

**Scottish Paediatric and Adolescent
Rheumatology National Managed Clinical
Network (SPARN)
ANNUAL REPORT 2019/20**

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1. Executive Summary

The Scottish Paediatric and Adolescent Rheumatology Network (SPARN) is a well established National Managed Clinical Network (NMCN) covering a range of rheumatological conditions. The focus for the network since designation in 2009 has been to support local delivery of paediatric rheumatology care.

Key successes for the network over the reporting period are:

- Continuation of a well established programme of education and information sharing including the delivery of an annual education meeting and 8 multidisciplinary short sessions delivered by video conferencing
- Audit of compliance with the network's Guidelines for a Paediatric Rheumatology Service
- Audit of the network's quality indicators for children and young people with Juvenile Idiopathic Arthritis (JIA)

The key priorities for SPARN in 2020/21 are:

- To undertake a forward planning exercise to agree network goals for the next few years.
- Continued delivery of the education programme and undertaking an engagement exercise to identify any gaps and ensure it meets the needs of all stakeholders
- To engage with patients and families to understand what improvements can be put in place that matter to them both for children and young people's services and for young adults going through the transition process.
- Building on the audit work undertaken in 2019/20, review the Guidelines for a Paediatric Rheumatology Service and the quality indicators collected by the network to ensure they are based on available evidence and expert opinion.

Since February 2020, understandably NHS Scotland's priority has been to prepare for and deal with COVID-19 impact and this has seen clinical and other resource diverted from network activity. The network has undertaken an exercise to not only capture the impact of this unprecedented situation on the current reporting period but also to assess the likely impact of the 20/21 work plan.

Areas of impact for 2020/21 include:

- Delivery of the education programme. The annual event has been postponed until June 2021 and the monthly education sessions cancelled for the first few months due to withdrawal of study leave. When there is clinical capacity to participate in the monthly sessions they will be re-established.
- Patient engagement. The planned patient and family event for young people with Juvenile Dermatomyositis (JDM) has been postponed until it is safe for it to continue. This may well be into 2021 due to the vulnerability of these young people. The patient experience survey will depend on the situation with re-establishing clinics.

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 rheumatological 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 to be 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.

To further support local delivery of care SPARN has developed:

- Paediatric rheumatology service guidance
- A suite of clinical guidelines
- A well established education programme facilitating sharing of knowledge and expertise

SPARN has also established a variety of methods to engage with patients, their families and representatives through patient and family events, questionnaires and the active involvement of third sector organisations SNAC and Versus Arthritis on the steering group.

3. Report on Progress against Network Objectives in 2019/20

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) 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.

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

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 2019/20.

3.1. Effective Network Structure and Governance

SPARN is overseen by a multidisciplinary steering group with members taking an active role in communicating with the disciplines that they represent. The group also includes third sector representation from SNAC and Versus Arthritis and is independently chaired by Paul Galea, retired Paediatrician. Full membership is provided in Appendix A.

The network has a number of work streams led by members of the steering group who provide regular reports on progress. The current work streams are:

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

Dr Neil Martin, Consultant Paediatric Rheumatologist has been the Lead Clinician of the network since September 2017 and his tenure is due to run until August 2020. Programme management and support for the network as well as data analyst resource is provided through the National Network Management Service (NNMS) based in NHS National Services Scotland.

The network has a current service agreement with NHS National Services Scotland as commissioners, running from 2018 until March 2021. A refreshed Terms of Reference document was approved in 2019. Following a review of the network in 2017, a strategic work plan was agreed setting out the priorities for the network until March 2021. A strategic planning session has been incorporated into the 2020/21 work plan to review progress against this and refresh for the future.

3.2. Service Development and Delivery

Service Audit

Following on from a pilot in 2019, SPARN undertook a full audit of services against the Guideline for a Paediatric Rheumatology Network Service. This guideline establishes a set of standards for what should be available in each paediatric rheumatology clinic in Scotland.

Responses were received from all clinics in Scotland and showed generally good compliance with the standards. Following presentation of the results to the steering group, the discussion highlighted that there may be legitimate reasons for differences in how services are delivered in some boards. It was therefore agreed that a further step be undertaken to feed back to each centre how their responses compared to the rest of Scotland and invite them to provide context where they are not meeting standards in line with other centres. Understanding the challenges to implementation and alternate models of care in local areas will then inform the revision of the guidance planned for 2020/21.

3.3. Stakeholder Communication and Engagement

Communication Strategy

A revised Communication Strategy was approved by the network in March 2020. One of the outputs of this will be a revived network newsletter.

Website

A key communication tool for the network remains the SPARN website: www.sparn.scot.nhs.uk

Analysis of the website shows an increase in both the number of times that people have accessed the website and the total number of pages viewed in Figure 1.

Full year report: from 1/4/19 > 31/3/20

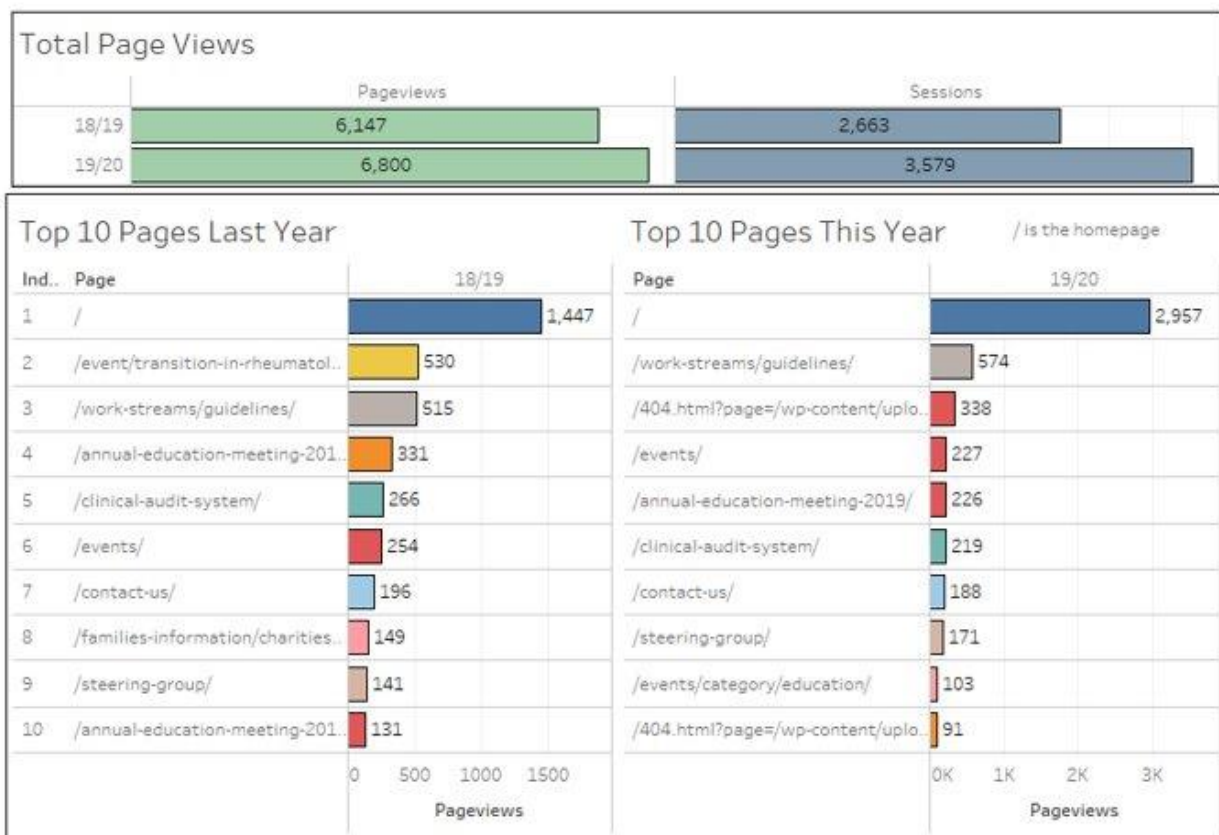


Fig 1: SPARN website activity 2018/19 and 2019/20

Of the top ten pages accessed this year, number 3 and 10 relate to COVID-19 advice which had been available on the website but has now been replaced by an updated version.

Patient Survey

Following on from the patient experience survey undertaken in 2018/19, a review of the results was undertaken by the survey subgroup to inform the development of a further survey. The survey had run for three months in 6 rheumatology clinics in Scotland. It was recognised that there had been some challenges with the questionnaire format and this had resulted in fewer responses to some questions, potential confusion about the meaning of the questions and difficulty with interpretation of responses. The revised questionnaire has been developed to identify patient/family priorities for improvement and will be tested with a few patients/families to ensure the questions are meaningful.

Results were received from 186 people and indicated a high level of satisfaction with the service with almost all who responded to this question being fully or mostly satisfied with the service. In particular interaction with service staff was seen as very positive.

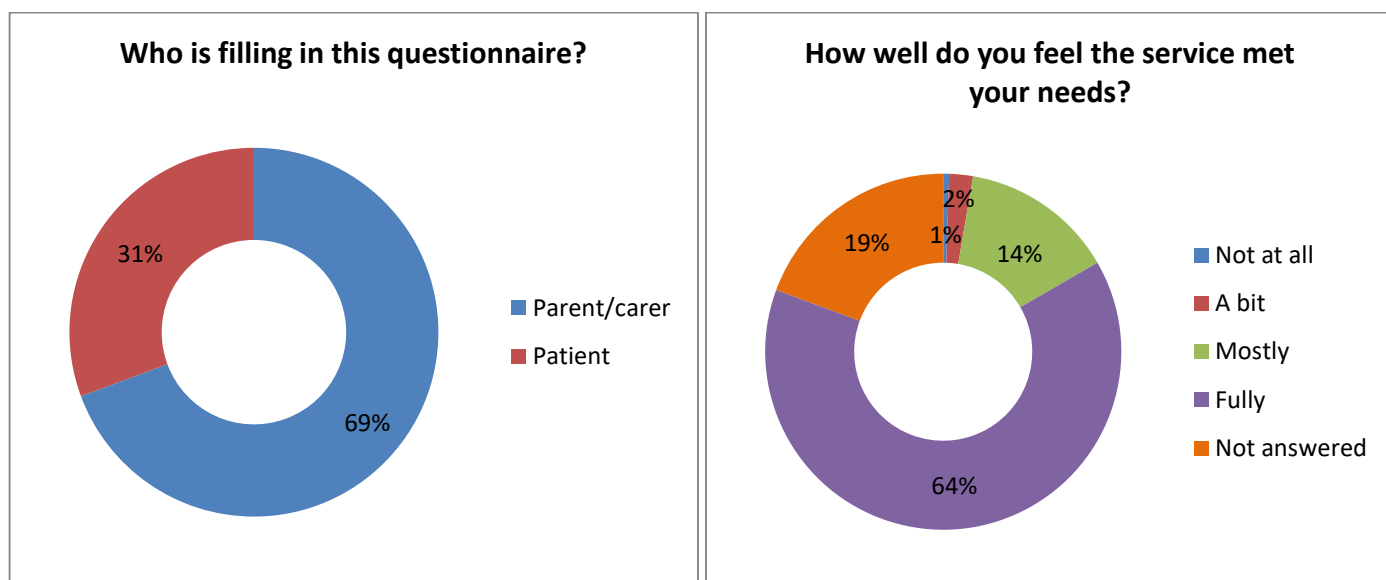


Fig 2 and 3: Feedback from patients and parents/carers 2019

3.4. Education

Annual meeting

The network held its annual multidisciplinary education day on the 3rd June 2019 at Forth Valley Royal Hospital focusing on the theme of Uveitis. There were 45 people in attendance at the event which was comprised of a mixture of talks and workshops. Most respondents to the evaluation questionnaire (86%) felt that it was highly or mostly relevant to their educational needs as can be seen in the Figure 2.

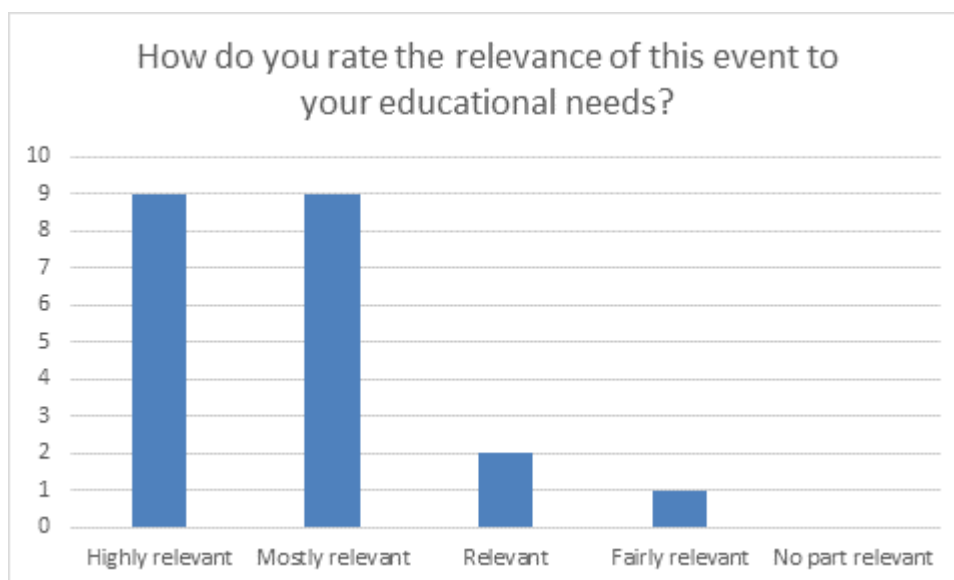


Fig 4: Education event feedback

A number of participants reported that this event would have an impact of their practice in managing Uveitis particularly around developing local contact with ophthalmology colleagues, following up on DNAs to the eye clinics, earlier treatment, capturing outcome measures and enhancing transition practice.

Multidisciplinary VC sessions

In 2019/20 the network has continued its well established programme of monthly education sessions. The sessions cover a variety of topics and are led by different centres around Scotland to enable sharing of knowledge and expertise. The breadth of topics covered can be seen in the programme in Appendix 3. The sessions continue to be well received with almost all participants attending by videoconference feeling this method continues to work well and the content relevant to their educational needs.

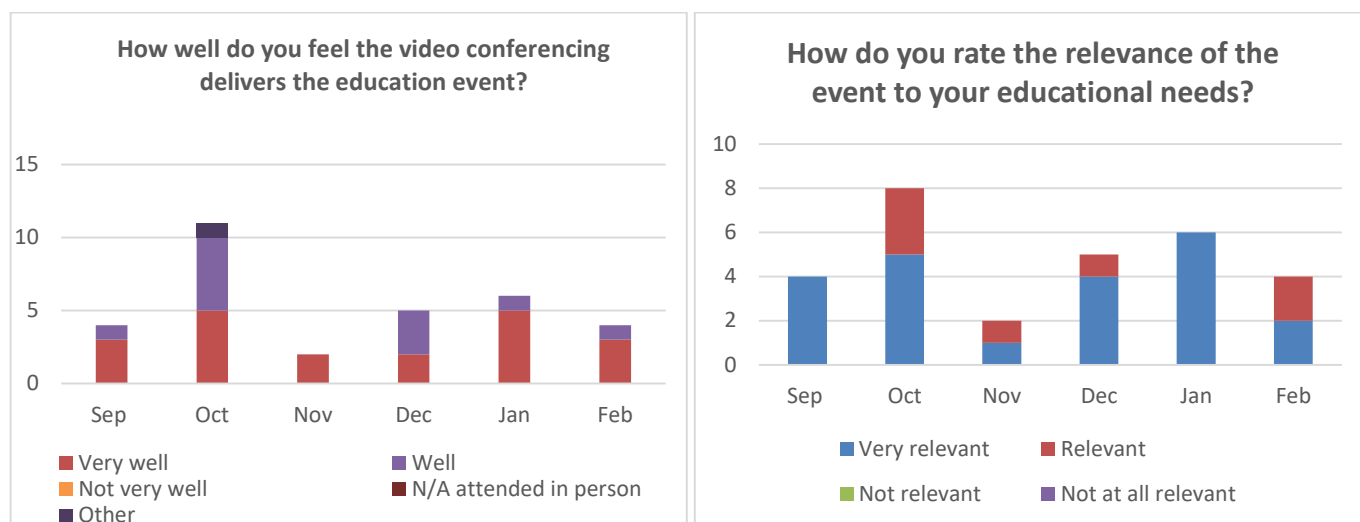


Fig 5 & 6: Monthly education session feedback Sep 19 – Feb 20

Unfortunately due to the withdrawal of study leave arising from the escalating COVID-19 crisis the March session had to be cancelled.

Education Strategy

To inform the refresh of the network’s education strategy, work has taken place to collate the educational opportunities available in paediatric rheumatology. This was to form the basis of engagement with the network around any perceived gaps or helpful additional resources planned for the education event in June 2020. Unfortunately due to the emergence of COVID-19 the education event has had to be postponed until June 2021 and another method of engagement sought.

3.5. Audit and Continuous Quality Improvement

Data Collection

The network uses the National Clinical Audit System to capture the condition and date of diagnosis of patients diagnosed with a rheumatological condition. It also captures some previously agreed quality indicator data for patients with a diagnosis of JIA.

To comply with changes to the General Data Protection Regulation (GDPR), the network undertook work to review the data in the system, remove people that were no longer patients of the service and to obtain active consent from the current patient group. This was a significant exercise and resulted in consent being obtained for approximately half the patient group. With a number of other networks similarly impacted, a process is under way at NSS level to reconsider whether there is a legal basis for holding the information on CAS thus removing the requirement for expressed consent.

One benefit from the exercise is that the data held within NCAS has been updated to remove people who are no longer patients of the service. Figure 5 shows the reduction in numbers following this exercise.

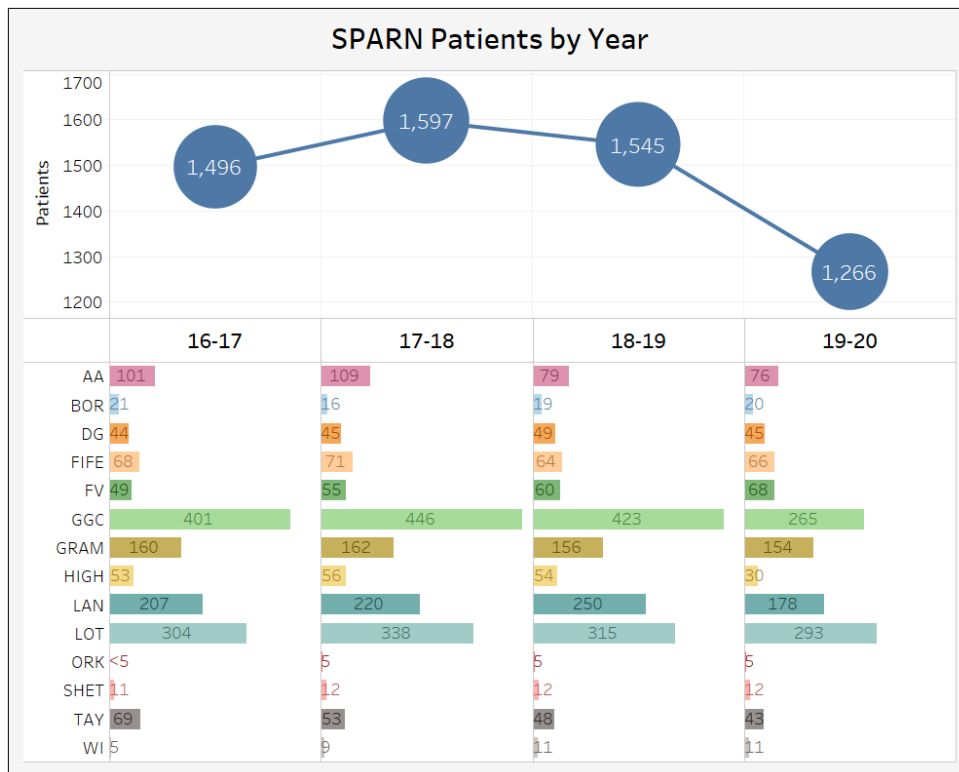


Fig 7: Number of patients recorded on CAS by year and Health Board

For patients with JIA, where there is a known prevalence of 1 in 1000 children, this has taken the numbers recorded in the CAS closer to the level expected for the population as shown in figures 6 and 7.

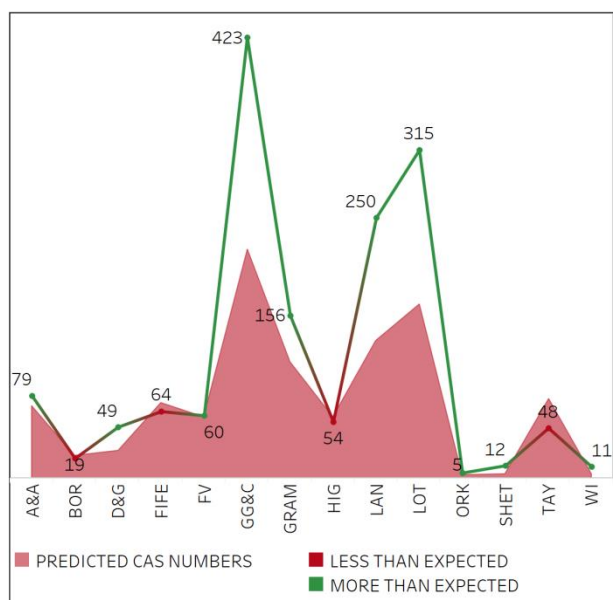


Fig 8: JIA cases recorded on CAS vs expected prevalence 2018/19

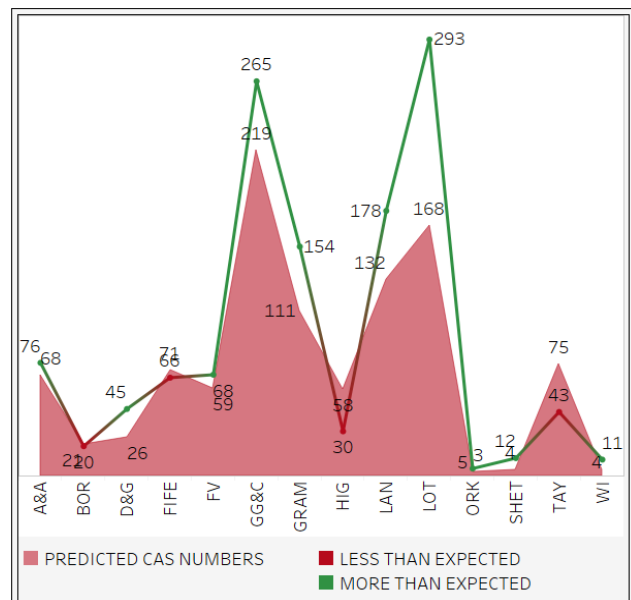


Fig 9: JIA cases recorded on CAS vs expected prevalence 2019/20

An exercise was also undertaken to update the Highland patients in the system and they will be included in 20/21 data reports.

SPARN has also worked to increase the percentage of patients with information about their condition and date of diagnosis on the system. The number of patients with a condition recorded has increased by 2% since last year and the number of patients with a date of diagnosis has increased by 7%:

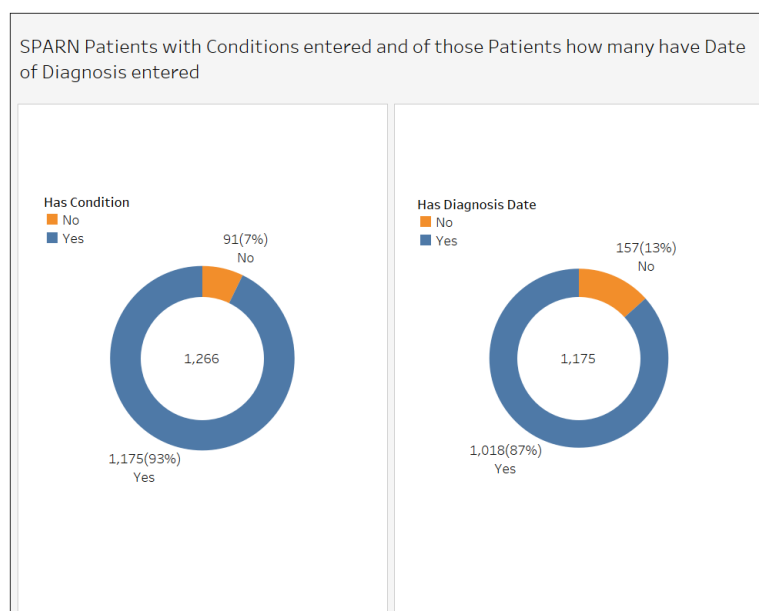


Fig 10: Patients with condition and date of diagnosis on CAS

Quality Indicators

SPARN has four agreed quality indicators focusing on children and young people with JIA. There were 47 patients with a JIA diagnosis in 2019/20 entered on to CAS. Figure 9 shows the performance against the quality indicators for this group.

As there had been a focus on obtaining consent in the early part of the year, limited quality indicator data had been collected. Work had been undertaken in the later part of the year to capture this data but unfortunately, due to COVID-19, the final exercise to capture a comprehensive picture of the quality indicators has been delayed. This will still be undertaken in May 2020 but results will not be available for this report. They will, however, inform the review of quality indicators planned as part of the 2020/21 work plan. Missing data has been reported in grey on the graphs below. It is also to be expected that COVID-19 will significantly impact data entry for CAS including both patient consent and new patients being entered onto CAS as well as data collection and entry for existing patients.

QI1 – Patients should be seen by paediatric rheumatology within 10 weeks of onset of symptoms

Of the 47 patients diagnosed with JIA in 2019/20, 8 (17%) had been seen within 10 weeks of diagnosis. This has fallen from previous years (comparison shown in Appendix 4). It does, however, rise to 19 patients (40%) seen within 15 weeks.

The biggest challenge to meeting this target is the time from onset of symptoms to referral to the service which can be considerable. For the 32 patients where referral data was available, 28 (88%) were seen by paediatric rheumatology within 10 weeks of referral.

As part of a review of quality indicators in the 2020/21 work plan, further investigation will be undertaken to establish if the network can influence any of the variables leading to the delay in referral and whether this quality indicator is viable in its current form.

QI2 - Patients under the age of 13 should be seen for eye screen within 6 weeks of referral

Following discussion, an issue with the previous reporting of this data was identified in 2019/20 as the indicator is only applicable for children under the age of 13. Of the 25 children diagnosed with JIA in 2019/20 under the age of 13, 14 (56%) were seen within 6 weeks.

It is recognised that the general target for health boards from referral to eye screen is 8 weeks and this target was met for 16 (64%) of the 25 patients.

For the 24/25 patients where data was available, all were seen within 12 weeks.

There does not seem to be an issue with any particular geographical area causing the delays and further investigation will be undertaken as part of the review of quality indicators to understand the reasons for the target not being achieved.

QI3 – Patients on Methotrexate

This was originally incorporated as a quality indicator when there were concerns about access to methotrexate for patients. In recognition that it is now available for patients when they need it and the results consistently support this (see Appendix 4), the quality indicator will be removed as part of the review of quality indicators. Further discussion will take place with each centre to confirm approach.

QI4 – Patients with JIA will receive a network approved patient information pack

There had been an assumption previously that the reason this indicator was achieving approximately 50% most years was that some of the resources used in the information pack were no longer available. A quality improvement project had therefore been planned for 2019/20 to look at electronic sharing of the information. However, following further discussion with the nurses group it became clear that there was a different set of information being used as standard and agreed by them as a group but still required sign off from the steering group. It was therefore agreed for this year that this indicator would be considered as met where the patient had been given age appropriate information.

It emerged that the challenge had been that with a number of new staff, not all were aware of the quality indicator or the need to record that the information had been given in NCAS. Following some awareness raising, the percentage of patients with a record of being given an information pack has risen to 68% for this year. In common with previous indicators it is likely that some data is missing rather than the remaining 32% have not been given age appropriate information. This will be picked up through the data cleansing exercise planned for 2020/21.

JIA Quality Indicators Dashboard

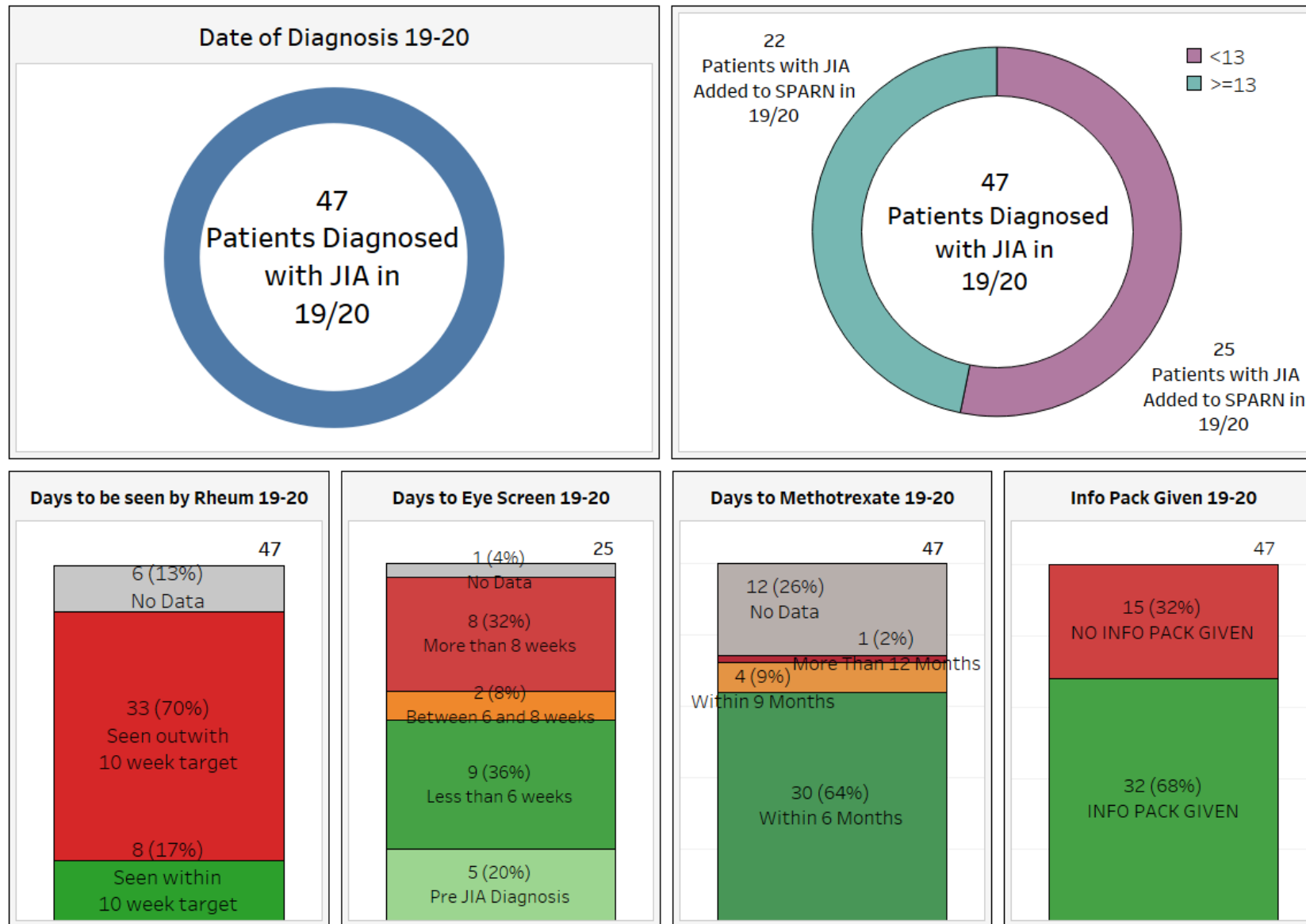


Fig 11: JIA dashboard

3.6. Value

SPARN continues to add value through supporting the delivery of equitable, locally based care to children and young people with rheumatological conditions. This includes:

- Delivery of a substantial programme of education and information sharing on a variety of topics related to paediatric rheumatology. The delivery of the monthly education sessions by video conference saves the time and expense of travel whilst sharing expertise and best practice from across Scotland
- Providing established standards for the care of children and young people with rheumatological conditions with good adherence to the standards in clinics across Scotland.
- Capture of quality indicator data for children and young people with JIA, to identify and address unwarranted variation.

4. Plans for the Year Ahead

The key priorities for SPARN in 2020/21 are:

- Undertake a forward planning exercise to identify network goals for the next few years.
- Continued delivery of the education programme and undertaking an engagement exercise to identify any gaps and ensure it meets the needs of all stakeholders
- Engage with patients and families to understand what improvements can be put in place that matter to them both for children and young people's services and for young adults going through the transition process.
- Building on the audit work undertaken in 2019/20, review the Guidelines for a Paediatric Rheumatology Service and the quality indicators collected by the network to ensure they are based on available evidence and expert opinion.

Risks and Issues

Since February 2020, understandably NHS Scotland's priority has been to prepare for and deal with COVID-19 impact and this has seen clinical and other resource diverted from network activity. The network has undertaken an exercise to not only capture the impact of this unprecedented situation on the current reporting period but also to assess the likely impact of the 20/21 workplan.

Areas of impact for 2020/21 include:

- Delivery of the education programme. The annual event has been postponed until June 2021 and the monthly education sessions cancelled for the first few months due to withdrawal of study leave. When there is clinical capacity to participate in the monthly sessions they will be re-established.
- Patient engagement. The planned patient and family event for young people with Juvenile Dermatomyositis (JDM) has been postponed until it is safe for it to continue. This may well be into 2021 due to the vulnerability of these young people. The patient experience survey will depend on the situation with re-establishing clinics.

5. Detailed Description of Progress in 2019/20

All work objectives are listed under the most appropriate heading. Headings correspond to the agreed network core objectives:

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

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6. **Timely:** reducing waits and sometimes harmful delays for both those who receive care and those who give care.

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

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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	Steering groups took place in June, November and March.	There are effective governance arrangements in place to support the outputs of the network.	B
2019-02	Produce Terms of Reference for the network	30/06/2019	Network Office	Approved at SG on 20 th November 2019.		B
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	A draft questionnaire has been completed and being tested with a few patients before pilot commences in GGC. Following results of testing and piloting, any learning points will be considered before roll out to the rest of Scotland in 2020/21.	There are improved processes in place to support the transition journey for young people. There is evidence to demonstrate that clinical services are meeting network standards.	A
2019-04	Rollout of project to measure services against network standards subsequent to successful pilot in 2018/19.	31/01/2020	Network Office	Survey has been completed with responses received from all centres in Scotland. Further work to be undertaken to fully understand variation.		G

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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
2019-05	Complete the process of authorising the new guidelines developed in NHS Lothian via the Steering Group.	30/06/2019	Steering Group	Delayed due to long term leave. To be completed in 2020/21.		A
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 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	Work to ensure the development of the website is ongoing. The website has been updated and out of date information removed.	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.	B
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	A revised questionnaire has been developed and will be tested with a few patients before full roll out in September 2020/21.		A
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 / Sp. nurses	Further discussion with the nurses group has identified that new information resources have been agreed for hand out so this issue no longer exists.		
2019-09	SPARN will develop a new Communications & Engagement Strategy to provide a framework for improvements in this area.	31/07/2019	Prog. Manager	Approved at the SG meeting on 4 th March 2020.		B

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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
4. Education Quality Dimensions 1,2,3,4,5,6]						
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 produced.	30/06/2019	Network Office / Education Lead	The event was successfully held on the 1 st June. Around 50 attendees were present.	Continuation and enhancement of the networks well received approach to providing education and training opportunities to clinicians involved in the management of rheumatological conditions.	B
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	Eight monthly sessions have been held in 2019/20. A planned ninth session for March 2020 had to be cancelled due to COVID-19. Evaluation of the events has been positive.		B
2019-12	The network will produce a new Education Strategy to provide a framework that underpins its educational output	30/06/2019	Prog. Manager	A review of educational opportunities is being collated and attendees at the education event will be asked to identify any gaps/areas for improvement to form the revised education strategy. To be carried forward to 2020/21.		A

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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
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	As part of the education event in June 2019, a workshop was held to discuss the further roll out of this audit across Scotland. A planning paper has been produced for commencement of the audit in 2020/21.	SPARN has a more robust approach to the collection and use of data to measure the quality of clinical care	A
2019-14	The network has developed an expansion of its CQIs and dataset on CAS. During 2019/20 this will be fully implemented.	31/03/2020	Data Subgroup	Further work has taken place between the networks data leads and the Information Management Service to develop the CAS instance to enable improved data collection.		G
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	The network made strenuous effort up to the end of May deadline to get as many patients consented onto CAS as possible. Despite this around half were not able to be consented. Patients continue to be consented but any		B

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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
				further work on this is on hold pending further advice.		
2019-02	The network will organise a mailout to the remaining patients in a final effort to increase the numbers of consented patients on the Clinical Audit System.	31/05/2019	Network Office / IMS	This work is now on hold pending advice.(see 2019-15)		N/A
2019-16	The network will produce and authorise a Quality Improvement Strategy to support SPARNs approach to service improvement	30/11/2019	Prog. Manager	This will be carried forward to 2020/21 to build on the refresh of the quality indicators.		A
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	As with the quality indicator data, this project has been delayed due to the focus on consent early in the year. The CAS has now been adapted to ensure the audit can be rolled out in other health boards and this project will be carried forward to 2020/21.	Prescribing cost savings are being made as a result of more efficient prescribing	A

6. Proposed Work Plan for 2020/21

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:						
2020-01	The network will organise three Steering Group meetings during 2020/21 to oversee strategic development of SPARN	March 2021	PSO		There are effective governance arrangements in place.	
2020-02	The network will develop an infrastructure using Microsoft Teams to enable more effective collaboration between groups/ work streams.	April 2020 – September 2020	PM/PSO		The network is structured appropriately to effectively deliver its objectives.	
2020-03	The network will undertake a forward planning session to refresh vision and goals for the next 3-5 years.	March 2021	LC/ PM		All stakeholders have clarity of vision and purpose to enable effective distributed working towards a common goal.	
2. Service Development and Delivery <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2019-03	Complete the pilot transition survey to identify what is important to young people and roll out to rest of Scotland.	April 2020 – September 2020	Transition Lead/ PM/ PSO		Development of services is influenced by what is important to the patients.	

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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
2020-04	Based on the results of the transition survey, identify key improvement projects to be taken forward by the network.	September 2020 – March 2021	Transition Lead/ PM/ PSO			
2019--05	Complete the process of authorising the new guidelines developed in NHS Lothian via the Steering Group.	March 2021	Guidelines Lead/ Steering Group		There is an equitable, evidence based approach to paediatric rheumatological care.	
2020-05	The network will revise the Guideline for a Paediatric Rheumatology Service, taking into account the results and feedback from the previous audit and current available evidence. The document will be structured to clearly demonstrate the rationale for each standard.	March 2021	SLWG		There is an equitable high standard of care for patients attending all 13 SPARN clinics based on current available evidence and expert opinion.	
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 undertaking and are involved and able to influence its work.						
2020-06	The website will evolve to become an effective communication/ training and information resource for patients, families and professionals.	March 2021	PSO		Stakeholders will have access to reliable and up to date paediatric rheumatology information.	
2019-07	Repeat the patient experience survey learning the lessons of the first year.	September – November	Survey Group		Development of services is influenced by what 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
		2020			important to the patients.	
2020-07	The network will hold an engagement event for patients with Juvenile Dermatomyositis (JDM) and their families.	June 2020	Nurses Group		Development of services is influenced by what is important to the patients.	
4. Education <small>Quality Dimensions 1,2,3,4,5,6]</small>						
Deliver education opportunities for NHS Scotland paediatric rheumatology staff						
2019-12	The network will produce a new Education Strategy to provide a framework that underpins its educational output		PM/ Education Lead		There is a clear approach to paediatric rheumatology education in Scotland that takes account of the needs of those delivering the care.	
2020-08	SPARN will undertake its Annual Educational Meeting in June 2020 in Aberdeen with a focus on Lupus.	June 2020	Grampian team/ Education lead/ PSO		Paediatric rheumatology care in Scotland is delivered by knowledgeable health professionals.	
2020-09	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	March 2021	Education Lead/ PSO		Paediatric rheumatology care in Scotland is delivered by knowledgeable health professionals.	

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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
5. Audit and Continuous Quality Improvement [linked to Quality Dimensions 1,2,3,4,5,6]						
SPARN will progress the use of data to identify areas for improvement and demonstrate improvements in service delivery and/or patient outcomes.						
2019-13	The network will oversee the national roll out of the Uveitis audit successfully completed in Glasgow.	March 2021	Uveitis Lead		Areas for improvement are recognised through identification of unwarranted variation in key aspects of clinical care.	
2019-16	The network will produce and authorise a Quality Improvement Strategy to support SPARNs approach to service improvement	September 2020	Prog. Manager			
2020-10	The network will establish a short life working group to identify key indicators of quality in paediatric rheumatology services, rationale and plan for measurement.	March 2021	Data Lead/ Short Life Working Group		Areas for improvement are recognised through identification of unwarranted variation in practice.	
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.	March 2021	Data Group		Cost savings are being made as a result of more efficient prescribing	

Appendix 1: Steering Group Membership

Name	Designation	Board / Organisation
Jed Bamber	Consultant Paediatrician	NHS Dumfries & Galloway
Harriet Bascombe	Physiotherapist (shared)	NHS Lanarkshire
Mary Brennan	Consultant Paediatric Rheumatologist	NHS Lothian
Klaire Connor	3 rd Sector representative	Versus Arthritis
Angela Cruickshank	Paediatric Rheumatology Nurse Specialist	NHS Fife
Julie Duncan	Consultant Paediatrician	NHS Lothian
Drew Fell	Paediatric Rheumatology Nurse Specialist	NHS Greater Glasgow & Clyde
Paul Galea	(Retired Consultant) Chair	
Jenny Hagger	Physio Representative (shared)	NHS Lothian
Kirsten Healy	Consultant Paediatrician	NHS Fife
Karen Lapsley	Paediatric Physiotherapist	NHS Forth Valley
Lynsay McAulay	Pharmacy Representative	NHS Lanarkshire
Jan McClean	Director of Planning	East of Scotland Programme Board
Neil Martin	Consultant Paediatric Rheumatologist	NHS Greater Glasgow & Clyde
Gill Meens	3 rd Sector representative	Versus Arthritis
Elaine Morrison	Consultant in adult Rheumatology	NHS Greater Glasgow & Clyde
Tracy Rendall	3 rd Sector representative	SNAC
Lynne Shields	Paediatric Occupational Therapist	NHS Ayrshire & Arran
Jo Walsh	Consultant Paediatric Rheumatologist	NHS Greater Glasgow & Clyde

Appendix 2: Finance

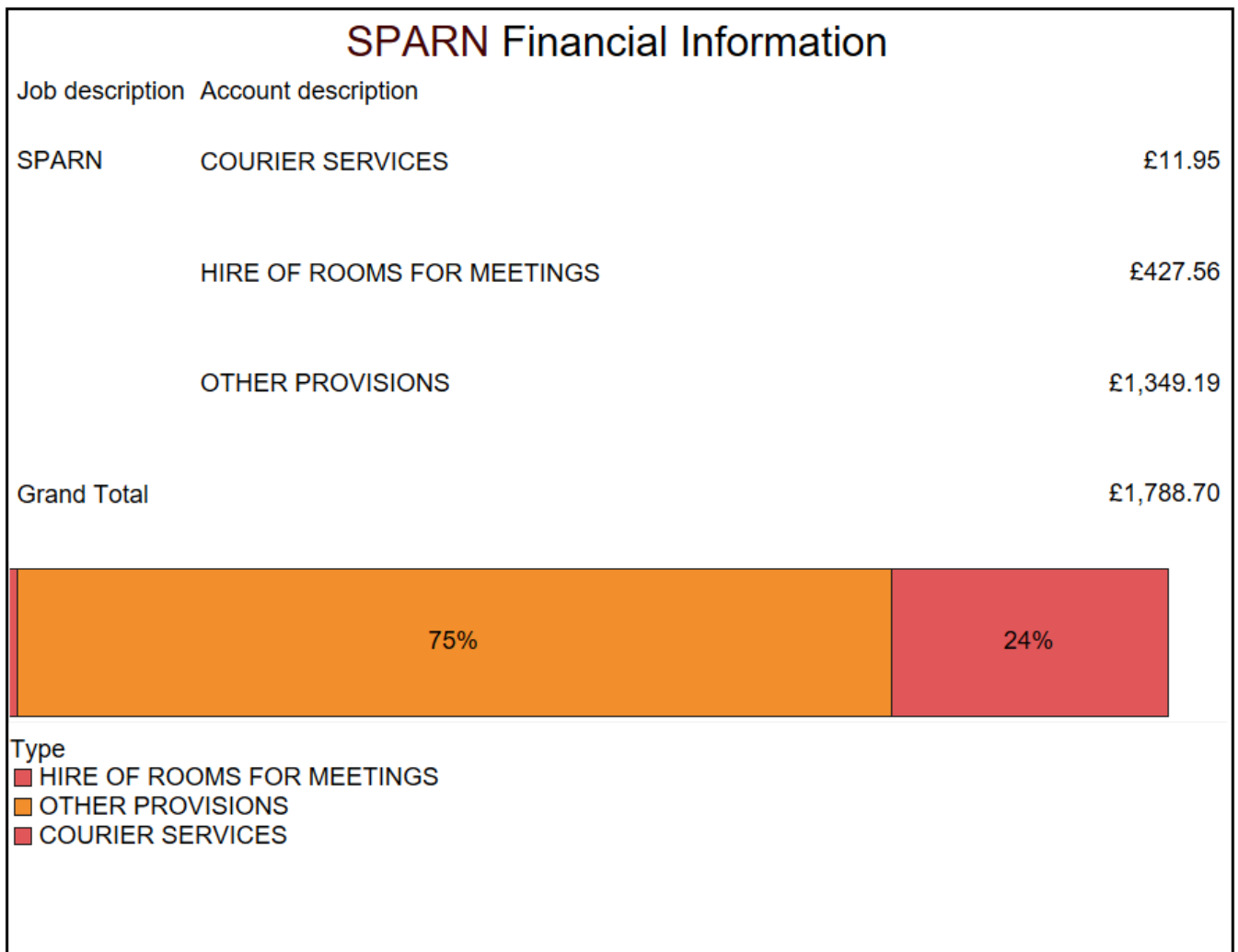


Fig 11: 2019/20 spend

Appendix 3: Monthly Education Programme

Date	Topic	Organiser/ Speakers
Thurs 25th April	Kawasaki Disease	Lead: Neil Martin & Edinburgh Team
Monday 3rd June	SPARN Annual Meeting Focus on Uveitis/ AHP sessions	Lead: Dr David Lynn and Forth Valley Team Forth Valley Royal Hospital, Larbert
Tues 27th August	Reflections: A Career in Paediatric Rheumatology	Lead: Jo Walsh & Mary Brennan
Thursday 26th September	Presentations from the Dumfries Team	Lead: Dr Jed Bamber & Jim Lemon
Mon 28th October	Medically Unexplained Symptoms	Lead: Jo Walsh Guest Speaker: Martin Donnelly
Wed 27th November	Treating JIA – a practical session Testing for Drug levels and AB Common parent questions	Lead: Jo Walsh
Mon 9th December	A Session on Backs	Lead: SPARN Physios
Wed 22th January 2020	"Will precision medicine make it in rheumatology for young or old?"	Lead: Jo Walsh Guest Speaker: Professor Iain McInnes
Tues 25th February	Macrophage Activation Syndrome	Lead: Mary Brennan Guest Speaker: Dr Ethan Sen
Wed 18th March CANCELLED	Ehlers Danlos Syndrome	Lead: Kirsty McLellan Paed Rheum Trainee Led Session

Appendix 4: Quality Indicator Trends

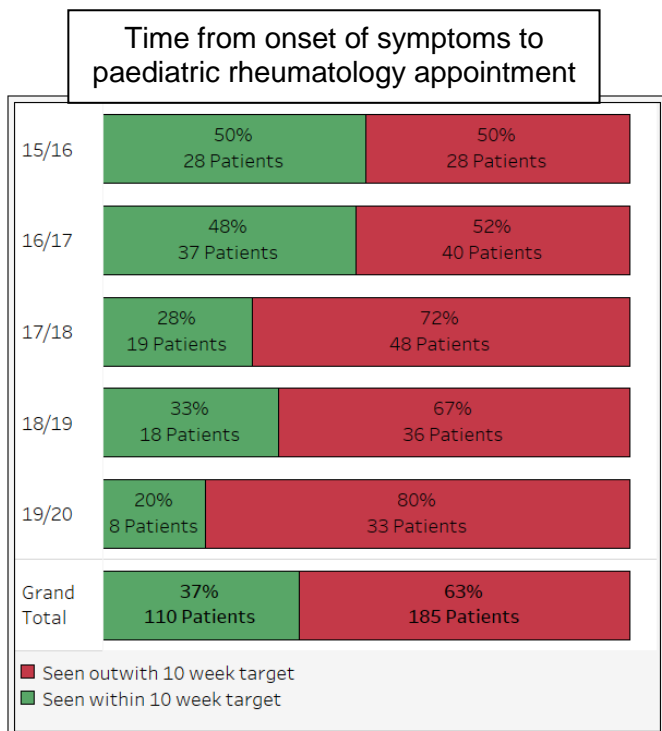


Fig 12: Trends in reporting for time from onset of symptoms to Paediatric rheumatology appointment

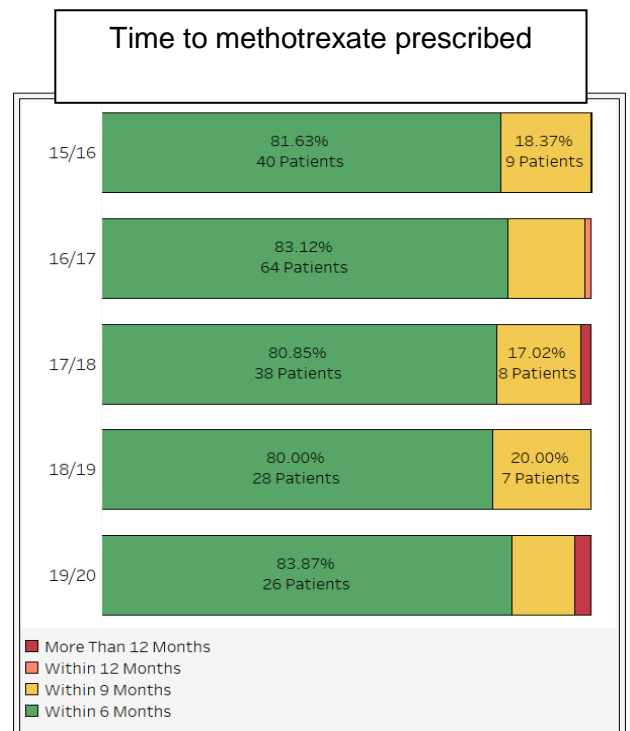


Fig 13: Trends in reporting of time to methotrexate prescribed

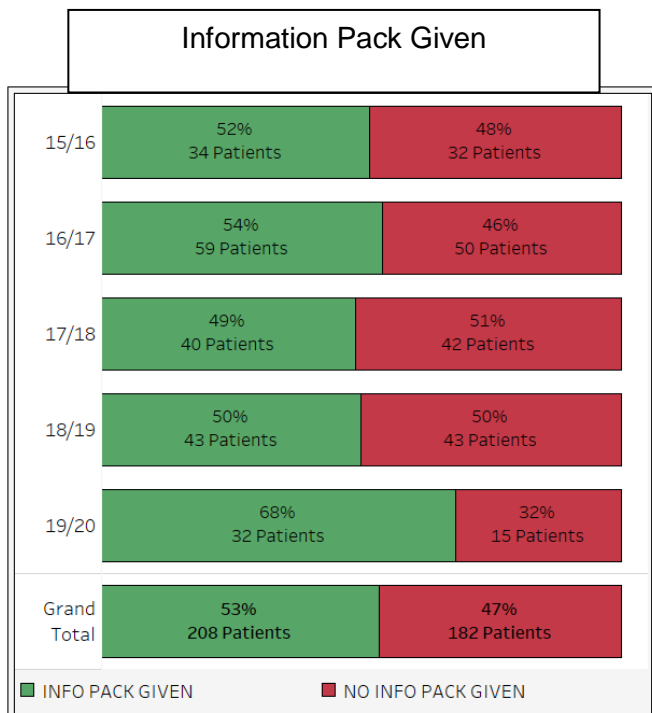


Fig 14: Trends in reporting of information packs given out