

Scottish Paediatric & Adolescent Rheumatology Network (SPARN)

Annual Report 2020/21

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Background

Managed Clinical Networks are defined as co-ordinated groups of health professionals that support clinical services to continuously improve service delivery in order to ensure equitable provision of high quality, clinically effective services.

The aim of the Scottish Paediatric & Adolescent Rheumatology Network (SPARN) is to ensure that all children with rheumatological conditions in Scotland are diagnosed promptly and managed appropriately. Since its designation in 2009, the network has facilitated local delivery of specialist care which means that children and their families no longer have to travel to tertiary centres to receive the care they need. Network clinics have been established in all board areas and these are supported by local multidisciplinary teams including nurse specialists, physiotherapists and occupational therapists. The network structure enables teams to work together across specialty and health board boundaries and develop flexible solutions to support local need.

To further support local delivery of care, the Network has developed a paediatric rheumatology service guidance, a suite of clinical guidelines and an education programme to facilitate sharing knowledge and expertise. The Network ensures that the care delivered in each clinic meets agreed national standards and supports services to improve care through continuous quality improvement.

Current position

The Network has demonstrated good progress against the 2020/21 workplan despite the challenges resulting from the COVID-19 pandemic. Progress against the workplan is detailed in Appendix 1.

Amongst the many challenges faced responding to the pandemic, the network was required to respond rapidly following the discovery of two new diseases linked to COVID-19. Paediatric Multisystem Inflammatory Syndrome (PIMS-TS) results from a severe inflammatory reaction to SARS CoV-2 and can lead to severe cardiac failure requiring intensive care support due to hyperinflammation. Another condition which can occur in people of any age, although more common in children and young adults, is COVID toes which results in the swelling/discoloration of a person's fingers and toes and mimicks conditions classically seen in Paediatric Rheumatology. The advent of these conditions has led to Network clinicians working closely with other paediatric colleagues to develop guidelines and referral pathways to support a new cohort of patients.

This year, the Network continued to support the education needs of staff involved in the care of children and adolescents with a rheumatological condition and developed its Education Strategy to inform the delivery of education in the future. The Networks well established programme of monthly education sessions continued throughout the pandemic with the sessions being recorded to allow people to watch at a later date. Weekly education sessions to support staff from across the wider paediatric landscape in developing their knowledge around PIMS-TS also took place.

The COVID-19 pandemic has resulted in the need to embrace new technology and to communicate with patients and families in a different way. Like all services, routine care was initially paused and when services

restarted, they were being delivered using NHS Near Me and telephone consultations. All Network meetings has taken place using Microsoft Teams and this has worked well with participation across the Network increasing. While many of the Network activities will continue to take place virtually, when guidance allows for in person events to take place, this format would be preferred for one Steering Group per year, the Annual Event and for patient/family events.

Staff within the Network have highlighted the changing pace of government guidance during the pandemic has been challenging with increasing contact from anxious parents and carers and staff having little of no additional information. The Network developed guidance specifically for children and young people with a rheumatological condition which was hosted on the Network's website along with some frequently asked questions and relevant useful links. The network saw a significant increase in activity from the previous year (12,034 page views in 2020/21 compared to 6,800 in 2019/20).

It was not possible to develop the Network's strategic workplan for the next 3 to 5 years or review the quality indicators as planned due to the impact of COVID-19. Due to be completed in 2021/22, these will inform the future direction of the Network and demonstrate the difference the network is making to children and young people with a rheumatological condition.

Highlights

Paediatric Rheumatology Network Service Audit

In February 2020, SPARN shared a survey with each network clinic to assess themselves against the SPARN 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. Across all centres in Scotland there was a high level of achievement against the standards as demonstrated in Appendix 2.

To help identify areas for local improvement, individual comparison reports reflecting network clinics performance across Scotland were shared in October 2021. Where certain standards were not met, those clinics were asked to provide additional information to help ascertain how they met local patient needs. All centres were asked to outline the approximate time allocated to the local core paediatric rheumatology team and to share any areas of innovative practice.

The data from this audit and the supplementary information provided will be used to inform the planned review of the Guideline and allow for any alternative approaches of delivering care to be considered as part of this review.

Education

The Networks Education Strategy, published in March 2021, aims to ensure that education and training opportunities are available to meet the needs of the multidisciplinary team of professionals involved in the care of children and adolescents with a rheumatological condition. The Network has developed a well-established programme of education based on a learning needs analysis.

Every year, an education event is held for professionals involved in paediatric and adolescent rheumatology care.

Local clinics rotate developing the programme and hosting the event, with a themed education session in the morning, and educational workshops and specialty group meetings in the afternoon. The education event planned for June 2020 was postponed due to the pandemic and will now take place virtually in June 2021 hosted by the Aberdeen team.

Throughout the year, the Network hosts virtual monthly education sessions covering a range of topics informed by members of the Network. These are open to all health care professionals who have an interest in paediatric and adolescent rheumatology in Scotland and further afield (including the Paediatric Rheumatology Network in Wales). The programme is promoted on the Networks website and shared via email with the whole Network, including colleagues in Wales. Sessions are recorded to allow those who are unable to attend to watch at a later date. Formal feedback has been limited for each session, however, informal feedback on the 2020/21 programme was positive. The table below notes attendance at each session and views of the session recordings:

Date	Attendance	Views of Recording
5 th June 2020	24	-
26 th August 2020	40	-
26 th October 2020	11	20
9 th December 2020	17	15
24 February 2021	28	17
23 rd March 2021	22	8

Paediatric Multisystem Inflammatory Syndrome (PIMS-TS)

Paediatric Multisystem Inflammatory Syndrome (PIMS-TS) is a rare and completely new paediatric disease characterised as a severe inflammatory reaction to SARS CoV-2, which has presented a novel challenge to paediatric services during the pandemic. The phenotype is severe and the importance of early recognition and aggressive early management became paramount but difficult as symptoms and signs were non-specific.

A collaborative approach between paediatric infectious disease, rheumatology, cardiology and intensive care teams allowed for the formation of a virtual 'hyper inflammatory' MDT involving the on-call members of specialist teams which is available anytime for paediatric teams across Scotland. This approach allowed the development of a referral pathway to the MDT, with input from all the different specialties, for use throughout Scotland. This resource has supported local clinical teams in diagnosing, managing and transferring some very unwell children and adolescents. To date all children in Scotland reported as having PIM-TS have had positive clinical outcomes. Children discussed by the MDT who did not have PIM-TS were diagnosed with a range of other conditions allowing alternate management to be instituted promptly.

Regular (weekly/monthly) virtual education sessions run by the MDT, open to all paediatricians across Scotland, have taken place and have been well attended (see Appendix 3). The sessions, which are planned to continue during 2021/22 reflect on cases and share knowledge about various relevant aspects of this syndrome, including haematological and cardiology aspects and intensive care management. Informal feedback has highlighted that these sessions were 'invaluable to the general paediatric clinical community' as they were a helpful forum to share knowledge, learn from other specialties and to

reflect on emerging evidence from the literature.

COVID Toes

A new disease which has been discovered during the pandemic is COVID-toes, which results in discoloration and swelling on the feet (or hands) of people who have COVID-19. More commonly seen in children and young people this mimicks what can be seen in other inflammatory conditions has led to numerous referrals and has required network clinicians to work closely with colleagues in dermatology. The Network supported the development of a guideline and a teaching session to support staff in understanding more about this condition.

Guideline Governance

A review of all guidelines and pathways on the SPARN website was carried out to check for review dates and relevance in accordance with agreed practice, with only a small number being archived. A checklist for “How to write a guideline” was agreed by the Network to improve the governance process around guideline development and consultation with stakeholders. A workshop is planned at the Annual Education Event in June 2021 to discuss accessibility of the guidelines, agree which are most helpful and also agree a process to ensure they continue to be a useful resource for all stakeholders.

Patient Welcome Packs

The Network reviewed and updated the welcome packs which are given to new patients to ensure provision of consistent information across Network clinics. These packs include a welcome letter, Clinical Audit System (CAS) information leaflet and leaflets from charities on specific conditions/medications. In addition, SPARN business style cards for nurses to add their contact details to were printed and distributed to each centre for inclusion in the packs.

Juvenile Idiopathic Arthritis (JIA) Audit 2019/20

An audit against the quality indicators for all patients diagnosed with Juvenile Idiopathic Arthritis (JIA) in 2019/20 is currently being undertaken. Patient data held within the CAS was shared with each centre to identify any missing data and ensure a full data set was available prior to the audit being conducted. The audit will be used to inform the review against the SPARN Guideline and to refine the quality indicators in 2021/22.

Looking forward

The Scottish Paediatric & Adolescent Rheumatology Network (SPARN) will continue to ensure that all children with rheumatological conditions are diagnosed promptly and managed appropriately through the development and delivery of its 3 – 5 year workplan. The 2020/21 Network objectives are outlined in the workplan in Appendix 4.

One of the key priorities for the coming year is to develop the Network’s Quality Improvement Strategy to support the Networks approach to service improvement. Building on the audit work undertaken in 2020/21, a review of the Guideline for a Paediatric Rheumatology Service and the quality indicators collected by the network will take place to ensure they are based on available evidence and expert opinion. The Quality Strategy will also be informed by feedback from patients through a range of engagement

activities planned for 2021/22.

Additional priorities for the network in the coming year include:

- Roll out of the transition survey across Scotland to identify what is important to young people and use this to identify key improvement projects to be taken forward.
- Update existing pathways and guidelines to ensure the delivery of ongoing improvements in the management of the care of children and adolescents with a rheumatological condition.
- Developing the Networks website so that this is an effective communication, education and information resource for patients, families and health professionals.
- Roll out of the Patient Experience survey to ensure that the development of services are influenced by what is important to patients.
- Hosting an engagement event for patients with Juvenile Dermatomyositis (JDM) and their families.
- Supporting the education needs of the multidisciplinary team involved in the care of children and adolescents with a rheumatological condition including the monthly online education events and the annual Network education event.
- Updating the uveitis guideline in advance of undertaking the national uveitis audit given the challenges of progressing the audit due to COVID-19 restrictions.

Finance

The network used a small proportion of its budget this year to print and distribute the SPARN business cards for nurses to include in the new patient welcome packs (£205). Due to the restrictions in place and the move to virtual meetings, anticipated costs associated with face-to-face meetings and education events have not been incurred.

Appendix 1 Detailed Description of Progress in 2020/21

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.

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2021	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	Steering group meetings have taken place on: <ul style="list-style-type: none"> • 01st July 2020 • 04th November 2020 • 08th March 2021 	There are effective governance arrangements in place.	B
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	A SPARN Team and channels for various workstreams have been established.	The network is structured appropriately to effectively deliver its objectives.	B
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	Postponed to later 2021 due to COVID19	All stakeholders have clarity of vision and purpose to enable effective distributed working towards a common goal.	R
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	Initial pilot in Grampian has taken place. Further roll out to be considered in 2021/22.	Development of services is influenced by what is important to the patients.	A
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	To follow on from questionnaire results. Delayed due to COVID19. This will be carried forward to 2021/22.		R
2019--05	Complete the process of authorising the new guidelines developed in NHS Lothian via the Steering Group.	March 2021	Guidelines Lead/ Steering Group	This was delayed due to maternity leave.	There is an equitable, evidence based approach to paediatric rheumatological care.	R

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2021	Anticipated Outcome	RAG Status
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	A working group has been established but due to work pressures arising from COVID19 it has not been possible to convene a meeting in 2020/21. This will be carried forward to 2021/22.	There is an equitable high standard of care for patients attending all 13 SPARN clinics based on current available evidence and expert opinion.	R
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	This continues to be work in progress	Stakeholders will have access to reliable and up to date paediatric rheumatology information.	G
2019-07	Repeat the patient experience survey learning the lessons of the first year.	September – November 2020	Survey Group	Questionnaire finalised to include patient/ parent experience of COVID19 but delayed hand out in clinic due to COVID-19. Exploring patient feedback received around Near Me to determine if further, more focused patient feedback is required to influence development of services going forward. To be carried forward to 2021/22 workplan.	Development of services is influenced by what is important to the patients.	A
2020-07	The network will hold an engagement event for patients with Juvenile Dermatomyositis (JDM) and their families.	June 2020	Nurses Group	This was delayed due to COVID-19. A virtual event was explored but in line with patient feedback the network is planning a face to face	Development of services is influenced by what is important to the patients.	R

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2021	Anticipated Outcome	RAG Status
				event in 2022 if COVID-19 guidance allows.		
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	Published in March 2021.	There is a clear approach to paediatric rheumatology education in Scotland that takes account of the needs of those delivering the care.	B
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	This has been postponed until June 2021.	Paediatric rheumatology care in Scotland is delivered by knowledgeable health professionals.	R
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	The Education Programme has continued successfully delivered via Teams with a total of 7 sessions held in 2020/21. Sessions did not go ahead in April and May due to COVID19	Paediatric rheumatology care in Scotland is delivered by knowledgeable health professionals.	B
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	The network will oversee the national roll out of the Uveitis audit successfully completed in Glasgow.	March 2021	Uveitis Lead	This was unable to be started in 2020/21 due to the constraints on space in hospitals due to COVID19. The potential to update the uveitis guideline in advance of undertaking the audit will	Areas for improvement are recognised through identification of unwarranted variation in key aspects of clinical care.	R

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2021	Anticipated Outcome	RAG Status
				be explored in the 2021/22 workplan.		
2019-16	The network will produce and authorise a Quality Improvement Strategy to support SPARN's approach to service improvement	September 2020	Prog. Manager	This is currently in draft form and will be carried forward to the 2021/22 workplan		A
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	A working group has been established but due to work pressures arising from COVID19 it has not been possible to convene a meeting in 2020/21. This will be carried forward to 2021/22.	Areas for improvement are recognised through identification of unwarranted variation in practice.	R
6. Value <small>[linked to Quality Dimensions 1,3,4,5,6]</small>						
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	Due to COVID19 it was not possible to capture all the data for this audit but the piece of work to move patients to the biosimilar Infliximab has been completed and cost savings achieved.	Cost savings are being made as a result of more efficient prescribing	B

Appendix 2 **Service Guideline Audit Results: Scotland**

In February 2020, SPARN circulated an online assessment for each of the thirteen centres to assess themselves against the [SPARN Guideline for a Paediatric Rheumatology Network Service](#). Responses were received from all thirteen centres. The information below demonstrates the national performance against the Guideline.

Access to Health Professionals

SPARN Standard: Minimum Core Team	
Professional	Scotland performance
General Paediatrician	85%
Nursing support	100%
Paediatric physio	85%

SPARN Standard: Other essential service components to be available locally	
Professional	Scotland performance
Paediatric OT	92%
Psychology	100%
SPARN Standard: Other essential service components to be available locally or via the network	
Paediatric Pharmacy	92%
Orthotics	92%
Podiatry	92%
Play Therapy	85%
Pain team	62%
Orthopaedic surgeon	92%
Maxillofacial surgeon	92%
Dietitian	92%

Ophthalmology

SPARN Standard: A recognised SPARN specialist service must include a named ophthalmologist delivering screening for JIA uveitis and able to access to appropriate management for children with uveitis.	
Patients with uveitis requiring systemic immunosuppression are:	92%
Patients with JIA requiring screening for uveitis are screened by:	77%
Patients with JIA requiring screening for uveitis are:	62%

Investigations

SPARN Standard: Local access	
Professional	Scotland performance
Routine X-Ray	100%
Routine ultrasound	85%
SPARN Standard: Access locally or via the network	
MRI with GA	92%
MRI without GA	100%
MRI with contrast	100%
CT	92%
DEXA	92%

Provision and administration of medication

SPARN Standard	Scotland performance
Provision of methotrexate at home or elsewhere in the community	100%
A biologic drug should normally be commenced within 4 weeks of decision to start	92%
All units should have access to Entonox to facilitate joint injections in older children by visiting consultant or member of local team	77%

An appropriate clinical environment

SPARN Standard	Scotland performance
Clinics should be held in a children's OP department	77%
Play materials for younger children	85%
Appropriate equipment for monitoring growth	92%
Suitable rooms for MDT clinics	85%
All teams should have local access to appropriate day case facilities for administration of parenteral therapies as necessary	85%
Access to paediatric hydrotherapy locally or via the network	69%
Access to appropriate paediatric inpatient care locally and via the network	85%

Transition

SPARN Standard	Scotland performance
Each unit should identify a named adult 'link' professional to facilitate transition for older teenagers.	92%

Standards/ Guidelines

SPARN Standard	Scotland performance
All children with active JIA should be seen a minimum of 4 monthly	92%
The local MDT should implement a system of annual review for all children with JIA	8%

Other

SPARN Standard	Scotland performance
All local teams should have access to the network CAS	77%
All local teams should enter data on the network CAS	69%
Each network team should undertake an annual patient satisfaction survey	77%

Appendix 3**Hyperinflammatory Teaching Meetings**

Hyperinflammatory teaching/VC meetings		
Date	Attendance	Views of recordings
22nd June 2020	38	
29th June 2020	42	
6th July 2020	23	
13th July 2020	19	
27th July 2020	27	
3rd August 2020	21	
10th August 2020	23	
17th August 2020	21	
24th August 2020	20	
7th September 2020	19	
5th October 2020	17	
2nd November 2020	25	
7th December 2020	14	
18th January 2021	28	4
22nd February 2021	23	4
22nd March 2021	15	4
17th May 2021	12	4

Appendix 4

SPARN 2021/22 Workplan

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

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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2021	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:						
2021-01	The network will organise three Steering Group meetings during 2021/22 to oversee strategic development of SPARN	March 2022	PSO		There are effective governance arrangements in place.	
2020-03	The network will undertake a forward planning session to refresh vision and goals for the next 3-5 years.	March 2022	LC/ PM	Carried forward from 2020/21 work plan.	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 2021 – September 2021	Transition Lead/ PM/ PSO	Initial pilot in Grampian has taken place. Further roll out to be considered in 2021/22.	Development of services is influenced by what is important to the patients.	
2020-04	Based on the results of the transition survey, identify key improvement projects to be taken forward by the network.	September 2021 – March 2022	Transition Lead/ PM/ PSO	To follow on from questionnaire results.		
2019--05	Complete the process of updating the guidelines and adapting locally developed guidelines to share these nationally.	March 2022	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 2022	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.						

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2021	Anticipated Outcome	RAG Status
2020-06	The website will evolve to become an effective communication/ training and information resource for patients, families and professionals.	March 2022	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.	June - September 2021	Survey Group		Development of services is influenced by what is important to the patients.	
2020-07	The network will hold an engagement event for patients with Juvenile Dermatomyositis (JDM) and their families.	Jan-March 2022	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						
2020-08	SPARN will undertake its Annual Educational Meeting in June 2021 in Aberdeen with a focus on Lupus.	June 2021	Grampian team/ Education lead/ PSO		Paediatric rheumatology care in Scotland is delivered by knowledgeable health professionals.	
2021-03	The network will deliver a focused programme of education designed to meet the needs of multidisciplinary staff delivering paediatric rheumatology service by delivering eight virtual monthly educational sessions	March 2022	Education Lead/ PSO		Paediatric rheumatology care in Scotland is delivered by knowledgeable health professionals.	
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	The network will explore updating the uveitis guidelines in advance of undertaking an audit due to challenges progressing the audit caused by COVID19	March 2022	Uveitis Lead		There is an equitable high standard of care for patients attending all 13 SPARN clinics based on current available evidence and expert opinion.	
2019-16	The network will produce and authorise a Quality Improvement Strategy to support SPARN's approach to service improvement. This will follow on from the revised approach	September –November 2021	Prog. Manager			

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2021	Anticipated Outcome	RAG Status
	to standards and indicators outlined in 2020-05 and 2020-10					
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.	Sept – Nov2021	Data Lead/ Short Life Working Group		Areas for improvement are recognised through identification of unwarranted variation in practice.	
6. Value <small>[linked to Quality Dimensions 1,3,4,5,6]</small>						