 sites attended across the sessions in 2018/2019, down slightly from 66 in 2017/18. Local centres and individual professional groups have led on an increasing number of sessions. A greater emphasis has been placed on rarer conditions in 2018/19. Two sessions have been evaluated in 2018/19 to ensure that they meet the needs of professionals working in SPARN and to monitor what impact the sessions are having on practice. The feedback from the evaluations was very positive with all 12 respondents scoring the events 4 or 5 (1 meaning poor and 5 meaning excellent). Comments back included;

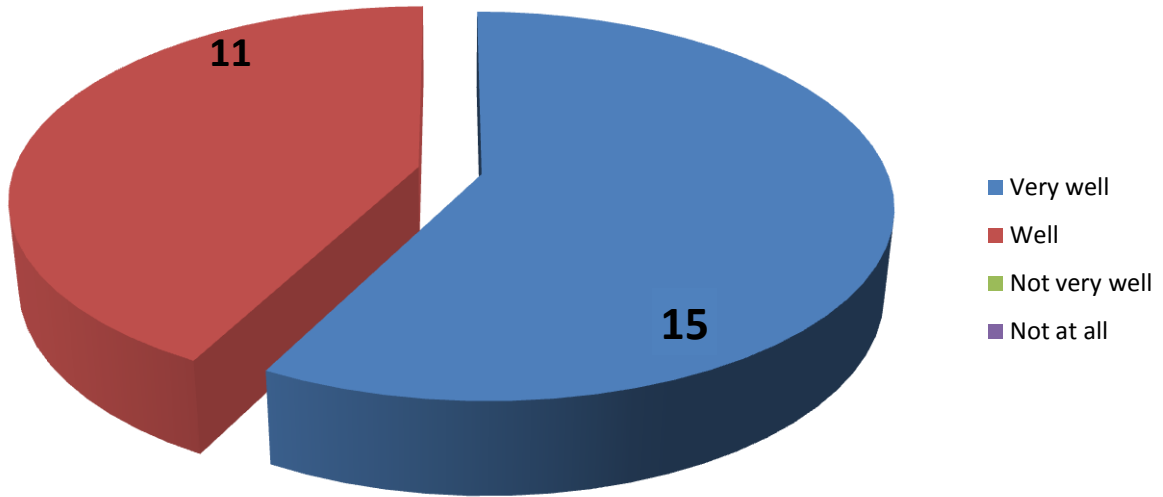
- I have a deeper understanding of the complexity of treating lupus
- Increased knowledge in the clinical features of SLE
- This session has increased mine and also the physio's who attended with me knowledge.
- a successful session with high quality education delivered

Annual Educational Meeting – May 2018

The SPARN Annual Education Meeting was held on the 18th May 2018 at Borders General Hospital, Melrose. The focus of the morning session of the event was Ehlers Danlos Syndromes (EDS), a group of genetic connective tissue disorders. The keynote speaker was the head of the EDS National Diagnostic Service in Sheffield. Case presentations from local registrars preceded the keynote talk. Finally there was a physiotherapy update on EDS.

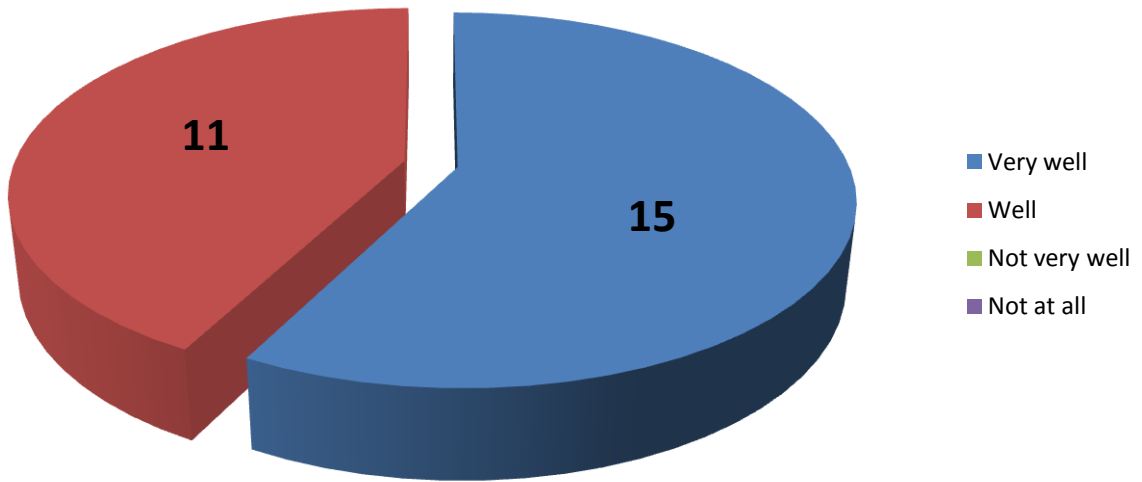
The afternoon session was the network focused content including a SPARN update, SPARN workshops, updates from third sector stakeholders and professional group meetings. A total of 57 delegates attended the event and there were 26 returned evaluation forms. These provided very positive feedback for the event.

How did you rate the relevance of the event to your educational needs?

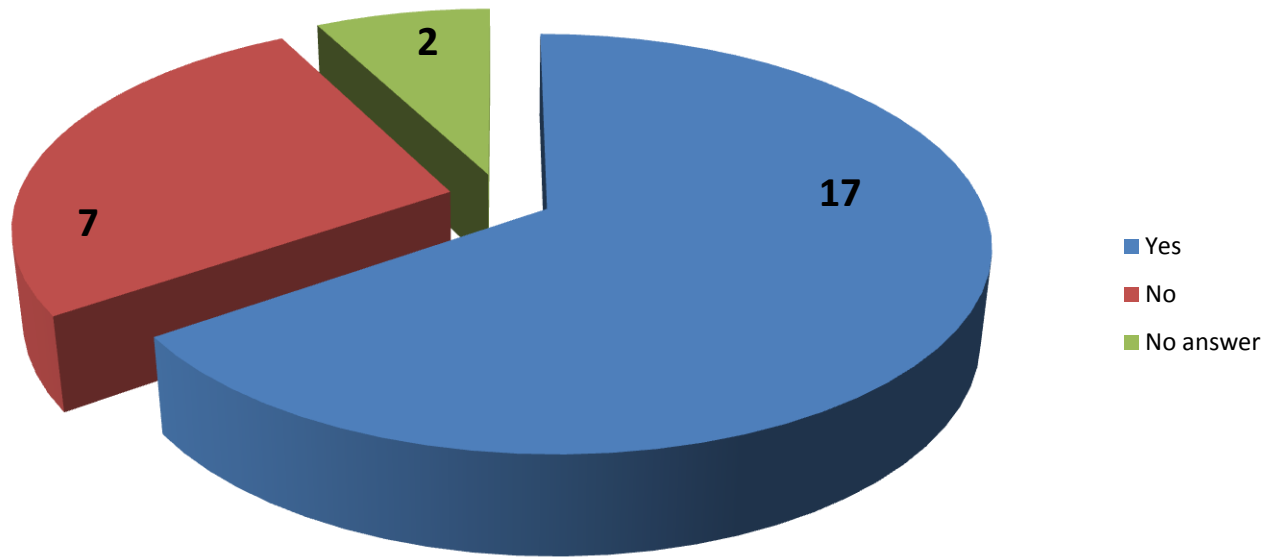


How did you rate the overall quality of education offered by this event?

Quality



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



Below are a number of examples of how clinicians stated their practice would change.

- I will be less likely to miss VASCULAR EDS in my future jobs!
- Much more vigilant regarding the complexities of this condition. Confidence improved
- I feel I have a better understanding of the different types of EDS and due to this be more able to think of this as a differential diagnosis.
- More aware of subtypes of EDS and overall physiotherapy management.
- Not having children on humira alone. More confidence managing EDS
- Checking serum calprotectin levels and anti TNF levels

3.5. Audit and Continuous Quality Improvement

Data Subgroup

The network initiated a Data Subgroup in 2018 to improve SPARN's direction and progress with its data and quality improvement agenda. The subgroup is made up of the programme manager, Lead Clinician, joint data leads (Consultant and Specialist Nurse, IMS data manager and an additional Specialist Nurse). The subgroup has met on three occasions to develop the network's approach to improving data collection, revising clinical quality indicators, developing clinical audit projects and the approach to meeting the General Data Protection Regulation (GDPR) requirements for consent on the Clinical Audit System (CAS).

Clinical Audit System Consent

A significant challenge for the network in 2018/19 has been to meet the GDPR for the patient data held on the Clinical Audit System (CAS). GDPR requires the network to gain the explicit consent of patients (or parents / carers) for their data to continue to be held for the purposes of clinical audit and data management. Approximately 1,800 patients had their data recorded on the system at the onset of addressing the consent issue.

The network has worked closely with clinicians (chiefly specialist nurses) to seek this consent. Network members across Scotland have made robust efforts to get written (explicit) consent. Support from the network and the IMS has supported this process. Lists of outstanding unconsented patients have been supplied to clinicians. However this has proved difficult to fully implement. At the 31st March (two months before the GDPR deadline) around 38% of patients on CAS had been consented. This figure is very likely

an under estimate as not all consented patients had their consent entered onto the system and work is still ongoing to remove records of non-active patients (e.g. those who have transitioned or been discharged). To date, the network has removed around 400 patients from CAS who have transitioned or been discharged from the service.

Uveitis Audit

Dr Gardner-Medwin undertook a Uveitis audit for the west of Scotland regional service. The audit showed a clear improvement in outcome due to the Uveitis screening and treatment guidelines and will be helpful for creating the updated versions, which remain in progress.

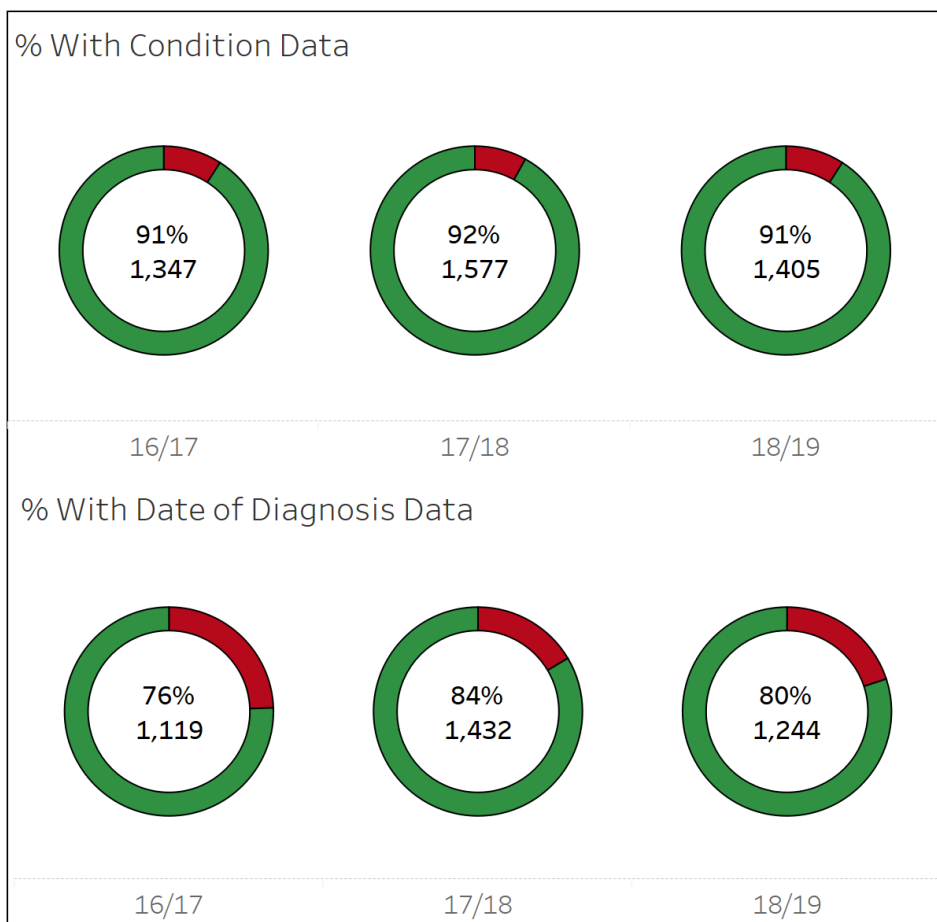
The next objective will be to capture data across Scotland. Obtaining data from District General Hospitals may pose an issue due to small numbers. The audit data would begin from when the service became a paediatric service with links between Paediatric Rheumatology and Ophthalmology departments. A project brief is to be written in 2019 with the aims, objectives and outcomes and a data collection proforma based on the original audit.

Report on Existing CQIs

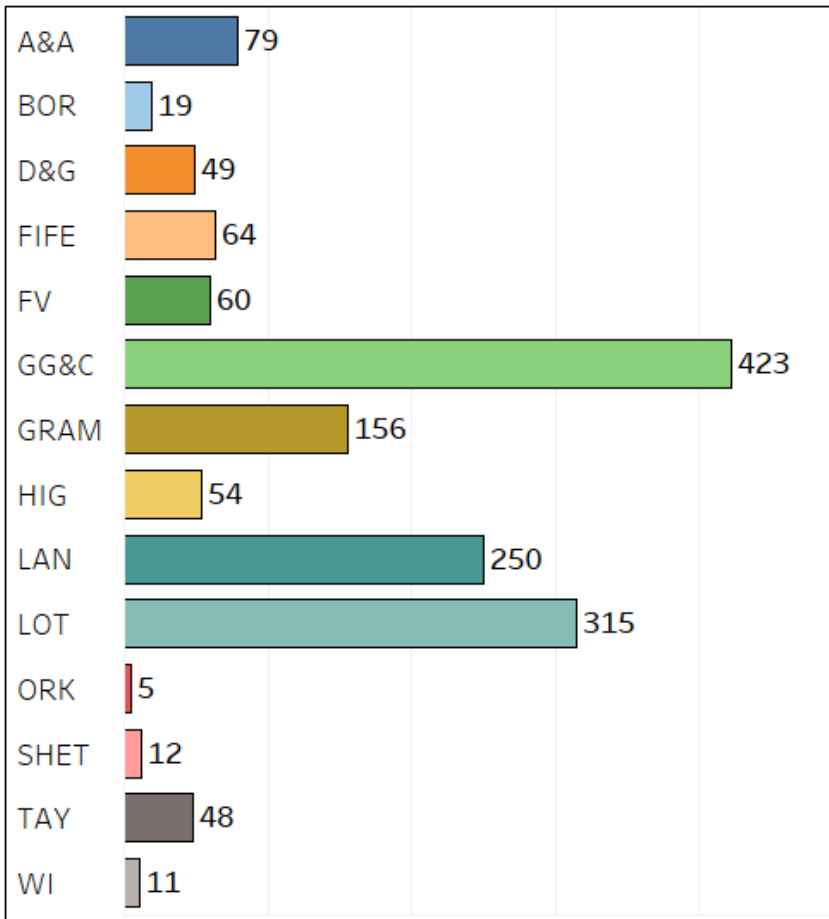
Introduction

In late 2018/19 the network undertook an audit to remove patients that were no longer seen by SPARN services. In particular the network wanted to audit patients over the age of 18 and/or those with a condition of "OTHER" or "UNCLEAR". Network centres were sent their respective patient lists in order to complete this task. The completed files were then returned and the 400 patient status' were updated as a consequence. This has resulted in a lower number of patients on the CAS, something that is likely to continue into 2019/20 as the network finalises revising this cohort.

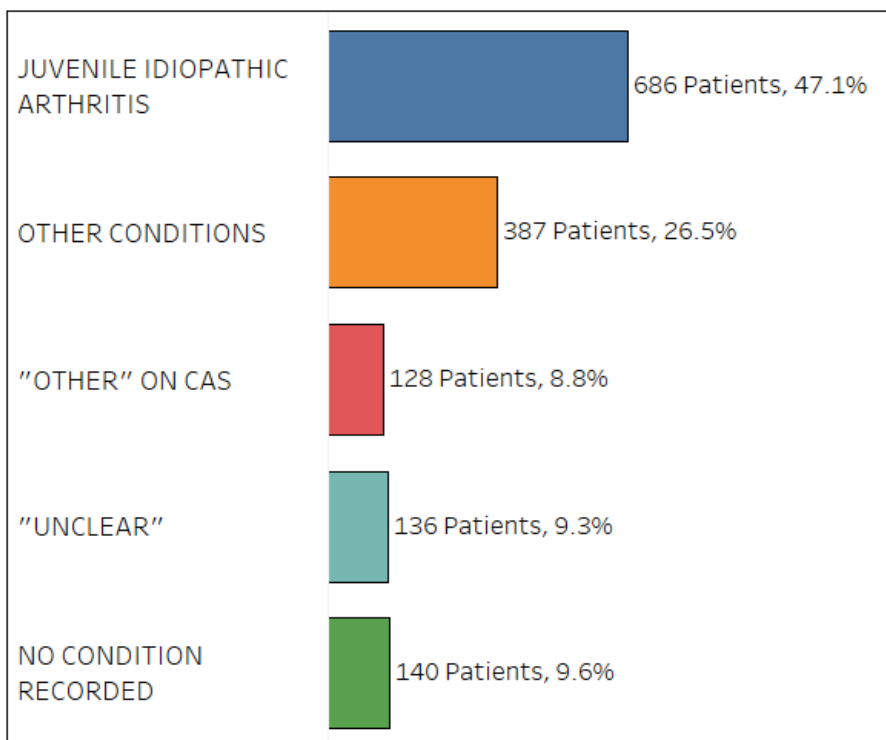
% of Patients on the Clinical Audit System with Condition Data



Total Number of Patients by Treatment Centre



Top 5 Condition Groupings (Most frequent conditions & "Other Conditions")

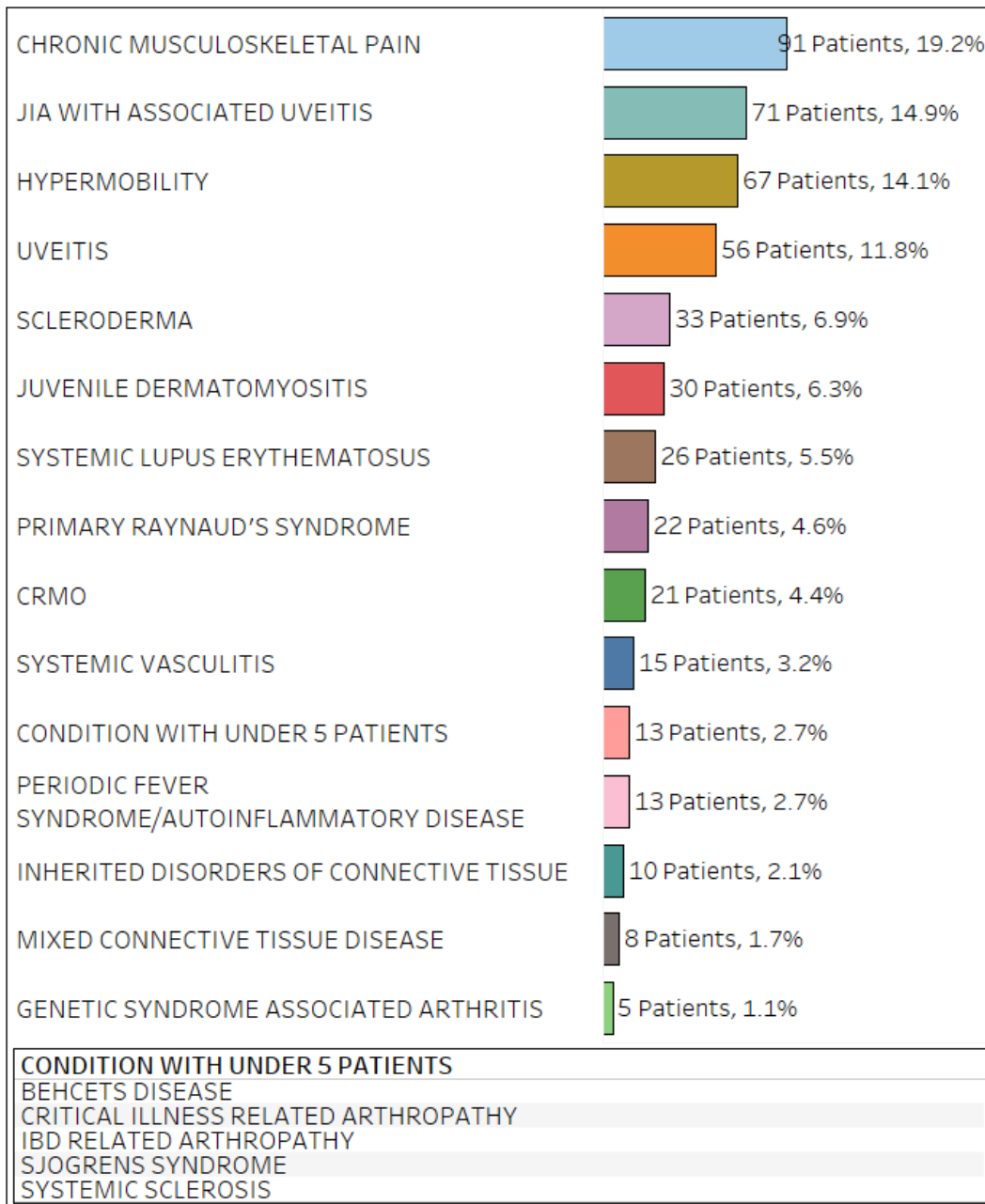


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The above graph shows the top 5 condition groupings on the SPARN CAS. Please note the following definitions:

- “OTHER” ON CAS: patients that are seen by a SPARN service, however their condition was not on the CAS list
- “UNCLEAR”: patients seen by a SPARN service but a clear diagnosis could not be made
- “OTHER CONDITIONS”: a grouping of patients with any of the other recognised conditions in the CAS outside the top 5 condition grouping.

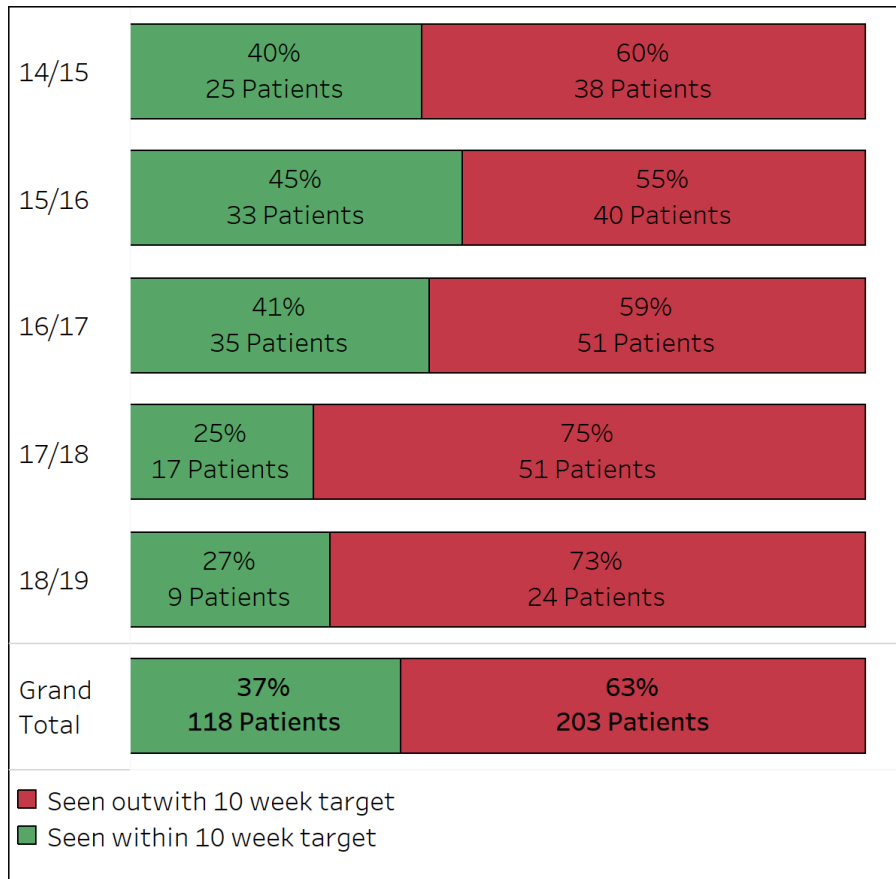
% Breakdown of List of “Other Conditions” Conditions



Quality Indicators

QI 1 – Time from onset of symptoms to first paediatric rheumatology appointment

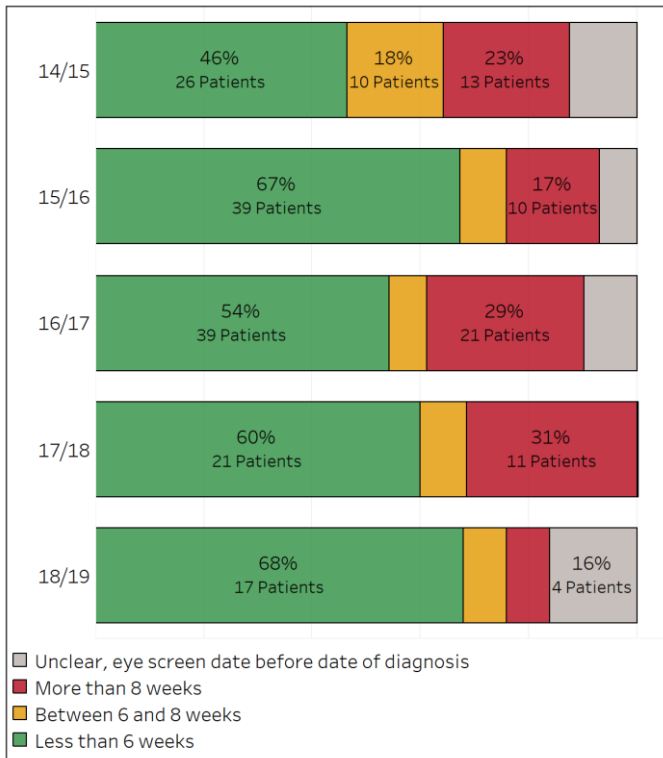
(BSPAR standard 10 weeks) The chart below shows the percentage of patients with JIA who are seen by a Paediatric Rheumatologist within 10 weeks of the onset of symptoms.



Although only 27% of patients are seen within 10 weeks of onset of symptoms in 2018/19, the average waiting time for a paediatric rheumatology clinic is 6 weeks. As with previous years the delay in diagnosis continues to be between onset of symptoms and referral to paediatric rheumatology. IMS have changed the format for reporting from calendar year to April to March which may explain some of the discrepancy in 2018/19. Also all data may still not be entered for all patients at their first appointment. However this is something the network will investigate in 2019/20.

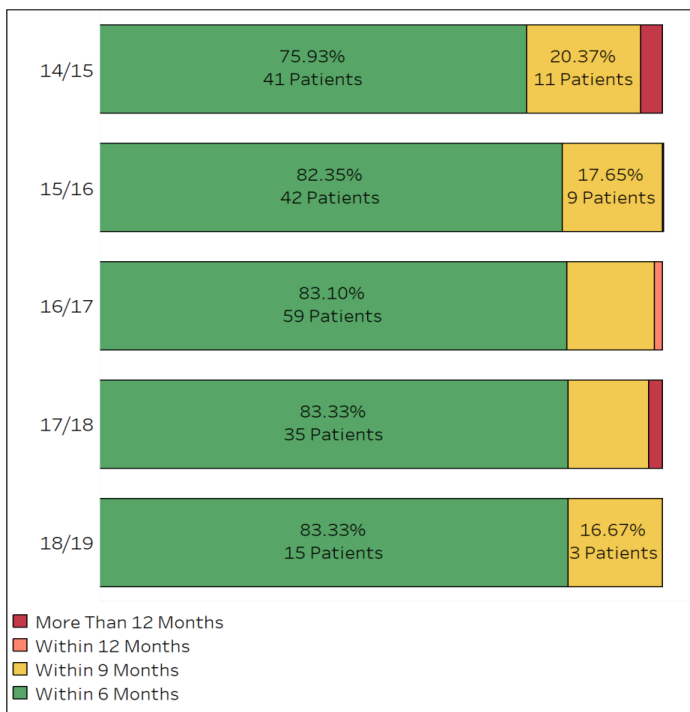
QI 2 – Time from eye screen referral to first successful eye screen (BSPAR standard 6 weeks)

The chart below shows the percentage of patients with JIA with a successful eye screen within 6 weeks of referral. The percentage of patients having a successful eye screen continues to improve.

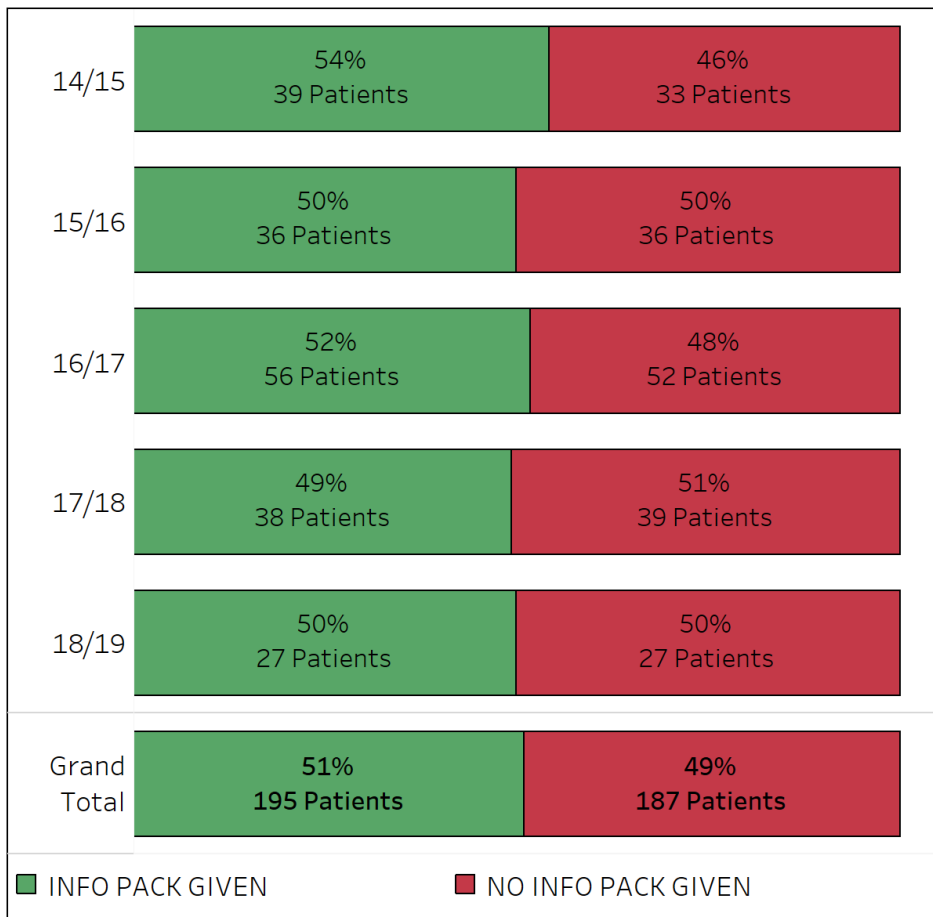


QI 3 – JIA patients on Methotrexate

The chart below shows the percentage of patients on methotrexate. This CQI is being removed in 2019/20 as it no longer relevant following sustained improvements in prescribing practice and a reduction in patient numbers.



QI 4 – Percentage of patients given a network approved JIA information pack



The number of families receiving a pack has remained static at around 50%. The network will develop an electronic resource in 2019 on its website to support the promotion of good quality patient / family information.

QI Strategy

The SPARN Quality Improvement strategy will be completed as a priority by summer 2019.

3.6. Value

AntiTNF Quality improvement

The Glasgow Regional service have developed and implemented a project to reduce prescribing costs in the west of Scotland. Specifically the aim of the project is to assess antiTNF drug levels in young people, alter various medications to delivery better patient outcomes and lower drug usage in an organised, safe, monitored process.

A specialist nurse from the service has lead on the project measuring biologics / antibody levels in Juvenile Idiopathic Arthritis and Uveitis and presented the work at a conference in Chicago in 2018. Thus far there had been a saving of more than £70,000, in the early cycle of this project in NHS GGC alone and without an increase in adverse events. The plan is to roll out the project across Scotland to deliver similar savings to prescribing budgets.

Genetic Chip Panel

The SPARN Lead Clinician has successfully engaged with genetics in Aberdeen for a genetic chip panel, similar to that used in Great Ormond Street Hospital, London. This is NHS funded and accredited. Samples will be analysed in Aberdeen and not require to be sent to London, cutting costs for NHS Scotland. Clear guidance and robust access around who could apply will be developed in 2019/20.

4. Plans for the Year Ahead

- National rollout of the audits on Uveitis and prescribing that have been successfully completed in Glasgow.
- Nationally implementing the Transition Survey with a follow up report encompassing that and the conclusions from the national transition event.
- Continuing the networks robust approach to education & training via the monthly MDT education sessions and the national Annual Education Meeting.
- Develop a robust Communication & Stakeholder Strategy to underpin SPARN's development in this key area for network delivery.
- Repeat the national family survey, with more health boards taking part.
- Organise and deliver a SPARN Family Day in partnership with partners in the third sector.

Risks / Issues

The CAS consent process will conclude on the 24 May 2019. Progress has been made but there may be some variation in how complete the consent process has been across Scotland. This may result in loss of data – which, without consent, cannot be legally kept beyond the May deadline – and impact on the network's ability to progress its audit and quality improvement work programme.

5. Detailed Description of Progress in 2018/19

Workplan Key

Please develop and update the table below to include the network's designation objectives and related agreed annual objectives. When planning for the year ahead, please consider the standard statements in the guidance section to inform the development of annual network objectives.

RAG status key

RAG status	Description
RED (R)	The network is unlikely to achieve the objective/standard within the agreed timescale
AMBER (A)	There is a risk that the network will not achieve the objective/standard within the agreed timescale, however progress has been made
GREEN (G)	The network is on track to achieve the objective/standard within the agreed timescale
BLUE (B)	The network has been successful in achieving the network objective/standard to plan

The Institute of Medicine's six dimensions of quality are central to NHS Scotland's approach to systems-based healthcare quality improvement; therefore objectives should be linked to these dimensions:

1. **Person-centred:** providing care that is responsive to individual personal preferences, needs and values and assuring that patient values guide all clinical decisions;
2. **Safe:** avoiding injuries to patients from healthcare that is intended to help them;
3. **Effective:** providing services based on scientific knowledge;
4. **Efficient:** avoiding waste, including waste of equipment, supplies, ideas, and energy;
5. **Equitable:** providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location or socio-economic status; and
6. **Timely:** reducing waits and sometimes harmful delays for both those who receive care and those who give care

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Workplan – SPARN 2018/19

Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective	Anticipated Outcome	RAGB status
2018-01	<p>Patient Experience Establish the patient questionnaire on family experience in all SPARN network clinics. Produce report with recommendations for further development of public engagement agenda</p> <p>Ensure continued patient representation on the Steering Group, investigate possibility of a parent rep for a non JIA condition</p> <p>A QI project on the provision of electronic patient information to children with rheumatic conditions and their families</p> <p>Continue to link with third sector organisations</p>	1,5,6	Ongoing	PM / PSO / 3 rd sector reps	<p>The annual patient experience questionnaire was distributed to all SPARN network clinics. Six undertook the survey fully and 169 questionnaires were returned. Analysis of the data is almost finished and will be presented at the national BSPAR conference in Edinburgh on the 15 May. The survey will be repeated later in 2019.</p> <p>Versus Arthritis are now represented on the Steering Group, bringing the number of 3rd sector organisation on the group to 3.</p> <p>Links with SNAC and The Teapot trust continue to add value to the networks outputs.</p> <p>The QI project will be completed as part of this year's Workplan.</p>	That public engagement is put at the heart of the networks activity and outcomes	G
2018-02	<p>Rare Conditions Undertake a family event for patients and their families with Uveitis as a scoping exercise</p>	1,2,5	Oct 2018	PM / PSO / LC	The network successfully held a family day for those affected by Uveitis in Glasgow on the 15 th September. The	An approach to rarer, complex rheumatic conditions which meets the needs of	B

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Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective	Anticipated Outcome	RAGB status
	<p>for further developments in support for rarer conditions</p> <p>Develop rarer condition sessions to be incorporated into the education programmes</p>		ongoing		<p>evaluations were very positive and a further event is likely to take place next year.</p> <p>Rarer conditions have been incorporated into the networks educational sessions and this will continue to be the case. These have included sessions on Enthesitis Related Arthritis and auto-inflammatory conditions.</p>	stakeholders and supports high quality clinical management.	
2018-03	<p>Evolution of Network Clinics Deliver a process whereby the quality of clinical care is measured against the networks Standards for a Paediatric Rheumatology Network Service. This will be done initially in 2 clinics. Report back to services individually and produce national report via a self audit questionnaire.</p> <p>Undertake a Quality Improvement exercise on a small number of cases to further examine the difficulties in achieving better results against Q11.</p>	1,3,5	March 2019	PM / PSO	<p>The pilot project on measuring services against network standards has been completed and will be presented to the Steering Group in June 2019. The results demonstrated a high level of compliance at the two clinics to the standards. A full rollout of the project will take place in 2019/20.</p> <p>The QI project was postponed to 2019/20 as it was dependant the quality standard Q11 being maintained, after the review of data collected by the network.</p>	That the network has a robust approach to working with teams to improve clinical care.	B

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Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective	Anticipated Outcome	RAGB status
2018-04	<p>Training & Education The network will deliver a programme of education designed to meet the needs of multidisciplinary staff delivering paediatric rheumatology service by:</p> <ul style="list-style-type: none"> - Undertaking an annual educational event - Delivering eight monthly educational sessions using videoconferencing 	3,4,5	Ongoing	PM / PSO / Education lead	<p>The network organised its national Annual Education Meeting at Borders General Hospital in May 2018. The event was attended by 59 clinicians and an evaluation report was produced highlighting very positive clinical feedback.</p> <p>Nine monthly education sessions have taken place, including some with guest presenters from across the UK. This excludes the March 2019 slot which was used for the Transition Education Meeting.</p>	Continuation and enhancement of the networks well received approach to providing education and training opportunities to clinicians involved in the management of rheumatic conditions.	B
2018-05	<p>Transition Circulate survey to patients who have recently transitioned from paediatric to adult services. This will help to understand how the transition process works for patients and their families. Produce report which identifies areas for improvement and further small tests of change.</p>	1,5,6	Sept 2018	PM / PSO / Transition lead	<p>On the 15 March 2019 the network organised and delivered a national conference on transition in partnership with the Scottish Society for Rheumatology. The event was aimed at both paediatric and adult services. 75 delegates attended the meeting. Evaluation was very positive.</p> <p>It was agreed by the SPARN nursing and transition leads to delay the transition survey</p>	Standardised and consistent transition from paediatric to adult services which meets the needs of network stakeholders, including children with rheumatic conditions and their families.	B

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					until after the meeting due to network workload pressures (CAS and the family survey) that were being placed on specialist nurses, in addition to their regular duties.		
2018-06	<p>Data Collection</p> <ul style="list-style-type: none"> • Establish data short life working group as lead for strategic direction on the networks approach to clinical governance • Production of a Data Plan for audit / data collection activity in 2018/19 	1,2,3,4	<p>May 2018</p> <p>May 2018</p> <p>Dec 2018</p>	Data Subgroup	<p>The data leads, working with the lead clinician, Programme Manager and the IMS, have developed an approach for the strategic direction of the network in this area. This has established enhancements to data collection requirements and a rationalisation of the conditions recorded on CAS to improve data quality and clinical engagement.</p> <p>Although a formal data plan hasn't been produced detailed actions have been kept throughout the year via the data subgroup and a QI Strategy will be written early in 2019/20.</p> <p>Additionally the CAS consent process has allowed the network to improve the data quality of the data through the removal of approximately 400 pts who have either</p>	SPARN quality indicators and data collection reflects current treatments and mirrors proposed UK wide data collections.	B

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Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective	Anticipated Outcome	RAGB status
					transitioned into secondary care or had nebulous clinical statuses. This process is continuing and will further improve data quality of the patient cohort on CAS.		
2018-07	<p>Guidelines The network will produce three new guidelines during 2018/19 including on the management of Infliximab and Non-Steroidal Anti-Inflammatory Drugs (NSAIDs) Ensure review of guidelines that are nearing the three year review deadline</p>	1,2,3,4,6	March 2019	PM / PSO / Guidelines Lead	<p>The network has approved its new guideline for Chronic Non-Infective Osteitis (CNO). Additionally a number of guidelines are awaiting approval from the network. The aim is to do this at the Steering Group meeting in June 2019. The guidelines are listed as follows;</p> <ul style="list-style-type: none"> • Rituximab • Cyclophosphamide • Tocilizumab • Illoprost • Pamidronate <p>The Lead Clinician is leading on a radiology guideline with radiology colleagues. This work is to be completed in 2019.</p>	Standardised care based on timely evidence and best practice. Resulting in better consistency of care for patients.	A
2018-08	<p>Network Governance Review the following during 2018/19</p> <ul style="list-style-type: none"> • Steering Group 	3,5	Feb 2019	PM / PSO	The membership of the Steering Group has been reviewed with new leads and members to replace those who have left / stepped down.	Each aspect of the networks governance will have been reviewed and updated where appropriate to ensure a consistent and robust	B

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Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective	Anticipated Outcome	RAGB status
	<p>membership</p> <ul style="list-style-type: none"> • Website content • Steering Group Terms of Reference • CAS Consent 				<p>Web content has been reviewed by the PSO. New Terms of Reference will be agreed at the June Steering Group, these are almost complete.</p> <p>The process of CAS consent has made great progress in ensuring that the bulk of pts remain on the system after the GDPR deadline. This has been done in partnership with the IMS. Some health board areas have failed to engage adequately with the process however and will lose pts.</p>	<p>approach to delivering the aims and objectives</p>	

6. Proposed Work Plan for 2019/20

1. Design and ongoing development of an effective Network structure that is organised, resourced and governed to meet requirements in relation to SGHSCD Guidance on MCNs (currently [CEL \(2012\) 29](#));
2. Support the design and delivery of services that are evidence based and aligned with current strategic and local and regional NHS planning and service priorities.
3. Effective Stakeholder Communication and Engagement through design and delivery of a written strategy that ensures stakeholders from Health, Social Care, Education, the Third Sector and Service User are involved in the Network and explicitly in the design and delivery of service models and improvements.
4. Improved capability and capacity in the care of women with a cardiac condition who is contemplating a pregnancy or has a pregnancy in Scotland through design and delivery of a written education strategy that reflects and meets stakeholder needs.
5. Effective systems and processes to facilitate and provide evidence of continuous improvement in the quality of care (CQI).
6. Generate better value for money in how services are delivered.

When defining network objectives please consider the NHS Scotland policy aims described in [Realistic Medicine](#), as well as the Institute of Medicine's six dimensions of quality, which are central to NHS Scotland's approach to systems-based healthcare quality improvement:

1. **Person-centred**: providing care that is responsive to individual personal preferences, needs and values and assuring that patient values guide all clinical decisions;
2. **Safe**: avoiding injuries to patients from healthcare that is intended to help them;
3. **Effective**: providing services based on scientific knowledge;
4. **Efficient**: avoiding waste, including waste of equipment, supplies, ideas, and energy;
5. **Equitable**: providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location or socio-economic status; and
6. **Timely**: reducing waits and sometimes harmful delays for both those who receive care and those who give care.

Key

RAGB status	Description
RED (R)	The network is unlikely to achieve the objective by the agreed end date.
AMBER (A)	There is a risk that the network will not achieve the objective by the agreed end date but progress has been made.
GREEN (G)	The network is on track to achieve the objective by the agreed end date.
BLUE (B)	The network has been successful in achieving the network objective to plan.

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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at	Anticipated Outcome	RAG Status
1. Effective Network Structure and Governance <small>[linked to Quality Dimensions 3,4,5,6]</small>						
Ensure SPARN has robust and effective governance arrangements and is structured appropriately to delivery its objectives:						
2019-01	The network will organise three Steering Group meetings during 2019/20 to oversee strategic development of SPARN.	March 2020	Network Office		There are effective governance arrangements in place to support the outputs of the network.	
2019-02	Produce Terms of Reference for the network	30/06/2019	Network Office			
2. Service Development and Delivery <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2019-03	Promote equity of access to paediatric rheumatology services in Scotland by building on the transition work already completed by undertaking the SPARN transition survey across Scotland.	31/03/2020	Network Office / transition Lead		There are improved processes in place to support the transition journey for young people.	
2019-04	Rollout of project to measure services against network standards subsequent to successful pilot in 2018/19.	31/01/2020	Network Office		There is evidence to demonstrate that clinical services are meeting network standards.	
2019-05	Complete the process of authorising the new guidelines developed in NHS Lothian via the Steering Group.	30/06/2019	Steering Group			
3. Stakeholder Communication and Engagement <small>[linked to Quality Dimensions 1,3,4,5,6]</small>						
SPARN will communicate effectively with a wide range of stakeholders to ensure its stakeholders are aware of the work that the network is						

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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at	Anticipated Outcome	RAG Status
undertaking and are involved and able to influence its work.						
2019-06	The website will evolve to become a more effective communication and information resource for patients, families and professionals.	1/4/19-31/3/20	Network Office		There will be effective, clear lines of communication between specialist rheumatology services, third sector agencies and children with rheumatological conditions, their families and other health professional stakeholders.	
2019-07	Repeat the national annual survey in late 2019/20, learning the lessons of the first year. This will involve broadening the methods for patients and families to undertake the survey.	31/3/2020	Network Office			
2019-08	Complete the QI project on the provision of electronic patient information to children and their families through the development of a section on the website and a postcard to be handed to families to promote it.	31/07/2019	Network Office			
2019-09	SPARN will develop a new Communications & Engagement Strategy to provide a framework for improvements in this area.	31/07/2019	Prog. Manager			
4. Education <small>Quality Dimensions 1,2,3,4,5,6]</small>						
Deliver education opportunities for NHS Scotland paediatric rheumatology Staff						
2019-10	SPARN will undertake its Annual Educational Meeting in June 2019 at Forth Valley Royal Hospital with a focus on Uveitis. An evaluation report will be	30/06/2019	Network Office / Education		Continuation and enhancement of the networks well received approach to providing	

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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at	Anticipated Outcome	RAG Status
	produced.		Lead		education and training opportunities to clinicians involved in the management of rheumatic conditions.	
2019-11	The network will deliver a focused programme of education designed to meet the needs of multidisciplinary staff delivering paediatric rheumatology service by delivering eight monthly educational sessions using videoconferencing	31/03/2020	Education Lead / Network Office			
2019-12	The network will produce a new Education Strategy to provide a framework that underpins its educational output	30/06/2019	Prog. Manager			
5. Audit and Continuous Quality Improvement <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small> SPARN will progress the use of data to identify areas for improvement and demonstrate improvements in service delivery and/or patient outcomes.						
2019-13	SPARN will oversee the national rollout of the Uveitis audit successfully completed in Glasgow	31/03/2020	Uveitis Lead		SPARN has a more robust approach to the collection and use of data to measure the quality of clinical care	
2019-14	The network has developed and expansion of its CQIs and dataset on CAS. During 2019/20 this will be fully implemented.	31/03/2020	Data Subgroup			
2019-15	SPARN will conclude its work to ensure that the network meets GDPR in relation to its data on the Clinical Audit System	30/06/2019	Network Office / IMS			
2019-02	The network will organise a mailout to the remaining patients in a final effort to	31/05/2019	Network Office /			

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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at	Anticipated Outcome	RAG Status
	increase the numbers of consented patients on the Clinical Audit System.		IMS			
2019-16	The network will produce and authorise a Quality Improvement Strategy to support SPARNs approach to service improvement	20/06/2019	Prog. Manager			
6. Value [linked to Quality Dimensions 1,3,4,5,6]						
2019-17	The network will, where possible, extend the audit Biosimilar Infliximab to the rest of Scotland, thus enabling this project to potentially make savings across Scotland.	31/03/2020	Data Subgroup		Prescribing cost savings are being made as a result of more efficient prescribing	

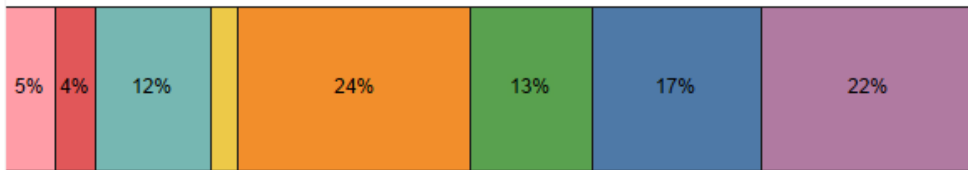
Appendix 1: Steering Group Membership

<i>Name</i>	<i>Designation</i>	<i>Board / Organisation</i>
Harriet Bascombe	Physio Representative (shared)	NHS Lanarkshire
Klaire Connor	Versus Arthritis Rep	Versus Arthritis
Angela Cruickshank	Nurse Representative	NHS Fife
Julie Duncan	Guidelines Lead	NHS Lothian
Drew Fell	Data Lead	NHS Greater Glasgow & Clyde
Paul Galea	Chair	
Jenny Hagger	Physio Representative (shared)	NHS Lothian
Kirsten Healy	DGH Representative	NHS Fife
Mandy Headspeath	Working with Families Lead	NHS Borders
Neil Martin	Lead Clinician	NHS Greater Glasgow & Clyde
Lynsay Mcaulay	Pharmacy Representative	NHS Lanarkshire
Elaine Morrison	Transition Representative	NHS Greater Glasgow & Clyde
Tracy Rendall	SNAC Representative	SNAC
Lynne Shields	OT representative	NHS Ayrshire & Arran
Jo Walsh	Education Lead	NHS Greater Glasgow & Clyde

Appendix 2: Finance

SPARN Financial Information

Job description	Account description	18/19
SPARN	BOOKS/PAMPHLETS - PRINTING ETC	£61.97
	EXHIBITIONS AND CONFERENCES	£326.00
	LECTURE FEES SPECIALISTS	£254.20
	OTHER PRINTING STATIONERY	£183.72
	OTHER PROVISIONS	£352.70
	OTHER STATIONERY	£40.00
	PROFESSIONAL FEES - OTHER	£75.00
	TRAVEL SUBSISTENCE	£172.66
Grand Total		£1,466.25

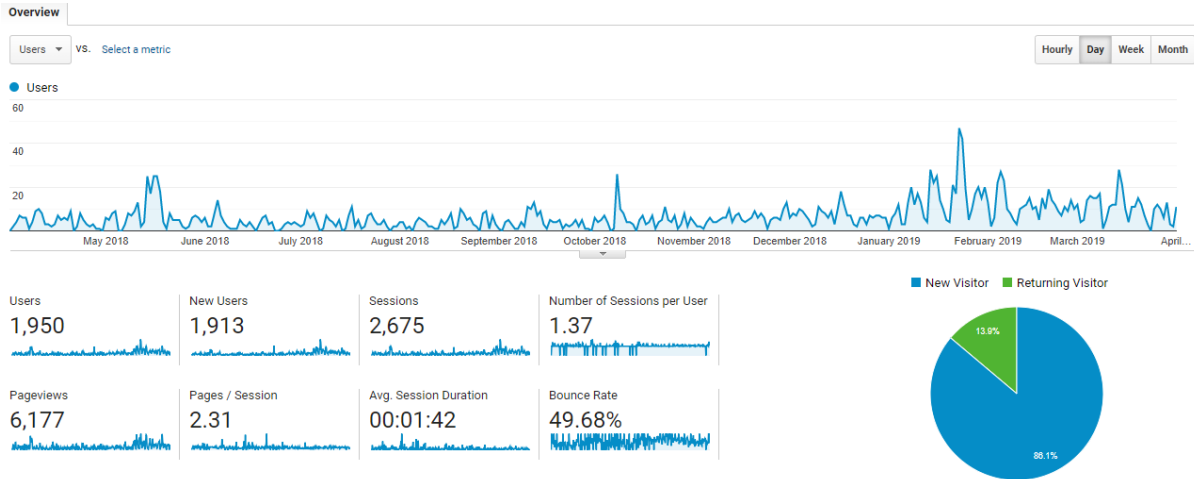


Type

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Appendix 3: SPARN Website Statistics



Page	Pageviews	Unique Pageviews	Avg. Time on Page	Entrances	Bounce Rate	% Exit	Page Value
	6,177 % of Total: 100.00% (6,177)	4,907 % of Total: 100.00% (4,907)	00:01:18 Avg for View: 00:01:18 (0.00%)	2,666 % of Total: 100.00% (2,666)	49.68% Avg for View: 49.68% (0.00%)	43.16% Avg for View: 43.16% (0.00%)	\$0.00 % of Total: 0.00% (\$0.00)
1. /	1,456 (23.57%)	1,194 (24.33%)	00:00:51	1,135 (42.57%)	35.12%	35.58%	\$0.00 (0.00%)
2. /event/transition-in-rheumatology-event/	530 (8.58%)	362 (7.38%)	00:02:07	264 (9.90%)	45.86%	58.30%	\$0.00 (0.00%)
3. /work-streams/guidelines/	516 (8.35%)	380 (7.74%)	00:03:41	132 (4.95%)	43.17%	59.50%	\$0.00 (0.00%)
4. /annual-education-meeting-2018/	331 (5.36%)	216 (4.40%)	00:01:29	117 (4.39%)	22.88%	31.72%	\$0.00 (0.00%)
5. /clinical-audit-system/	266 (4.31%)	201 (4.10%)	00:02:17	48 (1.80%)	81.25%	56.39%	\$0.00 (0.00%)
6. /events/	254 (4.11%)	198 (4.04%)	00:01:01	16 (0.60%)	31.25%	22.83%	\$0.00 (0.00%)
7. /contact-us/	196 (3.17%)	163 (3.32%)	00:01:44	70 (2.63%)	74.29%	61.22%	\$0.00 (0.00%)
8. /families-information/charities/arthritis-care-scotland/	151 (2.44%)	134 (2.73%)	00:01:27	124 (4.65%)	74.19%	76.82%	\$0.00 (0.00%)
9. /steering-group/	142 (2.30%)	123 (2.51%)	00:01:54	20 (0.75%)	70.00%	35.92%	\$0.00 (0.00%)
10. /annual-education-meeting-2019/	138 (2.23%)	76 (1.55%)	00:01:02	11 (0.41%)	9.09%	17.39%	\$0.00 (0.00%)