

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

**Annual Report
2021/22**

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 although this designation is currently being reviewed.

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

Following the request by NSSC to consider a model of care for paediatric renal services, extensive work was undertaken to understand the current service model. This included identifying the current resource, reviewing current patient numbers and developing key pieces of work and recommendation required to make this model work. This was an extensive piece of work which took place amid a pandemic. Virtual sessions resulted in an increased audience and better attendance. However this has also restricted the ability to facilitate wider engagement such as workshops.

A great amount of work has gone into re-engaging the renal and urology community in 2020/2021 with several patient and a number of professional events taking place. This has ensured re-engagement with the renal and urology community.

Lead clinician update

SPRUN has achieved a considerable amount in 2021/2022. Whilst the established network had existing joint renal clinics and a model structured to deliver equitable and local care near to home, a review in 2019 indicated that whilst there was a clear role for SPRUN, measures to improve its efficiency along with engagement of the wider nephro-urology community was needed, to add to its purpose and value.

A clear education programme has been established which continues to be well received. The pandemic has opened up benefits of online teaching allowing more accessible sessions, though at the expense of face to face meetings. The programme has been successful in its events and learning experiences of the wider nephro-urology community with much positive feedback received. The education sessions have served further to develop and present new guidelines adding to improving the quality of care delivered throughout the network.

Patient engagement, which perhaps has been lacking in the history of the network has clearly been established with close relationships developing with Kidney Kids Scotland. A couple of virtual family sessions aimed at families of patients with rare conditions, perhaps isolated during the pandemic and geographically have been instrumental in bringing families together for support. Patient information has been a focus and a ward introduction leaflet has been developed for the renal ward at the Royal Hospital for Children, Glasgow. Working in collaboration with Kidney Kids Scotland, a “Dialysis Options” booklet has been created to add to the “Journey to Transplant” booklet aiming to have an online version as well as paper copy soon.

World Kidney Day was hallmarked with the launch of our Kidney Health Poster – readily available for distribution to the wider network.

The SPRUN website has been revamped and continues to be a work in progress and further information is added to it in regular intervals, all aimed to support delivery of care for professionals as well as form a support for patient and families.

And finally, with all that has been achieved, re-engagement of the wider community has happened with a revitalisation of the network and what it can offer.

For the future, there remains much to be addressed with focus on auditing standards; delivering standards of care and continuing to support patients/families and professionals and SPRUN is looking forward to demonstrating this in 2022/2023,

Progress against network objectives in 2021/2022

1. Stakeholder communication and engagement

Engagement with stakeholders - Re-engagement with the renal and urology community has continued with a number of events taking place. For professionals, as well as extensive engagement around the model of care work, several education sessions also took place. This included a urology study day as part of a piece of work aimed at increasing engagement with urology. A number of the other education events have

included urology input in sessions as well as audit reporting. These sessions had engagement from throughout the network.

For patients, the network delivered a series of “coffee mornings” in conjunction with Kidney Kids Scotland. These events include presentations from professionals and allow patients and families to meet to discuss their condition with professionals and other patients. Two coffee mornings have taken place so far. These events were aimed at Nephrotic Syndrome families and patients who received a kidney transplant during the pandemic. Two main themes emerged from the feedback; attendees enjoyed hearing from clinicians about their conditions and found the opportunity to meet with other families in a similar situation useful. A snapshot of the feedback is below:

“It was great to hear from the professionals and learn more about treatments. It was also fantastic to meet with and chat to other parents.”

“Everyone has been so great and supportive, thank you for taking the time to do these coffee mornings as I think it’s a great support network to have.”

Due to the success of these events, further meetings are planned for 2021/2022.

Ward information booklet - An information booklet has been developed for patients being admitted to the renal unit in Glasgow for the first time. This booklet includes information relevant to an inpatient stay in the renal ward. It is planned that the impact of the booklet will be evaluated in 2021/2022.

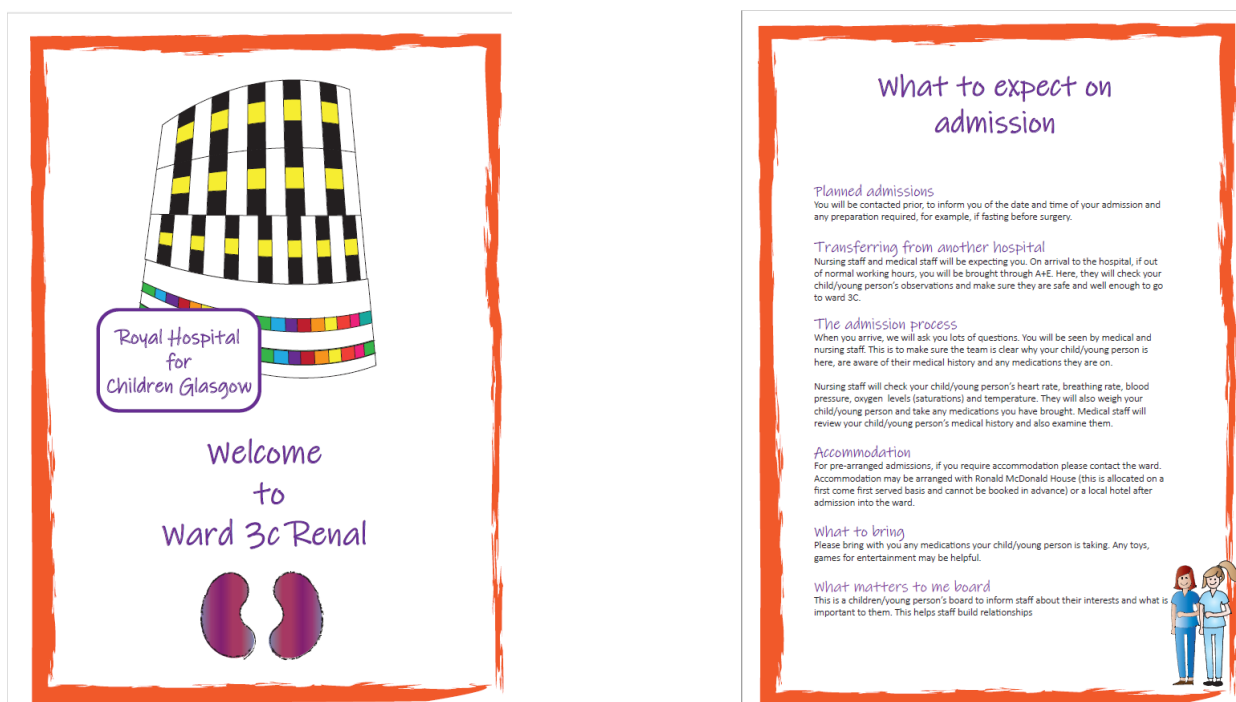


Figure 1 – Ward information booklet

World Kidney Day – World Kidney Day was marked with a launch of a SPRUN developed kidney health poster. This poster is a health promotion message aimed at the general population of children/young people and specifically to those who present with

bladder/bowel issues. Posters will be made available for local teams to display.

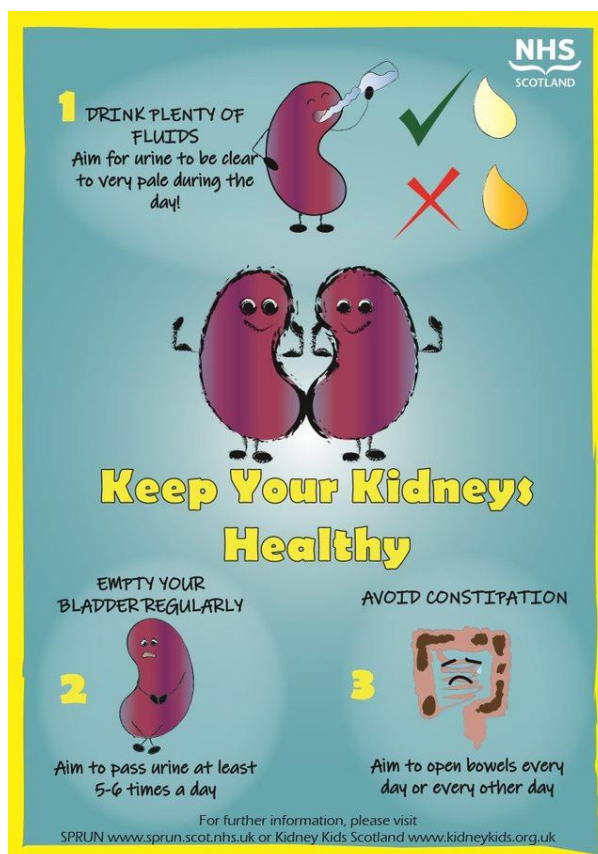


Figure 2 – Kidney Health poster

2. Service Development and Delivery

Model of care

Following the request by NSSC to consider a model of care for paediatric renal services, extensive work was undertaken to understand the current model of care. Several engagement events took place and a short life working group was established. This group took forward the piece of work to establish a future model of care, this begun by identifying the current resource and reviewing current patient numbers. It then progressed onto developing key pieces of work and recommendations required to make this model work.

The key pieces of work identified by the SLWG which would be required to support the model of care are:

Pathways of Care: During the first year of the expanded nationally commissioned service, it will be necessary to work with the local services to establish clear pathways into and out of the national service. This will also identify what is required at local level for pre and post specialist care management.

Standards of Care: In conjunction with the pathways of care, the standards would set out access requirements and condition specific recommendations to ensure equitable access

to services.

Data and Audit: There is a need for a data plan across specialist and local care to initially identify more fully the patient population and their needs to inform service developments, but also to consider longer term audit to ensure continued equitable access to high quality care and drive further improvements. This will require a standardisation of data collection and consideration of how this can best be collected given the challenges with access to SERPR.

Support for the MDT: As the service develops there will be a need to support the MDT through education, peer support and guidance.

The Scottish Paediatric Renal and Urology Network is ideally placed to facilitate some of the developments needed to deliver the model of local care for children with renal and urology conditions with access to specialist care when necessary. This included:

- Education
- Guidelines
- Patient engagement
- Quality improvement

Nephrotic Syndrome Guideline – A guideline for patients with nephrotic syndrome has been refreshed. It is anticipated that use of the refreshed guideline will be audited in the later half of 2022/2023.

3. Education

Education sessions - Education is currently provided by way of a Microsoft Teams Webinar lecture series aimed at paediatricians, general practitioners, paediatric nurses and allied healthcare professionals who care for children with bladder, and renal conditions. Lectures are delivered by members of the specialist multidisciplinary teams across Scotland. Events are a mix of short 2 hour sessions/ half day events and full day events. The aim of these sessions is to cover the nephrology syllabus over 2 – 3 year period, the sessions also incorporate nephron-urology conditions.

6 education events have taken place in recent months, 2 full day events and 4 afternoon sessions, with feedback overwhelmingly positive. The sessions and the number of attendees are noted below:

Date	Session topic	Attendees	Type of session
May	Bladder Study Day	41	Full day
September	Nephrotic Syndrome	31	Afternoon
October	Acute Kidney Injury	25	Full day
November	Haematuria	25	Afternoon
January 2022	Renal Calculi & Calcinosis	21	Afternoon
March	Research & Latest News	18	Afternoon

Some feedback received from attendees is below:

“an excellent study day, lots of information, always beneficial to hear of case studies & their outcomes” – Bladder study day

“Talk given by Dr. Malcolm on fluid management was excellent This teaching session was overall one of the best I have attended this year Thank you for arranging this via Ms Teams which enabled me (and several others) to attend and benefit - may not have been possible to attend if this was a face to face event (requiring study leave / travelling etc..)”
– Nephrotic Syndrome Study Day

“Excellent study day highlighting AKI and particularly the increased risk of CKD. Challenges of follow up of these patients - who? how often? where? Very interesting day, thank you”

“Excellent organisation Peter and really as a team SPRUN is really revitalised.”
– Acute Kidney Injury Study day

Exceptions

There were several exceptions to the plan for 2021/2022. This was mainly due to the resource required to deliver the model of care project and the impact of COVID on the wider workforce. Latterly the NSS directive to reduce impact on boards and staff absence also had an impact. The exceptions were:

- Develop a Haematuria guideline
- Refresh of joint clinic guideline
- SLWG to seek the views of patients and their families via a patient experience questionnaire.
- Implement ABPM action plan

These objectives will be carried forward to 2022/2023.

Looking forward

Following the completion of the work to identify a suitable model of care the network should be well equipped to support this development. A refreshed workplan is due to be progress with support from the NSD medical director. Work should include:

- Re-establish governance arrangements for SPRUN. Beginning with a refreshed Steering Group
- Continue to progress education strategy
- Develop standards of care for paediatric renal
- Develop a refreshed data plan to allow for standardised data to be collected across Scotland
- Continue with patient engagement, building on coffee mornings held in 2021/2022
- Continue to engage with Urology to develop an action plan for Urology input and engagement

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

Core Principles	Description of Work	Current status	Start Date	End date	Q4 RAG Status
Service Development and Delivery	developing and signposting to guidance on Attend Anywhere	Complete. Added to SPRUN website.	01/04/2021	31/03/2022	C
Service Development and Delivery	Nephrotic Syndrome pathways	Guideline complete	01/04/2021	31/12/2021	C
Service Development and Delivery	Haematuria guideline	To be completed	01/01/2022	31/03/2022	R
Service Development and Delivery	Refresh of joint clinic guideline	To follow after completion of service development work	01/01/2022	31/03/2022	R
Service Development and Delivery	work with stakeholders to describe the model of care required for paediatric renal services in Scotland.	Complete and submitted to SMG	01/04/2021	31/12/2021	C
Stakeholder Communication and Engagement	SLWG to seek the views of patients and their families via a patient experience questionnaire.	Postponed due to COVID	01/01/2022	31/03/2022	R
Stakeholder Communication and Engagement	Ward information booklet to be developed.	Complete	01/04/2021	31/03/2022	C

Stakeholder Communication and Engagement	Engage with Urology to explore their continued engagement	Complete	01/04/2021	31/03/2022	C
Stakeholder Communication and Engagement	Deliver a series of virtual family “coffee mornings” in conjunction with Kidney Kids.	Complete	01/04/2021	31/03/2022	C
Audit and CQI	Implement ABPM action plan	On hold	01/04/2021	31/03/2022	R

WORKPLAN – 2021-22* - this workplan is a draft due to ongoing work

NSS Strategic Objectives	Quality Domains	Realistic Medicine Aims	Description of Work	Owner
Improving the way we do things	Treatment, safety	1 - Shared Decision Making	Re-establish governance arrangements for SPRUN. Beginning with a refreshed Steering Group	Core team
Improving the way we do things	Treatment, effectiveness	4 - Reduce Unwarranted Variation	Develop standards of care for paediatric renal	Core team
Improving the way we do things	Health Improvement	4 - Reduce Unwarranted Variation	Develop a refreshed data plan to allow for standardised data to be collected across Scotland	SLWG
Improving the way we do things	Health Improvement	4 - Reduce Unwarranted Variation	Continue to deliver education as per SPRUN education strategy	Education lead
Improving the way we do things	Treatment, effectiveness	4 - Reduce Unwarranted Variation	Develop a plan for auditing the use of and refreshing guidelines	Data lead
Customer at the heart	Health Improvement	2 - Personalised Approach to Care	Continue with patient engagement, building on coffee mornings held in 2021/2022	Core team
Improving the way we do things	Health Improvement	2 - Personalised Approach to Care	Establish SLWG to seek the views of patients and their families via a patient experience questionnaire.	SLWG
Increasing our service impact	Health Improvement	2 - Personalised Approach to Care	Develop a plan to measure the impact of patient information developed by SPRUN - to include ward information leaflet and kidney booklet	Core team
Increasing our service impact	Health Improvement	2 - Personalised Approach to Care	Continue to engage with Urology to develop an action plan for Urology input and engagement	TBC