

**Scottish Paediatric Renal
and Urology Network
(SPRUN)**

**Annual Report
2020/21**

Introduction

The Scottish Paediatric Renal and Urology Network (SPRUN) is a nationally designated managed clinical network, established in 2004. The network encompasses renal and urological disease in children and young people up to 16 years old, who may require specialist intervention but who can also be managed locally. The Network facilitates the care of children and young people with renal disease via local teams delivering care close to home with information and intervention being provided, as necessary, by the specialist unit.

Paediatric renal and urology services provide care to children and young people (usually up to 16 years of age) from across Scotland who have kidney and bladder/urinary tract related health issues that require specialist input.

Tertiary paediatric nephrology services are based at the Royal Hospital for Children (RHC) in Glasgow, which also hosts national services such as the renal transplant service, acute and chronic dialysis service, as well as managing children and young people with severe acute kidney injury, complex nephron-urology and rare diseases such as tubulopathies. Only the paediatric transplant service is nationally designated.

Each local renal service comprises a paediatrician with an interest in nephrology, as well as nursing and wider multidisciplinary support. The local teams are supported by a visiting paediatric nephrologist from the tertiary centre who attends regular joint clinics. Some renal patients are managed locally out with the combined renal clinics.

Tertiary paediatric urology services are provided by three multidisciplinary teams in Scotland: Aberdeen, Edinburgh and Glasgow. They include Paediatric Urologists and Urology Specialist Nurses at each tertiary centre. The Paediatric Urology teams in Scotland work closely together and hold regular “bladder meetings” to discuss cases. All three centres provide outreach to local centres with satellite clinics and close communication to support the care of patients locally as much as possible.

Current position

A review of the network was undertaken in parallel with a review of the Scottish Paediatric Renal Transplant Service (SPRTS). Further to the findings, NSD SMG recommended to NSSC that a meeting of stakeholders from both SPRUN and PRTS be scheduled to come together in partnership to clarify the position, scope the implications, identify and explore options for a future model of service provision that meets relevant standards and is aligned with Scotland’s healthcare policy aims. This recommendation was endorsed by NSSC in September 2020. SPRUN objectives were therefore adapted to accommodate this mandate. This, together with a change of Lead Clinician and reduced capacity amongst clinicians to contribute to the network due to COVID-19 has hampered progress for a number of objectives.

Progress against network objectives in 2020/2021

Highlights

Model of care

A number of engagement events have taken place and a short life working group has been created. The group are taking forward a piece of work to establish a future model of care. This began with a scoping exercise to understand what is delivered as part of each service.

. Below is a snapshot of the results so far.

Local Access to Dedicated Paediatric Renal Nursing Support

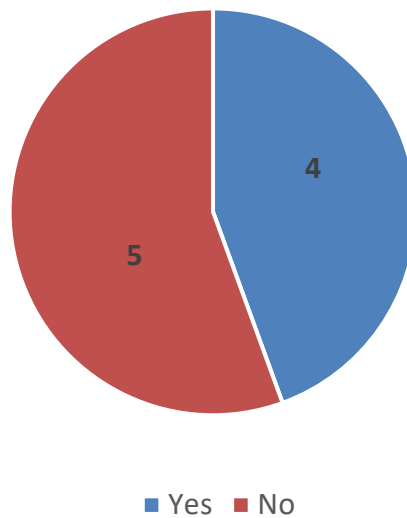


Figure 1 – Local Access to Dedicated Paediatric Renal Nursing Support

The above chart (Figure 1) illustrates that only four of the nine Board areas that responded have dedicated paediatric renal nursing support. However, the five who did not have dedicated paediatric renal nursing support did have access to general nursing support when required. Further discussion will take place to understand the impact of this for patients and service delivery.

Local Access to Services

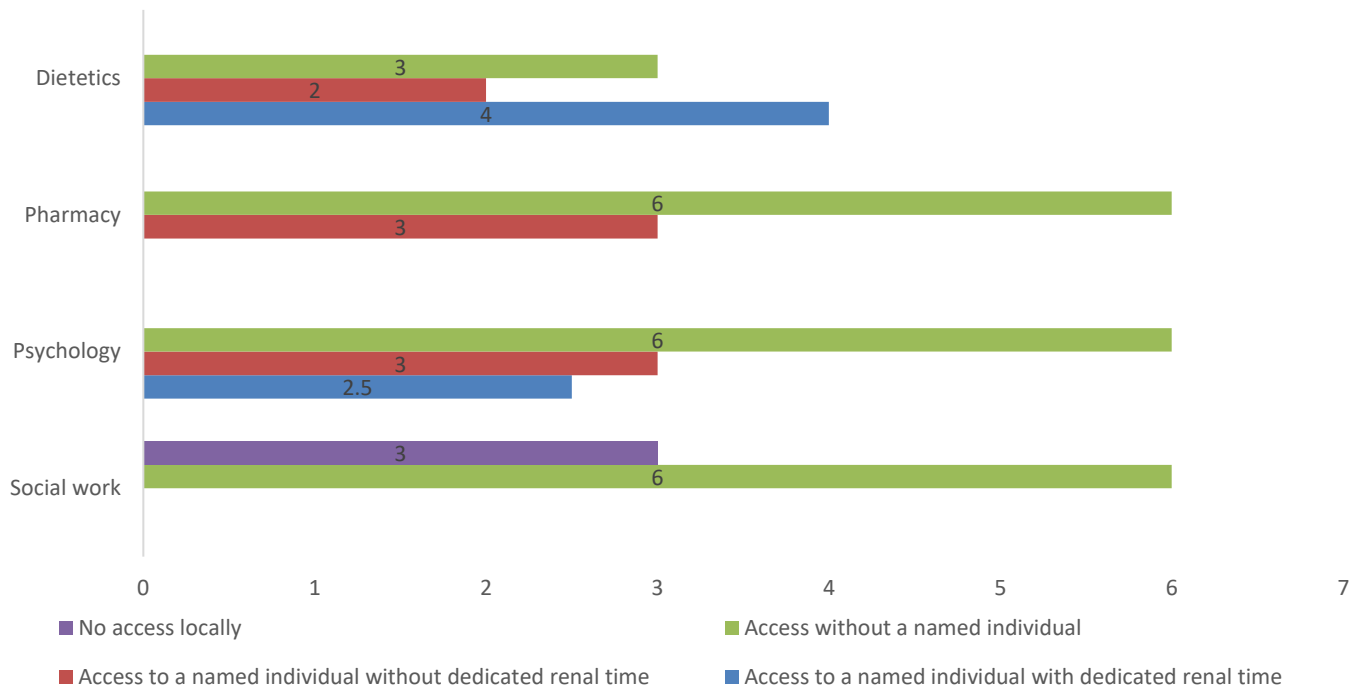


Figure 2 – Local Access to Services

Although respondents had access to most services, with the exception of social work, the main challenge to accessing these services was capacity.

Local Renal Clinics

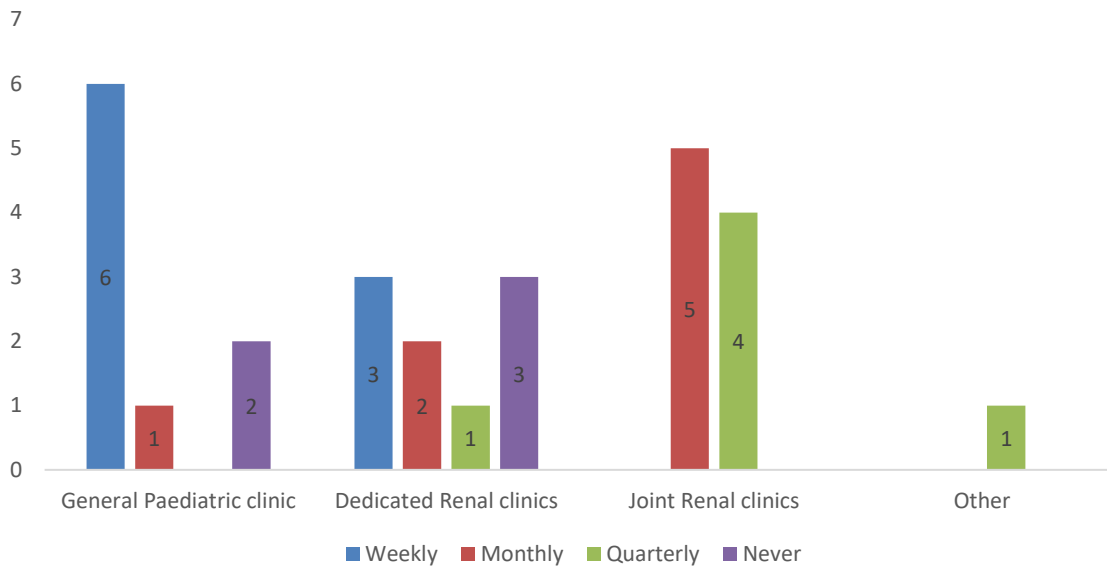


Figure 3 – Local Renal Clinics

Of the nine responses so far, seven services see renal patients in General Paediatric clinics, six have dedicated renal clinics where patients are seen and all had access to joint renal clinics with a visiting Paediatric Nephrologist. Five areas reported seeing renal

patients in General Paediatric clinics and dedicated renal clinics. One respondent also delivered outreach to another hospital.

It has proven difficult establish a complete picture of numbers of paediatric renal and urology patients in Scotland. The Strathclyde Electronic Renal Patient Record is used to capture information about patients attending the clinics in each board where there is tertiary level input. Further analysis of the data captured in SERPR will be undertaken in 2021/22 to identify the numbers of children seen in these clinics. There are further patients seen out with these clinics and further work will be required to identify the numbers. In order to begin to understand the numbers, centres were asked to give an estimate using the bands shown in Figure 4s key. Of the 9 centres who responded, 7 were able to provide estimates on their patient numbers. The other 2 centres responses were from new clinicians who were still working to properly define their case load. These 2 centres account for the majority of “unsure” responses.

Estimated Patient Numbers by Renal Condition

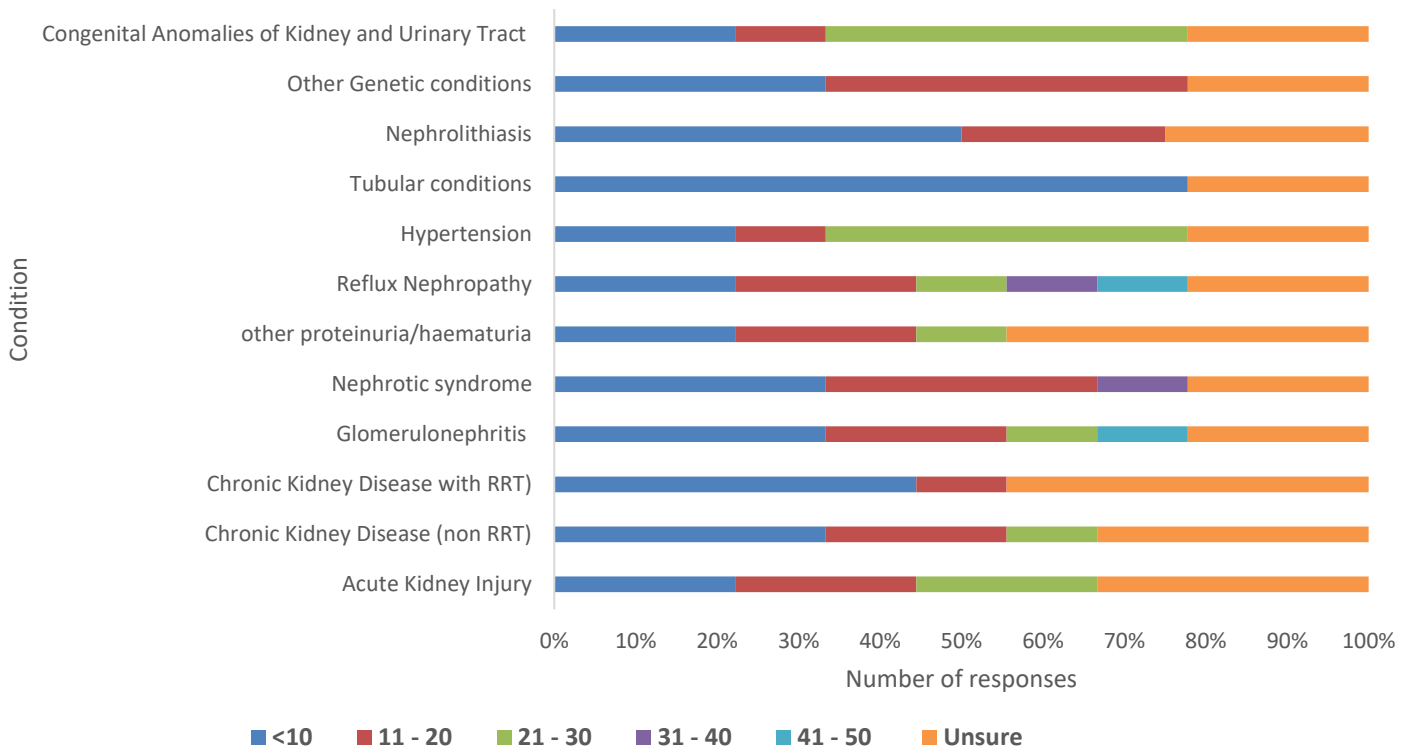


Figure 4 – Estimated Patient Numbers by Renal Condition

Figure 4 shows that there are relatively small numbers for each condition with the exception of Glomerulonephritis, Nephrotic syndrome and Reflux Nephropathy. Although numbers are small for many of these rare conditions their complexity means significant resource is required to manage them. This will be further explored at the next meeting.

This information is being used to inform a further meeting where pathways of care for each condition will be discussed and resource required to deliver these identified. The

impact of the variation in resource models highlighted above will be further explored to inform this work.

Education

The Paediatric Renal Unit at the Royal Hospital for Children Glasgow in association with the Scottish Paediatric Renal and Urology Network (SPRUN) held a Paediatric Renal Virtual Study Day on Monday 14th September 2020. A summary of results are as follows.

There were 58 delegates who attended. Evaluations were received from 16 attendees thus making the response rate 28%. Respondents to the survey were doctors and nurses from 6 different Health Boards.

While the feedback does not yet highlight the long-term impact of the sessions, respondents did confirm that the sessions provided participants with improved knowledge, understanding and increased confidence when dealing with renal patients.

Participants were asked how their practice would change as a result of this event. Although 10 of the 16 respondents did confirm that their practice would change there were no specific changes to practice identified.

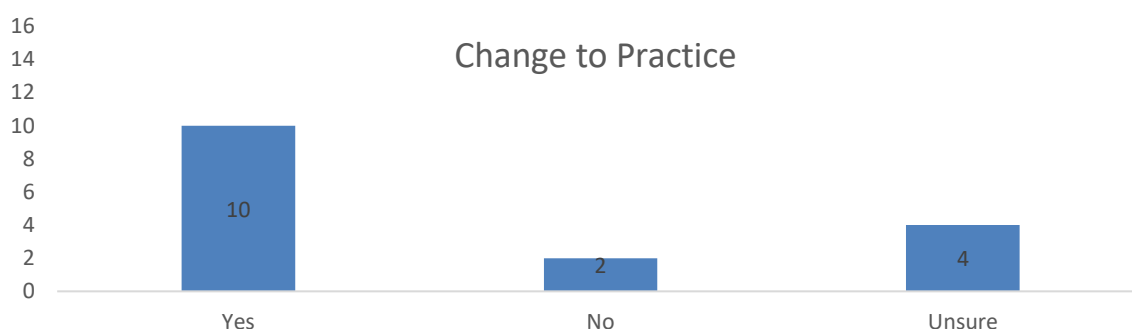


Figure 5 – Changes to Practice Following Education Event

Looking forward

Following the work to identify a suitable model of care the network should be well equipped to provide support for stakeholders, particularly in relation to guidelines, education and quality improvement. A new lead clinician has also been appointed and refreshed links to charity and support groups such as Kidney Kids have allowed for patient engagement events to be relaunched. A wider refresh of engagement with the tertiary centre in Glasgow and local centres will allow for further projects to be delivered.

Finance

No costs have been incurred in this financial period. This is mainly due to the move to remote working which has resulted in meetings and events being held virtually.

WORKPLAN – 2020-21

Please ensure that the annual work plan reflects the agreed objectives in the current network strategic work plan.

All work objectives should be 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 epilepsy care 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.

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 30 th September 2020	Anticipated Outcome	RAGB status
1. Effective Network Structure and Governance <small>[linked to Quality Dimensions 3,4,5,6]</small>						
2020-01	Identify a model that enables the network to function effectively, encouraging network members to take ownership and increase wider engagement.		Core team	Ongoing. Revised leads to some work streams and re-engaged membership working on a wider model of care objective.	Improved stakeholder communication and engagement	G
2020-02	Ensure the stakeholders are properly supported with new ways of working by developing and signposting to guidance on Attend Anywhere.		Core team	Complete. Existing guidance from all board areas has been collated into one single resource. Further objective agreed looking at impact		G
2. Service Development and Delivery <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2019-03	Develop Nephrotic Syndrome pathways and further resources following the review of current guideline		M Durkan	Delayed due to COVID-19. On being reviewed by nursing staff who routinely see NS patients.	Patients receive standardised care based on evidence and best practice	A
2019-04	Review Haematuria guideline using process agreed during Nephrotic Syndrome guideline review		TBC	Initial draft complete however further guideline development on hold.	Patients receive standardised care based on	R

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					evidence and best practice	
2020-02	Development of a programme of pathways or guidelines based on identified stakeholder priorities.		M Durkan	As above, 2020-01. Development of pathways and guidelines will form part of engagement with local services.	Consistent practice in Scotland delivering patient-centred care	R
2020-03	Refresh of joint clinic guideline to ensure reflects current picture and support the Scottish Government aim of delivering care as locally as possible. Once refreshed the guideline will be audited and a benchmarking exercise completed.		Core team	Initial draft complete however refreshed guidance may form part of model of care objective	Consistent application of joint clinics across Scotland to allow tertiary input close to home	A
2020-04	Support the development of a consistent transition process by: <ul style="list-style-type: none"> Establishing the current transition process Identifying areas of improvement and developing a plan for improvement 		M Durkan / L Watson	Survey complete and responses received.	Delivery of improved and consistent transition services	G
3. Stakeholder Communication and Engagement <small>[[linked to Quality Dimensions 1,3,4,5,6]]</small>						
2020-05	Set up a SLWG to seek the views of patients and their families via a patient experience questionnaire.		TBC	To be started. On hold due to a mixture of COVID and the impact of expansion to scope of Paediatric Renal Transplant Service	Improved engagement with patients and ensure SPRUN objectives reflect patient priorities	R

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2020-06	Scope the requirements and interest in re-establishing a nursing group to take forward nurse priorities		L Watson	Engaged with nurses and only one positive response was received. Appears no appetite for a group from nursing staff.	More effective network through involving key stakeholders	B
2020-07	Engage with DGH staff to understand the priorities of local teams and how SPRUN can continue to support them In the current climate this is likely to take place via Microsoft Teams meetings or similar.		Core team	Ongoing. Mapping exercise complete		G
4. Education <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2020-08	Engage with SPRUN stakeholders to allow them to feedback on how education is delivered going forward via a Learning Needs Analysis. To include at least: <ul style="list-style-type: none"> • Current priority topics • Optimal format 		I Shaheen	Survey has been circulated. Feedback being analysed.	Improved knowledge for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	B
2020-09	Continue to deliver a programme of education which meets identified needs of staff groups including continuing with annual education event		I Shaheen	Events have been scheduled.		G
5. Audit and Continuous Quality Improvement <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2019-15	Develop and implement ABPM action plan based on audit results		B Oates	Ongoing. Draft plan agreed.	Patients receive standardised care based on	G

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					evidence and best practice	
2020-10	Identify what data is already available from existing sources. Use this to identify audit and QI activity based of activities above and existing data sources.		M Durkan / L Watson / S Burns	Initial conversations have taken place and some data from SERPR discussed. Some initial patient numbers collected as part of mapping exercise.	Identified service improvement projects based on emerging outcome data	G
6. Value <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						

WORKPLAN – 2021-22

Please ensure that the annual work plan reflects the agreed objectives in the current network strategic work plan.

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

7. 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](#));
8. 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.
9. 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.
10. Improved capability and capacity in epilepsy care through design and delivery of a written education strategy that reflects and meets stakeholder needs.
11. Effective systems and processes to facilitate and provide evidence of continuous improvement in the quality of care (CQI).
12. Generate better value for money in how services are delivered.

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7. **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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2020-02	Ensure the stakeholders are properly supported with new ways of working by developing and signposting to guidance on Attend Anywhere.		Core team		Consistent practice in Scotland delivering patient-centred care	
2. Service Development and Delivery <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2019-03	Develop Nephrotic Syndrome pathways and further resources following the review of current guideline		M Durkan		Patients receive standardised care based on evidence and best practice	
2019-04	Review Haematuria guideline using process agreed during Nephrotic Syndrome guideline review		TBC		Patients receive standardised care based on evidence and best practice	
2020-02	Development of a programme of pathways or guidelines based on identified stakeholder priorities.		M Durkan		Consistent practice in Scotland delivering patient-centred care	

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 30 th September 2020	Anticipated Outcome	RAGB status
2020-03	Refresh of joint clinic guideline to ensure reflects current picture and support the Scottish Government aim of delivering care as locally as possible. Once refreshed the guideline will be audited and a benchmarking exercise completed.		Core team		Consistent application of joint clinics across Scotland to allow tertiary input close to home	
2021	Continue to work with stakeholders to describe the model of care required for paediatric renal services in Scotland.		SLWG		Consistent practice in Scotland delivering patient-centred care	
3. Stakeholder Communication and Engagement <small>[linked to Quality Dimensions 1,3,4,5,6]</small>						
2020-05	Set up a SLWG to seek the views of patients and their families via a patient experience questionnaire.		Core team		Improved engagement with patients and ensure SPRUN objectives reflect patient priorities	
2021	Ward information booklet to be developed. Introducing patient to the ward and the staff. Electronic “walkthrough” also to be explored		Core team		Improved engagement with patients, reducing anxiety for those attending Renal unit for the first time.	
2021	Engage with Urology to explore their continued engagement with SPRUN		D Athavale		Improved engagement with stakeholders	

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 30 th September 2020	Anticipated Outcome	RAGB status
2021	Deliver a series of virtual family “coffee mornings” in conjunction with Kidney Kids. Beginning with Nephrotic Syndrome.		Core team		Improved engagement with patients and ensure SPRUN objectives reflect patient priorities	
4. Education [linked to Quality Dimensions 1,2,3,4,5,6]						
2021	Continue to deliver a programme of education which meets identified needs of staff groups including continuing with annual education event		I Shaheen			
5. Audit and Continuous Quality Improvement [linked to Quality Dimensions 1,2,3,4,5,6]						
2019-15	Implement ABPM action plan		B Oates		Patients receive standardised care based on evidence and best practice	
6. Value [linked to Quality Dimensions 1,2,3,4,5,6]						